

The Techno-Inclusive Model of Disability: Motivations, Influences, and Applications

by

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I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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Abstract

In this thesis, I advance a techno-inclusive model of disability. I motivate the need for a techno-inclusive model by looking at the current state of affairs for both assistive technology and disability theory respectively. Seeing a gap in understanding and usefulness of current approaches to disability, I advance a techno-inclusive model of disability which is also inclusive of disabled perspectives and needs of a variety of assistive technology. I then apply the techno-inclusive model to the Ontario policy context as it relates to assistive technology and make a number of recommendations to improve the current system, and argue for these changes on the basis of the techno-inclusive model.

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Introduction

This thesis project seeks to answer two questions: one philosophical, and one applied. The first is: How does technology complicate commonly accepted models of disability and how can we modify our understandings of one or more of these models to create a model which is inclusive of technological considerations? The second and applied question is: how could such a model be used to ensure that disabled individuals' needs in a technological world are met, and in particular, how could the Ontario policy context be meaningfully influenced by such a model to bring supports for disabled people more in alignment with their needs in our current world? These motivating questions underpin the chapters which you will soon read.

Much of this project has taken place during the COVID-19 pandemic, in which we saw “unprecedented” shifts in how individuals lived and worked. During this time disability has been very visible in the vulnerability of disabled people to infection, in the potential for a much-increased disabled population due to “long COVID”, and in discourses around accessibility which suddenly seemed an easy feat to pull off once nondisabled persons needed remote options for their activities (Loepky, 2022). Therefore, this context is also a hugely influencing factor in looking at the ways that society can radically reshape and in considering how much of our day-to-day is mediated through technology and the software that has become integral to connecting with one another. It has also brought to the forefront how much the private industry which creates much of this technology influences and creates the world of our day-to-day life.

This project contributes to the philosophical literature by ensuring that debates around disability take into account the changing technological context, and the ways in which this rapidly evolving technological context reveals the often-contextual nature of disability. It is important for disability scholarship to keep pace even as more accessibility technologies are developed and become objects and software available on the market rather than as specifically therapeutic interventions that require interfacing with a medical professional to access. While it is not necessarily the case that technology not being a part of the medical establishment limits access to technology, the ways in which disability has been so intimately tied to medical establishments historically mean that without changes to these structures of social support, it often does make assistive technologies (AT) harder to access. This happens for at least two reasons. First, it happens because some disabled folks (and especially the newly or elderly disabled) may be unaware of assistive technologies available to them outside of what is recommended by a care team, and if care teams are not involved in prescribing and helping their patients gain access to technologies they may be unaware of what exists on the market, especially if it's an assistive technology that may not be explicitly marketed as such. Secondly, access outside of medical establishments may be more difficult because systems of funding often only support medical interventions, which places further financial burdens on disabled folks where non-medicalized assistive technologies are beneficial. Therefore, looking at the current medicalization of disability support is integral to understanding support that might exist for AT.

This project also contributes to an ongoing debate around the complexities of the experience of disability in a world with rapidly developing technologies. I believe this project is of particular interest both ethically and socially because it considers the broader social issues of technology. One of the driving motivators of this project is the fact that technology is often created and marketed for profit without adequate government regulation or intervention, and that its power contributes to eroding social security nets and the diminishing circumstances of the most vulnerable. This project reflects these broader social trends by examining the particular vulnerable group of disabled people in the context of particular technologies that are assistive (although it may be true that general technologies are required for assistive technologies, such as that you have to have a cellphone or tablet to run many apps), and the particular social security net of the medical establishment in Ontario. In the case of assistive technologies, without interventions, the increasing availability and usefulness of AT in the private marketplace may contribute to an eroded social safety nets because these types of AT represent an uncompensated cost of living increase, especially when considering ubiquitous technologies like smartphones are often prerequisites for AT apps. This could also lead to governmental institutions having a poor handle on what the evolving needs and desires of disabled persons are in regards to AT if disabled persons are not meaningfully involved in the distribution and development of AT. The questions in this project are ones which demand political will to solve, and describing what a solution might look like requires clear explication of the issues and stakeholder perspectives. It is that careful analysis and explication which I aim to provide in this project.

This project will contribute to the public by using philosophical methods to carefully examine the specific problem of obtaining meaningful access to assistive technologies that are desired by disabled people, and ensuring that that access is financially feasible. I believe that by approaching this problem using philosophical techniques, I will be able to contribute to activist work by teasing out the murky ways in which technologies are created, used, and categorized to then make a clear argument for how this should change in alignment with how we think about other aspects of disability and accessibility under existing models. I believe this will have a significant impact because despite the waning acceptability of medical models of disability, the medicalization of certain aspects of disability currently still seems to be intimately entwined with how and when individuals with disabilities are supported by the state.

0.1 Foundational Assumptions

There are some fundamental assumptions that I am taking to be inalienable in my pursuit of this project. While it is difficult to detail precisely all of these underlying assumptions and biases, it is my hope that in reading what I have put down here you will understand the gist of the position that I am writing from. Some of the assumptions that I believe importantly undergird my writing include assumptions that: there is a positive value in disabled lives, categorizing disability and identifying disability as either a positive or a negative is inherently messy, it is important to listen to disabled voices (although this is later justified), and the general movement (or at least openness to movement)

of both bioethics and general society is towards a better state of affairs for disabled people as a result of disabled activism and education efforts. These attitudes and assumptions are of course informed by my own social positioning and experiences which include being a white, queer economically privileged, highly educated citizen-settler who runs in very left-wing circles, and who, while “highly-functioning” experiences myopia and otherwise lives in a messy bodymind that struggles with anxiety, potential neurodiversity, and intermittent, but chronic pain related to my embodiment and past injuries.

It is these assumptions which also inform my language choices throughout this thesis. For instance, I choose to use so-called “identity first” vs. “person first” language (i.e. “disabled person” vs. “person with a disability”). If a particular disabled person were to tell me they preferred person first language I would, of course, attend to their labelling requests. However, it is my understanding and my experience that in general, disabled people prefer “identity first” language. The best analogy I have come across as a simple reasoning for this is that just as we wouldn’t refer to a gay person as a “person with gay” or an Indigenous person as a “person with Indigenous” so too, it is unusual to sever a disabled person from an integral part of their identity (as many disabled individuals do meaningfully intertwine their experience of disability with their personal identity) (Pyne, 2020). Therefore, in this thesis I use the identity-first language of “disabled person.” Similarly, in my writing I strive to talk about “disabled” vs. “non-disabled” people, as opposed to “abled” vs. “disabled” people. I do this in

an effort to center (as opposed to other) disabled persons, as well as to subtly point out the contingency of nondisabled-ness/being able-bodied.

0.2 Outline

This project comprises of 8 chapters. The first 5 chapters attempt to answer the first question of: How does technology complicate commonly accepted models of disability and how can we modify our understandings of one or more of these models to create a model which is inclusive of technological considerations? While the final 3 chapters attempt to answer the second question: how could such a model be used to ensure that disabled individuals' needs in a technological world are met, and in particular, how could the Ontario policy context be meaningfully influenced by such a model to bring supports for disabled people more in alignment with their needs in our current world? Let us now turn then to the particulars of what is forthcoming in these chapters.

The first section begins with Chapter 1 and an introduction of the AT landscape. In this chapter I provide a brief overview of the current practices of development, marketing, and distribution of AT, as well as how AT fits into a broader technological landscape. Importantly, in this chapter I identify three main classes of AT which are organized around their means and ease of access: mainstream, orphan, and bespoke AT. This classification will be used throughout the project.

In Chapter 2, I continue to provide the conceptual foundations for the project through an analysis of various models of disability including notably, the medical model, both minority and

social barriers constructions of the social model, the bio-psycho-social model, the mere-difference model, the human variation model, and others. Through this discussion and analysis I arrive at some desiderata for a model of disability which will be used to inform the development of a techno-inclusive model of disability.

To that end, in Chapter 3 I look at what those desiderata look like when they are focused on AT and how they might meaningfully influence the technological landscape. Furthermore, I identify various aspects of existing disability theories that can help craft a techno-inclusive theory of disability given the desiderata that I identify. Two key desiderata include a desire for “good outcomes” and the inclusion of a myriad of disabled perspectives in the formulation of a theory of disability. These desiderata require careful consideration of disabled testimony which are reserved for further, later discussion.

Therefore, in Chapter 4, I look specifically at disabled testimony as it relates to AT. I justify why it is so imperative to look at disabled voices and then examine the testimony and works of writers, activists, and everyday disabled folks discussing their experiences with #DisabilityDongles on Twitter. Through this analysis, I arrive at some revised desiderata for a techno-inclusive theory of disability, as well as some important considerations for the design and distribution of AT.

In Chapter 5, I take the work of the previous chapters to put forward a positive view of what a techno-inclusive model of disability might look like, as well as how it differs from and draws on

existing models of disability as well as from disabled persons' testimony. I also suggest some ways in which this theory might be meaningfully applied. This concludes section 1, my primarily philosophical work, and the bulk of the theoretical material of my thesis. It also answers the first of my driving questions.

Chapter 6 begins the second and applied section of my thesis which is organized around the question of how a techno-inclusive model of disability might be applied to a particular context. Chapter 6 therefore introduces the Ontario context to which I will be applying my techno-inclusive model to in the remainder of this thesis. It is a systematic discussion of the various supports available to disabled people in Ontario which might be used for the purposes of AT, and begins the discussion of the system's shortcomings.

In Chapter 7 I begin my analysis of the Ontario context, putting forward a negative analysis of the ways in which the Ontario system is inadequate both according to more generally or routinely used methods of analysis, as well as how it is inadequate under a techno-inclusive model.

In Chapter 8, I complete my analysis by putting forward a positive view of how the system ought to be improved and how such improvements could be justified and supported under a techno-inclusive model of disability. Thus concludes my second and final section and resolves my second motivating question.

0.3 Concluding Remarks

This is a beginning, an introduction, but even the larger project itself is a starting point, that will need iterating upon as technology progresses, as our understandings of disability evolve, and as the disability community itself changes as all communities change over time. It is my hope that I have provided for you here a grounding in the goals of the project, a brief outline, and an understanding of my own implicit values and perspectives which inform the project you are about to read.

Chapter 1: The Assistive Technology Landscape

Technology has seen rapid acceleration in last four decades, from the rise of the internet and household computers to personal smartphones which are becoming increasingly powerful and complex every year. This has been both a boon and a challenge to many aspects of society, and in the disability field it is no different. This project is chiefly concerned with assistive technology (AT), which while intimately intertwined with the larger technological landscape is its own distinctive group and challenge to our understandings of disability and our efforts to improve specifically the lives of disabled folks (and in some cases, their caregivers). In this chapter I will give an overview of the current AT landscape. I will begin by defining what I mean by assistive technology, and how I will be using the term in this project. Next, I will provide a brief history of some important AT landmarks. Then, I will provide a non-exhaustive list of some examples of AT to show the breadth of the landscape from mainstream tech that can be used as AT, to bespoke AT, to “orphan” AT which may be left behind. Finally, I will look at some of the limited data we have on broad experiences of AT by disabled folks and their caregivers, as well as on how AT is currently marketed and distributed. This landscape will then be used in Chapter 3, when I consider how AT affects our theoretical understandings of disability, and propose how disability theories can better accommodate AT and therefore, the current needs of disabled folks.

1.1 What is Assistive Technology?

The definition of assistive technology that I will be using in this project is that AT “refers to any item, piece of equipment, or product system— off the shelf, customized, or modified— that is used to increase, maintain, or improve the functional capabilities of disabled people,” (Seelman, 2001, 664). While some theorists in this space may also include broader technologies such as vaccines and pre-natal testing that seek to *prevent* disabilities (Wise, 2012, 170), I will be limiting my project to those technologies that already existent disabled persons and their caregivers use for their benefit.¹ Nonetheless, the definition I am using is still broader than someone unfamiliar with this space might expect. While an everyday person likely thinks of a wheelchair as a paradigmatic example of AT, and might include more widespread technologies like closed captioning, I think we are still not yet at the point where we recognize many software applications for mental health, organization, etc. as assistive for mental health or cognitive disabilities, nor do we necessarily recognize the breadth of what medical technology looks like with the proliferation of telecare apps, advancement in implants and prosthetics, and more. The definition I use is inclusive of medical devices (e.g. oxygen tank, implantable devices like an insulin pump, etc.), social devices (e.g. voice to text to aid with social communication), and systems technology that give people access to physical and digital environments (e.g. wheelchairs, voice to text again, etc.) (Seelman, 2001, 664). An important thing to note is that assistive technology need not be technology that is designed with a disabled user in mind. So long as a piece of technology *can* be used for assistive purposes, that is sufficient to designate it

¹ As such I will not be venturing into the various ethical debates around the potential harm that things like prenatal testing and other technologies that seek to prevent disabled persons being born in this project.

as an assistive technology. Some thinkers argue that AT is a “redundant term” since all technology is assistive to its user in some way or another, but nonetheless, the term has come to refer specifically to technology used by disabled folks for the purpose of their disability (Ladner, 2011, 25). This includes things like using technology to compensate or innovate around an impairment, but also might include things like using technology to mask visible markers of disability to prevent social stigma.²

1.2A Brief and Selected History of Assistive Technology

To correct our perceptions of AT, I think it is important to look broadly at the history of AT, which also includes the history of what we might simply consider “technology”, but in this section it will be demonstrated that even these technologies can be assistive or affect what ATs are necessary. In some ways, most of the history of human tool use falls under the umbrella of AT. For example, if we think of a paradigmatic assistive technology like the wheelchair, this technology clearly also involves the technology of the wheel. The wheel is often given as an example of a primitive human technology, and even before the wheelchair, it has surely been used for assistive purposes by disabled folks. Fundamentally, humans are vulnerable, and importantly, we are also toolmakers (Silvers, 2010, 13). We will always use and create tools to alter our environment to help combat those vulnerabilities when their removal or mitigation is desired.

² It would not include technology where disabled persons used technology in the exact same way as nondisabled persons, but I am reluctant to draw clear lines between nondisabled/disabled users and their use cases because a person might not identify as disabled but nonetheless, use technology in a way that is assistive (e.g. a person who identifies as abled might still prefer to use Dark Mode technology to prevent headaches or eye strain after long usage, and this seems assistive).

Aside from these implicit historical examples of assistive technology, we also have evidence of assistive technology qua assistive technology dating back to ancient times. There is evidence of prosthetic³ use in historical accounts from Herodotus, and complex prosthetics emerged as early as the middle ages, alongside crafts like watchmaking (Roulstone, 2016, 221). More modern prosthetics such as those with a “functional knee-joint and articulated foot with artificial ‘tendons’ were perfected” in the 1800s (Roulstone, 2016, 222). Even what we might think of as being more modern (and more controversial) ATs have long histories. For example, cochlear implants (CIs) were being used in clinical settings as far back as the 1930s (Roulstone, 2016, 209). We are then not simply dealing with modern, newfangled devices, but rather a lengthy history of complex and sophisticated AT that continues to become more sophisticated and widespread.

As mentioned earlier too, the development of technology itself can affect what AT is desirable or necessary, and can constitute AT itself. For instance, while the rise of the telephone made communication easier in general, its focus on aural communication (and related pull back on text-based communications like letter and telegraph) “made deafness an increasingly debilitating disability,” similarly, with computers the shift to text-based communications have “placed new burdens on the blind” (Wise, 2012, 171). Roulstone also notes that smaller shifts like that between DOS and Windows operating systems can also have profound impacts, and

³ A prosthetic is a particular type of AT device which acts as an artificial body part. As we will see though later in this section, some individuals like Harbisson use this to mean functioning as an artificial sense, or having an AT device that is integrated into the body itself. Some AT, like hearing aids, straddle the line between being a prosthetic and not, with many hearing aids that work as microphones being considered mere AT, while others that are bone-integrated are considered to be prosthetics (NIDCD, 2013). Prosthetics are used for both aesthetic and functional purposes.

different impacts across populations. While Windows was “positive for many disabled people, [it] presented major barriers to workers and jobseekers with visual impairments who felt more accustomed to the linearity and non-visual world of DOS” (Roulstone, 2016, 127). Technology then, can be assistive for some, while increasing the burden of impairment or even creating new impairments for others.⁴

In fact, now we see that the majority of assistive technologies are, or are dependent on what we think of as being “mainstream technologies”— namely, computer and communication technologies. This trend too though might be older than we think. As will be expanded upon later in this chapter, there is a dearth of research on assistive technology, but one study from 2000 (pre-I Phone) that provided AT to disabled folks indicated that 21% of all AT devices distributed were computers. Additionally, communication devices represented 16% of the field, and adapted software represented 7% of the field, further computer-adjacent AT that comprised the total included things like scanners, printers, computer upgrades, and microphones (Reimer-Reiss and Wacker, 2000, 47). This will be further expanded upon in the next section which identifies three distinct groups of technologies: mainstream, bespoke, and orphan.

1.3 Examples of Assistive Technology

In addition to this brief history of AT, I would now like to turn to some examples of AT, and provide some categories I argue will be useful in later sections for understanding how

⁴ In chapter 4, I provide Reaume’s account of how technology is disabling to individuals with visual processing disorders because of their reliance on blue light and backlit screens. Reaume argues that technology like laptops and our reliance on these technologies is part of what disables her and that the reliance on these technologies has essentially created new disabilities for those who had not struggled with paper/pencil before (Reaume, 2020).

AT is developed and accessed. These categories are mainstream, bespoke, and orphan. First, I will discuss “mainstream” technologies— those technologies which are ubiquitous because they are used by nondisabled and disabled folks alike, but may be ubiquitous either because nondisabled persons have taken up AT or because disabled persons have benefitted from technologies not explicitly designed for them. In this section I will also provide a brief definition of universal design and give an overview of universal design principles. Then I will look at some examples of “bespoke” AT. This is AT that is designed with particular users in mind and often involves deep consultation and collaboration with disabled persons throughout the design or modification process. Finally, I will discuss “orphan” AT, which is AT that has a small user base and either risks losing or loses support which can make the technology hard to access, repair, or update.

1.4 Mainstream AT & Universal Design

Complementing the general overview of mainstream AT that I discussed in the brief historical section, here I want to provide some current “living” examples of how mainstream tech can constitute AT and improve the lives of disabled folks. Mainstream tech can be designed with abled users in mind, but still be valuable AT (e.g. Dark mode, GPS), designed with disabled persons in mind, but become mainstream (e.g. Closed Captioning, Snuggies, weighted blankets), or be designed with a universal design philosophy from the start. Smartphones— now the most ubiquitous AT is of the first class— have revolutionized portable, computerized AT. They can assist with mobility for those with mobility impairments through both general and specialized GPS software (Roulstone, 2016, 102) (Geomate, 2021). They also have wide application for groups who may not classify themselves as disabled but nonetheless have impairments and

benefit from the use of AT, such as the elderly. Smartphones are important for telecare⁵ monitoring of individuals with dementia and “frail elders” or elders who are “prone to falls” (Roulstone, 2016, 155). They also have applications for those with cognitive disabilities, or who suffer from mental illness, as they can have apps for everything from mood disorders (Roulstone, 2016, 102) to brain injuries. Amanda Reaume in “What do you Do When Your Disability Keeps You from Writing? What I Learned When I Launched a Brute Force Hack on my Brain” writes about the benefits of mainstream technology as seemingly innocuous as “dark mode” on smartphones, websites, and apps can have for those whose brain injuries leave them struggling with screens⁶ (Reaume, 2020). Other technologies might be considered mainstream if they have applications both for disability and for general use, or conditions which may not always be classified as disability (e.g. diabetes, dementia, etc.). Some of these are represented in an AT home design put forward by the Hertfordshire government and include devices like: carbon monoxide detectors, medication dispensers, smart plugs, temperature monitors, and more (Hertfordshire, 2021).

As mentioned, a second class of mainstream AT are AT that are designed with disabled people in mind but are taken up by non-disabled people, or people who may not self-identify as disabled even if they find such AT valuable. These ATs can include things like some push wheelchairs (widely used in hospitals, often available in big departments stores) for the sick or

⁵ “telecare” is usually defined as “sensor and monitoring devices, detectors, alarm systems, communication devices, video or imaging devices, smart phone apps and specialized medical devices connected with the internet”, i.e. devices that focus on monitoring, although some may use the term more broadly to mean “telemedicine” which can more broadly include physical and social-emotional care. (Roulstone, 2016, 154, 171)

⁶ This also demonstrates the contextual/environmental/constructed nature of disability which will be expanded upon in the next chapter.

those temporarily lacking mobility. Other examples include things like closed captioning which is sometimes even preferred by nondisabled folks for a myriad of reasons. Even on the side of neurodiversity and cognitive disabilities, innovations like weighted blankets are often touted as beneficial for those with autism, but are now widely marketed to disabled and nondisabled folks alike. The breadth of these devices show the breadth of our human activities, as well as the potential vulnerability of all individuals, but in particular those with disabilities to a variety of environmental changes.

The ubiquity of smartphone technology, and convenience of integrating or piggybacking AT applications via software is not without its challenges, however. The rapid development in this space means that the third class of mainstream AT, that which is universally designed, is becoming increasingly necessary as adaptive designs simply cannot keep pace (Wise, 2012, 184). Universal design emphasizes principles such as equitable use, flexibility in use, simple and intuitive use, perceptible information, a high tolerance for user error, low physical effort needed for use, and sizing and approach for use that accommodates a broad range of body sizes and mobility levels, (Universal Design, 2020). The goals of universal design in relation to devices are that they should be able to be “used by any person” (Universal Design, 2020). This has a two pronged approach— first, to push “the boundaries of ‘mainstream’ products, services and environments to include as many people as possible,” and second, to “minimise the difficulties of adaptation to particular users” (Universal Design, 2020). A universal design ethos seeks to identify and accommodate all possible users of a product and their needs. A case example from Universal Design, OXO Good Grips, made efforts to design a vegetable peeler “that was easy to hold and use, regardless of strength of manual dexterity.” To that end, in user testing they

included folks in a variety of age ranges, with different hand sizes, and strength and dexterity profiles (Universal Design, 2020). Without a universal design ethos, we may simply continue to see non-compliance with accessibility standards, such as was the case with webpages in the 2000s. Since updated web accessibility standards in many jurisdictions in 2011, we simply don't have data on accessibility compliance when it comes to webpages (Roulstone, 2016, 103). Wise also suggests that a lack of universal design will also lead to more orphan technologies in the future (Wise, 2012, 184).

While orphan technologies will be covered later in this section, we can see here the beginnings of potential tensions between different kinds of AT. Assuming resources (whether that be money, political will, etc.) are scarce, decisions will need to be made in terms of what kinds of AT to prioritize. Increasing options that are universally designed risks increasing the orphan nature of orphan technologies by decreasing the user size further and lessening support. Similarly, supports for orphan technologies may come at the expense of pushing for universal design if disabled persons are seen to be covered by the “special needs” accommodations of orphan AT. Either extreme can be harmful by leaving out groups of disabled people who may prefer, have an easier time accessing, or otherwise require one kind of AT over another.

1.5 Bespoke AT

In addition to AT that constitutes or piggybacks on “mainstream” technology, there are also bespoke ATs, some of which tend to become very visible and receive media attention. These ATs are specialized for the individual who is using them and their particular needs, and are often designed for a particular task which is usually more specific than what is required in

everyday living. Examples include sports, art, or work related prosthetics. For example, Aimee Mullins is a disabled model and speaker who discusses her “12 pairs of legs”. She uses prosthetic legs that are designed specifically for her and her modelling and include legs that make her taller, that grow vegetables, glass legs, jellyfish legs, and carved wooden legs that look like elaborate boots. All of these legs are created to be fully functional as well as artistic. To create her legs she works with artists and prosthetic designers to create objects that are specifically tailored to her and to her artistic and aesthetic needs (Mullins, 2009). Neil Harbisson represents another example of a “bespoke” AT user. Harbisson has a visual impairment which results in him seeing the world entirely in greyscale. In collaboration with innovator Adam Montadon and an unidentified surgeon⁷ Harbisson created an “eyeborg” which allows him to feel color. The eyeborg is a camera which is surgically attached to Harbisson’s skull and sits above his head. It allows him to perceive color by translating it into sound waves that he can feel and hear in his bones. He also uses it for artistic demonstrations that meld sound and color together (Harbisson, 2012; CNN, 2014). These are just two examples of bespoke technologies, but other examples could include homemade ATs or modifications to other ATs that are designed for a specific individual or niche task such as Jordan Reeves’ homemade “Project Unicorn” prosthetic arm that shoots glitter (Amputee Store, 2020).

Although this is the common use case for bespoke ATs, many disabled persons take off the shelf mainstream or orphan ATs and modify them to make them bespoke. These ATs are so vast and varied that they are impossible to catalogue, and certainly many are not known to the

⁷ The surgeon refuses to be identified due to the ethically dubious nature of the surgery Harbisson underwent to have the eyeborg permanently integrated into his skull.

media. Reaume gives one example of modifying her glasses using a piece of tape around the nose bridge to prevent “fusing”— a part of her visual impairment (Reaume, 2020). Another woman, Betsy talks about how she created her own accessible device to open cans by wiring a can opener to a cheese grater to make it easier to grip (Jackson, 2018). The modifications that individuals make to their “off the shelf” devices are not well documented, though we do know they exist and that it is very common for disabled people to “re-invent” their devices, design “additions or modifications tot heir devices to meet their unique needs” (Reimer-Reiss and Wacker, 2000, 45). These bespoke ATs depend on either personal financial resources, engineering acumen, or connections and networks that give them access to one or both of the first two.

1.6 Orphan AT

Finally, there are “orphan” ATs. Many ATs that are aimed specifically at disabled persons become orphan technologies. This term comes from the US designation of orphan drugs, which denotes drugs that are for rare diseases or conditions (affecting fewer than 200,000 persons in the US) (Seelman, 2005). These technologies are usually marketed to healthcare providers and insurers and focus on “medical, not social use criteria,” and this potentially narrow application and/or small user population, can result in tech becoming “orphaned” and unsupported (Seelman, 2001, 665). Not all devices marketed specifically as AT are orphan— for instance, wheelchairs have robust markets— but important AT such as telebraille (45,000-50,000 US users) do end up orphaned (Seelman, 2005). Companies generally require incentives such as tax credits to encourage them to produce or upgrade orphan products (Seelman, 2001, 689). This is suggested to be at least in part because the niche markets that orphan technologies are

targeted towards do not allow for economies of scale (Seelman, 2005). With the rise of computerized technologies, and an increasingly aging population, there is a trend away from creating and designing orphan technologies and instead moving towards creating technologies that have universal designs and are appealing to multiple groups, but where orphan technologies may still be required, it is likely that government intervention to support them in regards to “research and development, commercialization, distribution, marketing and sales, and reimbursement” will be necessary moving forward (Seelman, 2005).

The rapid movement of software technologies now can make it increasingly difficult for accessible technologies to adapt, especially if those mainstream technologies do not comply to standards of universal design, and compliance with accessibility standards on the internet are unfortunately likely still very low, though compliance with more recent guidelines has still not been widely studied (Roulstone, 2016, 103). The “orphan” nature of a technology can also be associated with geography that makes a certain technology more desirable or workable in a particular setting. For instance, wheelchair use rates are much higher in the USA where roads and ramps are more common vs. wheelchair use rates in France where stairs are still the norm (Roulstone, 2016, 182). Different types of the same technology may be orphans where a use case is more or less common (e.g. push wheelchairs vs. power wheelchairs), or where a technology is analog vs. networked (networked technologies become obsolete much faster due to lack of support for software changes). I will use the term orphan technology going forward to refer to technologies with limited use cases or a small demographic of users, even if those technologies are still currently supported. This umbrella term is meant to represent the difficulty that disabled people face when accessing these technologies since they are often inaccessible without the

support of professionals, and disabled persons face the risks of their AT becoming obsolete or unsupported.

Here I have provided an overview of three categories of AT: mainstream, bespoke, and orphan. I have used these categories rather than a different potential categorization scheme (such as the purpose an AT is used for either in terms of the impairment or realm of life) to emphasize the ways in which these technologies are *accessed* by disabled persons. Mainstream tech is accessed like any other consumer good. It is ubiquitous and easy to access inasmuch as it does not require any kind of diagnosis, though it may still be expensive. Bespoke technology is accessed via personal engineering acumen or specific relationships with those who have that acumen (perhaps in conjunction with the accessing first of a mainstream or orphan technology that is then modified). Orphan technologies are accessed through systems specifically for disabled people whether that is through a doctor or occupational therapist, etc., and access to them tends to be more contingent on government support of the technology, and insurance approval. This is key for the purposes of my project because the ultimate goal is to suggest changes to practices in Ontario to make desired and efficacious AT more accessible to disabled persons.

1.7 Selected Research and Data on the Use of AT

Now that we have an understanding of the AT landscape, and the primary ways in which AT is accessed I would like to flesh out the landscape by looking at the empirical data we have on how disabled persons respond to AT and how AT is marketed. In doing so, current gaps in our understanding of AT and potential associated problem will be highlighted. Unfortunately, data on the use and efficacy of AT is spotty at best (Wise, 2012, 173) and as stated earlier, the

impacts of accessibility legislation is similarly “under researched” (Roulstone, 2016, 103). Ripat and Woodgate also argue that this is especially true when it comes to the interactive nature between AT and cultural environments (Ripat and Woodgate, 2010, 87). Roulstone finds that the dearth of research on the impacts of AT might be related to wider cultural values as well, since “much of the academic work on the promise of technology was published in the 1980s and 1990s when technological optimism was at its height,” but now data is scarce and small-scale (Roulstone, 2016, 135-136). It seems reasonable to posit that the rapid shifts in technology might impact the ability to research the impact of AT in a meaningful way in a similar way that it impacts the design of orphan technologies. If by the time researchers are able to make conclusions on AT but that AT is no longer on the market or something better and new has replaced it, research would not even necessarily be a meaningful endeavor.⁸

Part of the challenge in researching AT both in regards to developing AT in the first place and determining its impacts is the burden that such research places on disabled persons. Since disabled persons are already vulnerable both in regards to their disability, and also because disability is often associated with lower economic means and status, it can be ethically and practically challenging for researchers to recruit disabled persons to develop and test AT (Mankoff et. al, 2010, 7). In many cases, research outside of industry does not have the funds to adequately compensate disabled people for their time, and even within industry disabled people may not be adequately compensated or credited for their work. Disabled people may also be

⁸ For the purposes of this project, I limited my research primarily to articles written in the last 20 years to ensure I was meaningfully engaging with the current state of affairs. However, even that information seems contextually woefully out of date considering the emergence of the I-Phone in 2007 has dramatically changed the state of technology even in the last 14 years.

emotionally harmed through exposure to ableist assumptions if the technology they are testing is not already at a certain standard of accessibility, or if a product itself is found to be ableist. More on this will be discussed in Chapter 4. Mankoff et. al. note that digital software tools which can simulate impairments are becoming more common, and these can help with initial challenges in the development of AT, and allow researchers to lessen burdens on disabled participants by ensuring a minimum accessibility threshold is met before they are asked to participate. However, these types of tools carry with them their own potential pitfalls as they might “reinforce problematic opinions” about disability such as that disability is a predominantly negative experience or that the simulation of impairment is the same as the experience of disability (Mankoff, et. al. 2010, 7). Additionally, similar to the problems that exist for orphan technologies, if the group of disabled users for a given technology is expected to be small, the heterogeneity of the disabled population can mean that testers are not representative of users, and in general, accessibility of things such as webpages is “almost never” tested with target users (Mankoff et. al., 2010, 7). Some AT though, is never developed with disability in mind, or applications to disability come much later, as is the case with “exoskeletons” for mobility impairments. Exoskeletons were first developed for military purposes in the 1960s and were essentially “a powered suit of armor” (Roulstone, 2016, 228).⁹ Universal design would naturally erase such distinctions, but in the absence of universal design, we should consider how such technologies are modified for AT purposes, and for what purpose these marketing or design

⁹ And perhaps this explains negative sentiments towards such devices in the disability community, which I will explore in chapter X.

differences are made, and who is requesting and engaging in the translation of such tech into AT (i.e. are disabled people involved in and driving this process).

In addition to software that simulates disability being a potential, partial solution to the challenges involved in creating AT and gathering data about its use and benefits, I will now highlight some findings that help us to further understanding the AT landscape. Inasmuch as the continued use of AT can be considered to be correlated with AT efficacy and positive sentiments in AT users, we have some evidence of what can make AT better. Roulstone, citing, Philips and Zhao, notes that “orthotic and mobility devices were more likely to be abandoned [by users], with aids to daily living less likely to suffer the same degrees of abandonment”, and counterintuitively, ease of access to AT was “cited as a factor increasing abandonment” (Roulstone, 2016, 100). Similarly, Reimer-Reiss and Wacker in a 2000 study find that historically, 29.3% of AT use was discontinued¹⁰ (Reimer-Reiss and Wacker, 2000, 44). They found it was very common for disabled people to “re-invent” their devices, devising “additions or modifications to their devices to meet their unique needs” (Reimer-Reiss and Wacker, 2000, 45). Continued use of technology was associated with professional support, and also “when users believe their opinions are taken into consideration in the selection process” (Reimer-Reiss and Wacker, 2000, 45). Some technology discontinuance though was not due to negative factors but rather changes in user’s priorities and/or needs” (Reimer-Reiss and Wacker, 2000, 45). Nonetheless, consumer involvement was determined to be key in the adoption of AT (Reimer-

¹⁰ For the purposes of this study, “discontinuance” was measured via the question “Are you still using your assistive technology?” If the answer was no then the AT was considered discontinued (Reimer-Reiss and Wacker, 2000, 46)

Reiss and Wacker, 2000, 48). We should pay careful attention to factors that lead to continued use of AT because this gives us one indication as to what AT disabled users find valuable, and therefore represents a more efficient use of resources from a policy standpoint.

Ripat and Woodgate in “The Intersection of Culture, Disability, and Assistive Technology” look at technology use across different cultural groups and reference studies that show there is a difference in uptake of AT across those groups. For instance, one study noted that white disabled persons used home modification devices at a high rate, whereas Black disabled persons were more likely to use portable AT (Ripat and Woodgate, 2010, 91). They also note that sometimes there can be resistance to the visible use of AT because when AT use is visible it can lead to stigma and draw attention to the person’s disability which is not always desired. Cellphones and AT associated with cellphones are extra beneficial in these cases because they don’t draw attention due to their ubiquity (Ripat and Woodgate, 2010, 92). They believe that it is important for “AT service providers” to improve AT, and the match between AT and users by clarifying individual and family beliefs and being attentive to individuals’ social and cultural environments in addition to their impairment related needs (Ripat and Woodgate, 2010, 94).

With regard to the use of AT we are then left with a few issues that are important to keep in mind moving forward as these both constrain and guide any work on the ethics of AT. First, it is difficult to study AT in a rigorous way, and little research currently exists. Second, it is both difficult and potentially harmful to involve disabled people in the development process of tech, however, the meaningful involvement of diverse disabled users is key to creating good products. Third, it is important to evaluate how disabled persons use and choose their AT, including cultural or location forces that might guide their decisions and preferences. These give

us a landscape-level view as to some of the challenges AT poses. The specific expression of these challenges will be explored more at length via personal testimony in Chapter 4.

1.8 Marketing and Distribution of AT

The final piece of the AT landscape puzzle is: how are these technologies marketed and distributed? In “Representations of disability and normality in rehabilitation technology promotional materials” Phelan et. al look at how cochlear implants and gait trainers are marketed and sold. They note that rehabilitation discourse still largely promotes “medical model” narratives of disability. Models of disability will be discussed at length in the next chapter, but for our purposes here we can consider this discourse to include claims such as disabled people “have the right, and should receive intervention to be enabled or rehabilitated ‘back to normal’” (Phelan et. al, 2014, 2073). Literature which looks at the marketing of AT notes how AT technologies are promoted to family members by promising relief of caregiving burdens, “successful outcomes for patients and an opportunity to access ‘cutting edge’ healthcare” (Phelan et. al. 2014, 2073). These technologies are promoted using images of “smiling, middle class, white, apparently heterosexual families” (Phelan et. al. 2014, 2075) and “persuasive one-sided language” interspersing testimonials with research and scientific language (Phelan et. al. 2014, 2077). Ripat and Woodgate note that advertisement materials also use targeted messaging that rely on “Western philosophies and ideologies that favour autonomy, independence, and self-determinism (Ripat and Woodgate, 2010, 91). With the technologies that Phelan et. al. looked at in particular, marketing was largely targeted to parents rather than disabled users themselves, highlighting that the technologies would give their children “Opportunities for a *normal* life” and prevent their children from experiencing bullying or

exclusion (Phelan et. al. 2014, 2076). This practice of targeting marketing at other players in the disability space rather than disabled persons themselves seems to be unfortunately common.

In “Better than New! Ethics for Assistive Technologists” Silvers notes that engineers who design and create AT usually perceive the “real purchasers” of AT and hence the real “employers and clients” of those engineers to be “physicians or other therapeutic or rehabilitation professionals, family members, or insurance systems” (Silvers, 2012, 10). This is problematic because while well-meaning, these “real purchasers” may misconstrue what is actually in the best interests of the disabled user of AT. Where disabled users are seen as the “real purchasers” they are likely to be more able to influence design according to their self-identified needs and interests.¹¹ Similarly, Roulstone notes that in professional settings, getting AT for the purposes of workplace assistance is dependent on the sign off of occupational health, health workers, or occupational therapists (Roulstone, 2016, 143). This is problematic because it tends to restrict which disabled persons have access to which ATs. He claims that “Some disabled people are refused access to wheelchairs due to medical conceptions which connect certain impairments with ‘wheelchair need’ and not others.” This is an ethical issue for AT because similar gatekeeping would be strange if it were applied to technology such as cars and bikes, because we would not conceive of those mainstream technologies in regards to a needs/does not need binary, (Roulstone, 2016, 4). Even if we concede that tech such as cars and bikes is not usually funded through social programs or insurance, the conception of such a

¹¹ A good example of this is found in the case of thalidomide babies who were encouraged by their parents and caregivers to use prosthetics. Later in life these children testified that they preferred to use their “stumps” instead. (Scully, 2008, 69). One can imagine a scheme in which these children or other newly disabled persons being more respected by engineers fitting technology to their needs rather than fitting themselves to the technology were disabled persons viewed as purchasers.

binary is still problematic and does not acknowledge that people have different needs at different times and for different purposes.

Finally, insurance is an important part of how certain AT makes it to disabled consumers (whether that be public social health insurance, or private insurance). While some AT products like cellphones and apps might be easily and widely available¹² access to others can require diagnosis or in the case of certain prosthetics or devices like cochlear implants, surgery. This leads to situations such as those described above by Roulstone where a disabled person might benefit from but be denied access or funding to a particular AT because of a lack of diagnosis or inaccurate conception that a particular diagnosis does not need a particular AT. Similarly, orphan technologies or less well publicized AT like apps may not be familiar to professionals that disabled folks interface with, and so disabled folks may only learn about such AT via disability communities, as was the case with Reaume (Reaume, 2020). This can be problematic especially for newly disabled folks who have not accessed or don't know about/don't know how to access disabled communities, and whose first and primary avenue of education is likely to be professionals who are socially positioned as experts. The policy landscape in regards to which technology is funded, given what regulatory hoops are jumped through, and what percentages of the costs of AT are covered by various provincial and private insurance plans in Ontario will be covered in a later section.

It is clear then, that there are a number of harms related to the marketing and distribution of AT that currently need to be addressed by a techno-inclusive model of disability.

¹² At least in theory. The actual accessibility of such devices given funding schemes, and in particular, lack of funding schemes for this type of AT will be discussed further in a later section.

Namely, we see harms emerging from the rhetoric used in the marketing of AT that may reinforce ableist attitudes and/or cause disabled persons to feel shame. There is also potential harm here if disabled people avoid products that could be beneficial to them but they avoid them because of the way they are marketed. Secondly, there is a major access problem where facets of the AT landscape make it such that products might require a specific diagnosis, there might be misconceptions as to which AT is beneficial to which users, and where advisors and disabled persons themselves may not know what AT is out there that would be beneficial to use.

1.9 Conclusion

To conclude, in this chapter I have provided a broad overview of the AT landscape. I have provided a definition of AT as well as discussion of various subsets of AT including mainstream AT, bespoke AT, and orphan AT. In my discussion of mainstream AT I also provided a brief overview of universal design. Additionally, I highlighted the lack of data on the outcomes of AT use, as well as what indicators from the limited data do show. Finally, I provided a brief overview of how AT is currently marketed and distributed to disabled folks, and gestured at some of the various processes disabled folks might have to go through to access medicalized, often orphaned AT, more of which will be highlighted later when I look at the current policy landscape around access to AT in Ontario.

Just as I have provided an overview of the AT landscape in this chapter, in the next chapter I will provide an overview of the disability theory landscape and in the third chapter I will look at how the AT landscape that I have described here fits into current disability theory and how disability theory can be improved in light of the complexities that AT raises.

Chapter 2: Models of Disability

To understand how assistive technology impacts the lives of disabled people¹³, and furthermore, to imagine a scheme as to how assistive technology research and access should be supported by governmental systems and policy, it is important to also understand the conceptual landscape of disability. This conceptual landscape is fraught. While one can chart the historical course of how we have conceptualized disability and disabled people's role in society, there is substantial disagreement as to what disability is conceptually. This disagreement is compounded by further disagreement about how disabled persons should be supported in navigating their disability. It is possible for multiple systems to point to the same persons as being disabled for different reasons, while others might be left out of the category of disability under certain systems. For example, visual impairments might be considered disabilities by medical models which privilege impairments, while not by social models who see the impact on day-to-day life of many visual impairments to be low. Still other social models may have interest in a very inclusive model of disability to illustrate the wide need for a variety of supports, while others might blur the boundary between "disease" and "disability" and include chronic conditions such as diabetes. Even within the same systems different authors might emphasize different disabilities as being more salient, and few are interested in creating a comprehensive list of conditions which qualify one for membership in the disability community— this is much more commonly a practice for policymakers. In short, disability is a contested category, and what

¹³ I use "disability first" language rather than "person first language" as I take it to be the common preference of disabled persons. Disability first language recognizes that disability is an important part of identity for many disabled individuals. Furthermore, it aligns disability language with other minority identities— we call individuals "queer persons" or "female persons" not "persons with queer" or "persons with female," etc.

qualifies as a disability is a contested category, and what is disabling about disability is even more questioned.

Nonetheless, in this chapter I will provide a background on the landscape of disability theory, and provide a summary on what the key disagreements are, as well as providing a list of desiderata that current models and critiques indicate are important when devising a theory¹⁴ of disability. I will start by providing an overview of the history of the disability movement, and how the social model emerged as a contrast to the implicit values that have been theorized as the medical model used by healthcare practitioners and government systems. Next, I will look at revised social models, such as the bio-psycho-social models, and how they critique social models, as well as other more general criticisms of social models. Then, I will consider neutral and mere-difference conceptions of disability, as well as the model of human variation, phenomenological models of disability, and models of disability which separate out different aspects under different social and economic umbrellas. Finally, I will engage in a synthesis of the presented models, and propose some shared desiderata, as well as reiterate the key points of conflict that emerge in the literature.

2.1 History of Disability Theory

It is widely accepted that the history of modern disability theory began with the activism of the Union of the Physically Impaired Against Segregation (UPIAS) in the early and mid 1970s (Goodley, 2016, 11; Shakespeare, 2006, 43; Beaudry, 2016, 225; Terzi, 2004, 143; Oliver, 2013, 1024). It is those writings which first put forward a social model of disability, and in doing so,

¹⁴ I use the terms “theory” and “model” interchangeably.

revealed the underlying values of governmental policies and healthcare practices which in contrast have come to be known as the medical model of disability. Since then, the social model has undergone much development and critique, and the dialogue that this has created has opened up new avenues for conceptualizing and talking about a wide range of disabilities and disabled experiences. While the majority of this chapter will focus on such theories that have emerged, and those theories are most important overall to my project, I would first like to take a brief step back to show a broader scope.

After all, disabled persons have always existed, and before modern disability theories there were other historical perspectives on disability that can potentially be seen as leading up to the declarations of UPIAS in the 1970s. For example, Davis in *Bending Over Backwards: Disability, Dismodernism and Other Difficult Positions* notes that historically there was little attention paid to a large swath of disabilities such as those suffered by King James I¹⁵, in contrast to “deformities” such as dwarfism, intersex conditions, and conjoined twins (Davis, 2002, 53). We also have evidence that shows that historically, acquired disabilities or disabilities that mimicked acquired disabilities were conceptualized very differently from congenital disabilities like dwarfism, etc., and that these acquired disabilities were largely seen as a part of everyday life. While some of those with congenital disabilities or their parents were stigmatized by folks who thought such things were divine punishments, others had a stable place in society as “signs from heaven” and sources of wonder within their communities (Davis, 2002, 54). In contrast to this, normalcy is a

¹⁵ Davis notes that “Almost no one knows or mentions, even in his lifetime, that he was a person with disabilities,” however, some textual evidence tells us that his legs were weak and he was unable to stand unassisted, and furthermore that he was unable to work for extended periods of time, struggled with speaking clearly and had difficulty drinking without liquid dribbling from his mouth (Davis, 2002, 51)

relatively new idea, emerging from modern data gathering and the rise of statistics about 150 years ago. This idea of normalcy or typical functioning though, is now central to many theories of disability and to their critiquers (Davis, 2002, 105). Other scientific advances such as the emergence of genetics led to disability becoming linked to narratives around the suitability of disabled persons to reproduce and eugenic practices emerged in concert with institutionalization which separated disabled persons from general society and imposed restrictions on them. Disability also became more concretely linked with divine punishment for sins such as laziness, women (and in particular, poor women) became blamed for birth defects and disabled persons became seen as “deserving or underserving” where the poor were seen to have developed disabilities “through their laziness or lack of care,” or were seen as faking where other disabled persons “often women, children, or older people,” who were sickly were seen to be virtuous and struggling to “triumph over their disability” (Davis, 2002, 57).

We can chart historical attitudes that shift from this innocent conception of disability to one of institutionalization and a need for charity to support those unable to work in the post-industrial revolution time period. Snyder and Mitchell in *Cultural Locations of Disability* note how this institutionalization of the disabled body in the 20th century became commonplace, with institutions like “the asylum, the courts, the prison, the clinic, and educational facilities,” becoming sites “where pathology is meted out in order to make bodies ‘legible’ and thus productive,” (133-134). With the rise of industrialization and standardization particularly in factory lines, we see the push to standardize and understand bodies according to particular measurements as a way of understanding the relative worth and value of those bodies. It is in this landscape of pathologization, where bodies are separated into bodies and issues with the

body that need to be treated, where disabled people are met with charity under scrutiny of their relative worth that UPIAS and the social model emerge.

2.2 Models of Disability

In the next sections, I will discuss various models of disability that have been described or advocated for by disability theory scholars. These models all focus on different aspects of disability and often conflict in regards to what they conceive disability to be and furthermore what, if anything, should be done to modify¹⁶ the effects of disability. While initially it might seem that these models have little in common with one another except for their subject (and the particular lines around that subject are definitely subject to debate), after this discussion I will propose some common themes throughout these models and the implicit goals these models advance.

2.2.1 UPIAS and the Medical and Social Model

As previously stated, the beginning of modern disability theory really begins with the UPIAS. Their declaration that “In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society.... Disabled people are therefore an oppressed group in society” (UPIAS, 1976, 3-4) is taken to be the founding idea of the social model of disability. This view has evolved to be and is presented in contrast to the

¹⁶ I use “modify” here rather than lessen to reflect the fact that some models may find some of the effects of disability to be positive. Similarly, this leaves room for the negative effects of disability to be lessened while the positive effects of disability may be enhanced.

common attitudes of healthcare workers and policy makers which treat disability as though it were something inside the disabled person to be solved through treatment.

While the social model of disability that has emerged from UPIAS can take on many different flavors, it is always considered to be in opposition to the medical model which posits that disability is an individual problem, where disability is viewed as misfortune and something to be avoided and treated where it does emerge. Disability is classified as “a defect or deficit located in an individual”, and both defect and deficit is determined by comparison with a “norm of physical or mental structure or function” (Scully, 23). The defect or deficiency is conceptualized as an “impairment” which is identified with reference to some norm of functioning, sometimes identified in the literature by both defenders and opponents as “species-typical functioning,” (35). It is against this statistical yard stick that normalcy, and disability in contrast to normalcy, has been measured. The medical model is the milieu of society’s treatment of disabled persons throughout the 20th and 21st century. We can understand the medical model to be the perspective of some well-meaning healthcare provider or bureaucrat who sees the impairment of a disabled person as being an inherently a bad thing (because it limits the range of opportunities one might have access to) and also potentially leads to other badness (e.g. pain, difficulty navigating the world, etc.). This well-meaning person then seeks to solve that badness by eliminating the impairment. The impairment is located in the individual and therefore it is the individual that is treated in some way to eliminate the bad effects of impairment (this model is also sometimes conceptualized as the “individual model” or “personal tragedy” model of disability (Shakespeare, 2006, 15)). Despite the pervasiveness of the medical model’s claims about disability in policy and medicine, there are few who would advance a pure medical model

(as opposed to a bio-psycho-social model, which will be expanded upon later). Some scholars argue that “it makes little sense” to even talk about debates between medical and social models when there are no explicit defenders of the medical model (Devidi and Klausen, 2017, 358; Shakespeare, 2007, 15). While there are current initiatives to eliminate or ameliorate the discrimination disabled persons experience via human rights and other legislation, disability in general society is still largely considered to be an individual issue that depends on diagnosis and individualized medical treatments and supports. As Beaudry writes, “the individual/medical model remains influential in biomedical circles, at least insofar as disability is often assumed to be a negatively valued state associated with physical anomaly,” despite the fact that, “healthcare professionals are doubtlessly increasingly aware of environmental factors contributing to disability” (211). Therefore, rather than thinking of this as being a prescriptive model that is actively advanced by scholars, I think it is more helpful to view this as a descriptive model that is advanced mainly by the inertia of systems which already use it, and by holdover charitable attitudes which need to identify some particular misfortune to be able to label someone worthy of help and support.

This is one of the reasons why there is so much pushback on the implicit ideas of the medical model from groups like UPIAS. These groups have tried to show that while disabled persons may behave in “abnormal” ways, or hold different capabilities, there are no simple correlations between medical assessments and ability when disabled individuals are allowed to complete tasks through modally different ways. However, discriminatory attitudes lead social and medical systems to prioritize form over function and end up incorrectly estimating disabled persons’ abilities based on their impairments, (Amundson, 2000, 41). This then, makes the

problem of “species-typical” functioning as a yardstick twofold: first that measurements of functioning are taken in ableist environments which privilege abled ways of being and moving, and second that there is little flexibility in these measurements to accommodate for people meeting the same or similar goals via different methods.

We now largely differentiate two groups of social model proponents— the “minority model”, and the “social barriers” model. The “social barriers” model comes directly out of the UK UPIAS movement and is primarily concerned with what causes exclusion in various spheres of life. Under this model disability is socially constructed via the “barriers that prevent access, integration and inclusion to all walks of life,” (Goodley, 2016, 13). For example, a social barrier to disabled participation in the workplace might be the social idea that workers can only do their best work on-site on a 9-5 schedule. This barrier precludes disabled people from being seen as strong workers if they cannot access a physical work space or need alternative schedules and excludes them from the workplace. The goal of the social barrier view is to increase “accessibility of places and services,” and to create “broad systemic change” (Goodley, 2016, 13). For example, by eliminating rigid ideas of what conditions produce good work, and by extension, the bias it causes against disabled workers. The social barriers model is often also associated with disability pride and affirmation of positive aspects of disability experience including disability arts and Deaf culture (Goodley, 2016, 12).

The minority social model of disability is more closely aligned with other “identity politics” and has been more prevalent in North America (Goodley, 2016, 12). This model

explicitly positions disabled people as a minority group¹⁷ which experiences discrimination and whose rights have been violated (Goodley, 2016, 13). This model also can develop into disability pride and specifically helps to build group solidarity. The goals of this model are largely identical to the goals of the social barrier model, but where the social barrier model focuses on common challenges (regardless of the reason for that commonality), the minority model focuses on common identity and sees the social barriers that disabled persons experience as discrimination and infringing upon rights (Goodley, 2016, 13-14). These models can share goals and claims because while the social barrier model may see the barriers as causing disabled people to be an “oppressed group” and the minority model might see the minority status and oppression of disabled folks as leading to social barriers, both groups agree that both facets of experience exist and are important to remedy. There may exist a chicken-and-egg question, but ultimately, this question is held by both groups as being less important than the facts that disabled persons do encounter environmental barriers, are oppressed, and need significant work to be done on social interventions over and above medical interventions to rectify the state of affairs that causes disability.

2.2.2 Bio-psycho-social Models and Critiques of Social Models of Disability

The emergence of the social model of disability has, of course, led to critiques of that view. Commonly, the social model is critiqued on the basis that it erases the facts of and

¹⁷ i.e. a group of individuals who are singled out for some particular characteristic they share and who are oppressed on the basis of that characteristic, whether or not the perception of that characteristic is correct. People in these groups tend to wield less power, hold less wealth, and experience other negative effects in a disproportionate way to the statistical space they take up in society. Other minority groups include women (who are considered a minority even though they make up a slight majority of people), queer folks, persons of color, and more.

experiences of bodily impairments which lead to disability. In this next short section I will elaborate on the bio-psycho-social model of disability¹⁸, popularized by Tom Shakespeare, which attempts to solve this issue while retaining considerations of the social dimension of disability, as well as discuss a few more general critiques of the social model.

Shakespeare's bio-psycho-social model and others that take after him¹⁹ is largely spurred by a desire to maintain a social aspect and a recognition of the social contingencies of disability without erasing impairment and the difficulties that some disabled folks see impairment as causing²⁰. Social model critiquers argue that the social model erases impairment because in focusing on environmental barriers, and discriminatory social attitudes, the social model ignores real bodily differences between abled and disabled folks, and that those bodily differences exist outside of societal constructs. In *Disability Rights and Wrongs*, Shakespeare argues that the erasure of impairment is harmful to disabled folks. This harm is twofold. First, there is the psychological and social harms to disabled folks who identify impairment as being central to their experience of disability and a locus of pain for them (Shakespeare, 2006, 40). These folks, Shakespeare argues, may not feel comfortable speaking up about their experiences and perspectives on impairment because it is contrary to now-dominant narrative of the social model, and therefore

¹⁸ I use the term "bio-psycho-social" in the sense of those writers referenced here, *not* in the sense of Waddell and Aylward. Shakespeare himself argues that the Waddell-Aylward BPS model doesn't actually bring together biological, psychological and social factors, and is rather "a causal explanation of sickness absence, with advocacy for a particular approach to disability management," and that this model explicitly rejects the relevancy of the social model which his bio-psycho-social model does not. (Shakespeare et al., 2017)

¹⁹ Such as Kafer (2013), DeVidi and Klausen (2013), Shakespeare and Watson (2002).

²⁰ Tremain (2001) argues that the social model is incorrectly conceived of by these folks, since impairment is the thing which differentiates disability stigma/exclusion from other kinds of exclusion, and advocates for a bio-psycho-social model which recognizes that impairment is also socially constructed, but I take this position to be less distinct on a practical level from the social view than the bio-psycho-social model as advocated for by Shakespeare and Kafer.

individuals who identify impairment as central to their experiences of disability might be ostracized or left out of valuable disability communities. Additionally, the erasure of impairment can be harmful because it might halt attempts to “mitigate or cure medical problems” that are associated with disability. The idea is that the focus of the social model on environmental modifications rather than endeavoring “to meet the special needs of impaired individuals” can lead to those needs not being met, as scarce resource and medical dollars might be diverted to purely social and environmental interventions (31-32). In short, these thinkers argue that the social model ignores that not all problems can be solved via environmental modifications, and might restrict disabled persons’ access to medical interventions and therapies for their impairments. This restriction might come either in the form of political changes and priorities which mean there is less funding for medical treatments of bodily impairments, or via social pressures and coercion in which disabled persons might feel ostracized if they don’t “toe the party line” of the social model. It should be noted that Shakespeare does not think that cure is always or even often the best path forward for disabled persons, rather, his point is that medical interventions including cures are “not contrary to other objectives of disability rights, and activists and scholars should be critical supporters of the endeavour to mitigate or prevent impairment” (Shakespeare, 2006, 125).

Kafer, similarly, in *Feminist, Queer, Crip* sees disability as being more complex than the traditional social model might allow for. While she, like Shakespeare, feels sympathetic towards the social model, she believes that “drawing a hard line between impairment and disability... makes it difficult to explore the ways in which notions of disability and able-bodiedness affect everyone.” The notion of dividing disability from impairment she thinks prohibits us from

considering the nuances of disability where individuals who are not “disabled” may nonetheless feel pressured to engage in body altering medical treatments (such as shorter than average children being treated with growth hormones), and where able bodied persons who associate with disabled persons may experience guilt, discrimination, or otherwise be affected by ableist attitudes even if they themselves are not disabled. This broad range of personhood and society being integral to the understanding of disability is something she explores in her text especially in relation to queerness and how the additional social identity of queerness can affect experiences of disability (and vice-versa) (Kafer, 2013, 8). This notion of considering the nuances of identity that disabled persons can hold in addition to be disabled and how that affects their social location is a key feature of the bio-psycho-social model. These authors ask us to, however messily, integrate notions of impairment, oppression, social location and environment, and to acknowledge that neither disability nor its solutions can be monoliths. Shakespeare notes that this model leaves us with “no prior assumptions that one approach is automatically preferable in all cases” instead, this model involves the recognition that “judgements about how to improve individual situations are complex and should be based on evidence, not ideology,” (Shakespeare, 2006, 62). In some cases we should focus on impairment, in others oppression, and it is not possible in all cases that universal design will be a panacea.

Others such as Terzi and Anastasiou also critique the social model on the basis of its disregard for the importance of impairment. They worry that even if alternative models are messy and do not offer easy solutions and ways forward (though it’s arguable that a social model is no easy roadmap to solutions either) eliminating ideas of impairment, and therefore normal and non-normal functioning risks eliminating ideas of disability itself and therefore motivations

to provide assistance for disability and to disabled people, (Terzi, 155, Anastasiou, 448). This is at least somewhat supported by the fact that government schemes have a history of assigning objective values to levels of impairment and providing compensation to disabled individuals on the basis of their level of impairment (Bickenbach, 79).

However, counterpoints are made to these critiques of the social model. For instance, Snyder and Mitchell argue that the practice of dividing up resources based on some seemingly objective measure (such as impairment) and providing charity selectively to that group creates “division between hosts (those who produce and consume in equal amount) and parasites (those who consume without replenishing what they use up,” and leads to discriminatory and oppressive attitudes (56). Furthermore, others like Silvers in the next section will argue that impairment or underlying condition is not a good indicator of need.

2.2.3 Other Models

In addition to the medical, social, and bio-psycho-social models of disability, still other theorists take on other conceptions of disability which may share elements with medical, social, or bio-psycho-social models. Or they might propose models which are useful in one area of life and society or which pick out one aspect of disability to highlight. Finally, there are theorists which are less concerned with models of disability and more with the valuation of disability and seek to propose more value-neutral conceptions of disability.

For example, Scotch and Schriener propose a “Human Variation,” model of disability which positions itself along similar lines to a social barriers social model of disability where the concern is primarily with discriminatory environments that disabled persons find themselves

within. In particular they focus on the employment context. They argue that approaches that focus on human rights and other solutions that focus on universal design or emphasize that disabled persons are a discriminated against group have largely failed to rectify that discrimination or provide appropriate supports (2001, 101; 1997, 154). While they agree that anti-discrimination measures and universal design are valuable things to take into account, they think a more pragmatic additional angle to take in the fight for disabled folks is to adopt a human variation perspective where “the problems faced by people with disabilities might be seen as the consequence of the failure of social institutions (and their physical and cultural manifestations) that can be attributed to the institutions’ having been constructed to deal with a narrower range of variation than is in fact present in any given population” (155, 1997). They then advocate for both universal design and individualized solutions which take into account the fact that individuals who share common impairments may still have a wide variety of needs and preferences when it comes to the accommodation of impairments (e.g. an accommodation for Deafness might involve any of: cochlear implants, Braille, sign language, and more) (102, 2001). They also importantly note that accommodation preferences and needs not only varies between individuals with similar impairments, it might also differ for the same person at different times in their life. The focus on individualized solutions in addition to universal design as an answer to environmental barriers keeps this model from fitting neatly into the social barriers social model. However, the perspective they take that a diagnosed impairment tells us little about what accommodations should be provided, as well as their focus on non-medical interventions as a means of accommodation keeps it from being more in alignment with bio-psycho-social models. This also importantly leaves the door open for the human variation model to be used as a

rationale for accommodating a wide range of ways of being and moving through the world that might not always be classified as an impairment or a disability, since the focus is on the fact that humans and their capabilities exist along a vast spectrum which is not currently being accommodated and should be accommodated. Finally, the focus on the duty of society and workplaces to accommodate these individualized situations keeps this model from treading into a more medicalized ground, as the onus of “fixing” the “problem” of disability is still on society/businesses for failing to consider the range of human variation.

Models of disability such as those proposed by Bickenbach and Ladner which consider disability in the realms of policy and assistive technology respectively carve up various facets of disability based on how systems accommodate disability. Bickenbach, for example, takes the categorizations of the ICIDH²¹: disability, impairment, and handicap and associates those with medical, economic, and social approaches to disability. Impairment then becomes how medical and associated systems diagnose and treat disability (Bickenbach, 1993, 69-79), while disability is how economic systems compensate for the lost economic productivity of disability and businesses’ lack of employment of disabled people (Bickenbach, 1993, 93-131), and handicap is the discrimination and lack of access that social realms deal with (Bickenbach, 1993, 137-158). This allows us to understand disability differently in different realms of experience and also allows for the fact that impairment may not neatly line up with handicap or disability. For example, a person who is perceived to have an impairment might be discriminated against and

²¹ This scheme has been replaced by the ICF which now states that disability is “an umbrella term for impairments, activity limitations and participation restrictions,” (WHO, 2002, 2). This uses updated language, but still correlates to the impairment, disability, and handicap classifications that Bickenbach uses, where disability is activity limitation and handicap is participation restriction.

therefore have a handicap as a result, even if they do not *actually* have an impairment, or don't have the impairment that is suspected. Similarly, a person who does have an impairment may not experience disability or handicap if their impairment is well-managed and/or socially acceptable, as is the case with persons who wear glasses.

Ladner looks at disability specifically in regard to assistive technology, and the realms in which assistive technology is made or not made available. He calls these models, although they are more like realms where individuals may or may not have access to technologies. These realms include medical, rehabilitation, special education, legal, and social (Ladner, 2011, 26-28). This attempts to get a holistic picture of how disabled persons might acquire assistive technology and what types of assistive technology they might need in general in each aspect of their life. This shows the points at which disabled persons needs specifically in regards to assistive technology intersect with various desires they have and systems they interact with, and will be discussed more at length in the next chapter.

Another incomplete model of disability which picks out only one aspect of disability is Martiny's phenomenology of disability. This model highlights that despite the work that has been done in this field, there are still aspects we leave out. It might be desirable to integrate a model such as this with other theories of disability to show a richer interiority of the experience of disability. Preliminary results from Martiny's work seem to indicate that this kind of approach shows a clearer dichotomy between experiences of congenital vs. disabilities (Martiny, 2015, 556-557), and which indicate political and legal systems, and societal attitudes towards disability have a large influence on post-reflective experiences of disabled persons (Martiny, 2015, 562). Post-reflective experiences are significantly different from pre-reflective or reflective experiences of

disability. Pre-reflective experiences of disability occur before the experience is recognized as being or being related to disability (e.g. blurred words while reading due to chronic pain) while reflective experiences are those in the moment being cognizant of the disability cause, and post-reflective experiences make sense of what came before.

Finally, we have Anita Silvers and Elizabeth Barnes who start from the conception that disability is, or at least, should be value-neutral, and in many ways unremarkable. Silvers calls her conception a “neutral” conception of disability. This conception attempted to remedy an older divide²² between bioethicists and disabled persons. She claims a neutral conception of disability would endorse neither a social, nor medical model of disability (Silvers, 2003, 477). The reasoning that underpins this conception is the idea that disability *by itself*²³ does not require any interventions, and that accommodations should be made based on specific needs, i.e. people who need painkillers should get them because they need them for pain, not because they are disabled. She says that while disabled people often need healthcare and other goods, these needs “often intersect[] with but should not be conflated with, the disability category” (Silvers, 2003, 479). This also helps us to help those who are in need but for whatever reason might be unwilling or unable to take on the identity category of “disabled”.

²² While it may be true that some bioethicists still hold eugenicist views towards people with disabilities and see disability as straightforwardly bad, as a disability scholar writing nearly 20 years after the publication of this article, I see the bioethics space as being much more open to disability pride and seeing the value in disability. Additionally, there is currently no consensus in the bioethics community that the eradication of disability via gene therapy or prenatal testing is permissible or a desired outcome either for society or for disabled persons.

²³ Here it is unclear whether Silvers uses the term “disabled” to mean “has the status of a person with disability,” or “has an impairment” (though the difference between the two may be moot since governments traditionally confer the status of disability on the basis of some diagnosed impairment). In either case, she is referencing the idea that either the status or impairment needs intervention only in concert with some particular goal or co-occurrent symptom, and in those cases it is the goal that should be enabled or the symptom that should be treated, as is elaborated in my example.

Barnes' view is a more recent conception of this value-neutral idea of disability, that she calls the "mere-difference" view. She identifies that disability is like any other minority-identity category such as being a racialized person, being 2SLGBTBQ+, being a woman, etc. These social minority locations are not generally considered to be bad in-and-of themselves (e.g. being gay does not make one worse off). However, experiences of oppression and other external factors which exist in society, outside of these individuals and their bodies, might result in them being worse off, but it is the prejudice against them that results in the badness (e.g. gay persons out in public may fear or experience violence from others) (Barnes, 2016, 54). However, this oppression she does not consider to be part of disability, which sets her view apart from the minority social model of disability, and is at least somewhat corroborated by an important point from Bickenbach which is that individuals without an impairment and who may not be identified as disabled by themselves or by others may nonetheless be discriminated against at times if strangers perceive a disability that is not there and treat them with discrimination as a result (Bickenbach, 1993, 54). Furthermore, Barnes admits that while some experiences of disability might be bad for some persons, on the whole, across all persons, bad effects of disability will balance out with good effects of disability (Barnes, 2016, 75). In addition, she thinks that what might generally be considered to be "bad effects" of disability are not bad effects of disability at all, but rather are a consequence of a mismatch between a particular environment (physical, social, cultural, etc.) and a particular desire (Barnes 2016, 100-101). While bio-psycho-social proponents like Shakespeare will still state that even in a perfect environment some disabilities (such as those involving chronic pain) will be bad, Barnes uses testimony from disabled persons with chronic pain to argue that this is still a mere-difference that might promote different

friendships, values, and ways of living that can still be valuable. She also notes that chronic pain is complex, understood differently in different cultures, and can be highly affected by attitudes towards it (Barnes, 2016, 73-74, 115).

2.3 Desired Qualities of a Model

As we have seen the range of models of disability is vast. This range represents differences in conception of disability, in weight given to particular aspects of disability, and in priorities for various projects, outcomes, and supports that should exist for disabled persons. Despite this, modern disability theories seem to share a common goal: a better life for disabled persons, however that might be conceptualized. This goal seems to lead to some underlying implicit desiderata for a comprehensive model of disability that many models share even if the expressions of these things or their subsequent outcomes differ. While partial or more focused models such as Ladner, Bickenbach, and Martiny's are useful in understanding an aspect of disability, it is hard at times to understand the implications of their views or how those views should guide us as they tend to be more descriptive in nature rather than prescriptive. In contrast, comprehensive models of disability share the above common goal and have prescriptive elements. It is that kind of comprehensive model which I will be building up in a techno-inclusive way in future chapters.

It seems then that some common desiderata of a good theory of disability are that the theory should be: descriptively accurate, politically motivating, be sensitive to a wide range of

experiences and types of disability, and result in good outcomes for disabled persons²⁴. Of course, the ways in which these desiderata might be evaluated, and perspectives that evaluators bring to the table in evaluating these desiderata will vary. That is to say, models may vehemently disagree over *what is* descriptively accurate, motivating, sensitive, or a good outcome, but a comprehensive model of disability will address each of these in some way, and models which critique or enhance existing models usually do so on the basis of one of these grounds.

For example, in regards to the first desiderata, descriptive accuracy, the social model and bio-psycho-social model differ on what is an accurate description of disability. Similarly, models like the phenomenological model attempt to tell us that our current description of disability is not as holistic as it could be, and would be more complete with the addition of that element. This desiderata is also intertwined at times with the third desiderata of sensitivity to the heterogeneity of disability. In addition to telling us *what* disability is, a model should also be somewhat congruent with intuitions arounds who counts disabled²⁵. While there is of course contest over this there should be some way of reckoning with the breadth of disability as encompassing those with sensory impairments, learning disabilities, mental health concerns, and in some cases chronic conditions. It should also have some way of classifying the wide range of self-reported feelings towards disability (for example, the medical model might tell a person who

²⁴ All models of course desire to strive for good outcomes for disabled persons. However, not all models have been measured in terms of their good impacts on disabled persons (especially since in regards to policy we have been stuck largely in the medical model with some aspects of the social and biopsychosocial), and some proponents claim that models do not have in actuality, good outcomes (or good *enough* outcomes) even if they might fulfill the other desiderata. This is elaborated on further in the next paragraph.

²⁵ This is not meant to leave out persons who might not be visibly marked as disabled, but rather to illustrate that a definition of disability should generally include those who self-identify or are identified by disabled peers as disabled. For instance, we cannot simply define disability as illness because then this would leave out a group of amputees who generally consider themselves and are considered by the disabled community to be disabled.

thinks their disability is in fact a good thing that that person is mistaken, but the model still needs to acknowledge such persons and experiences exist).

In regards to the second desiderata, social and bio-psycho-social models clash again as to which conception will be politically motivating and in which directions that motivation will propel the disability movement. Although the social model has resulted in a widespread social movement and the emergence of disability pride, the bio-psycho-social model critiques both it and mere-difference conceptions of disability on the grounds that they are alienating to individuals who feel their impairments are the substantive portion of their disability, and that those impairments/disability is largely negative (Devidi and Klausen, 2013). Similarly, a medical model is motivating, just in the direction of increased healthcare scope and funding, and moves towards the cure and prevention of disability. This also shows how the desiderata of political motivation and the desiderata of heterogeneity might be intertwined in some cases, since bio-psycho-social folks think the political position of social models is at least in part weakened by the exclusion of those folks who see their disability as being wholly or largely constituted by their impairment. However, there are also cases where a particular model might be politically motivating, as it seems that social models have been in the last forty years, but might still be critiqued as not leading to good outcomes. For example, the human variation model could be used as a critique of the minority social model on the grounds that the advancement of disabled persons rights has resulted in insufficient pragmatic effects and have failed to make a meaningful difference in the lives and work of disabled folks (Scotch and Schriener, 1997).

One might argue that models on their own do not, or need not commit to particular political motivations or policy positions. This might seem especially tempting if we want to place

a divide between the descriptive elements of a disability theory and the prescriptive elements of a disability theory, or because not all theories have explicitly prescriptive elements. Of course, not all disability theories are comprehensive, as I have stated above. Those that are more robust though, I argue do hold particular policy and political positions whether they are explicit or not. At the very least a description of disability precludes some policy positions. For instance, the social model precludes policy positions which construct disability as a disease to be treated. Furthermore, the history of disability scholarship, the delineation of *what disability is* is itself political. It says something about how disability should be conceived of in the public and this has ripple effects. If disabled people are not seen as real, equal people then this encourages policies of disenfranchisement and exclusion. Given this history, I argue that disability theories which do not have either implicit political positions which can be drawn out or explicit ones are incomplete as theories. These positions and policies will be of a higher level, not a granular one²⁶, but nonetheless, they are an important part of disability theory. The core of these theories all have goals for disabled people which require certain political commitments to achieve those goals.

Good outcomes might take the form of quantifiable metrics such as economic engagement by disabled folks in the form of employment data, or in terms of years of life

²⁶ There are social contexts and contingencies which may require more localized policy recommendations. For instance, it would be unreasonable to expect a disability to recommend “a person with disability x in y place should receive exactly \$z per month.” Or even to recommend just one of those variables down to a particular. However, it is perfectly reasonable to expect a disability theory to hold a position on whether or not disabled individuals should be provided the necessities of life or what, in general principles those necessities of life might be as they relate to disability. Again, this may not be explicitly stated, but such theories are created in collaboration with others, are built and iterated on, and are compatible or incompatible with various recommendations.

extended. This could of course vary from disability to disability. It might also take the form of more qualitative data such as testimony from disabled persons on their quality of life, or positive effects for their caregivers.

2.4 Conclusion

So, while there still are still myriad grounds on which to critique models of disability that take into account descriptive accuracy, political motivations, good outcomes, and inclusivity, it seems that a good model must at least have a position on each of these issues. In the next chapter I will consider how the models discussed here interact with concerns regarding assistive technology, and argue that assistive technology is difficult to classify under the traditional medical and social models, as well as why it does not fit neatly into existing policy predicated on these models. I will then propose that to remain descriptively accurate, pragmatically impactful, politically motivating, and sensitive to a wide range of disabled experiences, disability theories need to incorporate these technological concerns.

Chapter 3: Disability Theory and Technology

In the first chapter, I described the current AT landscape, by establishing the myriad different types of AT that exist. I argued for a classification of mainstream, bespoke, and orphan AT in order to emphasize how AT are accessed by and developed (or not developed) for disabled persons. Furthermore, I described some select examples of the ways in which technology more broadly can either create or minimize barriers that disabled persons face. Then, in the second chapter, I looked at the current landscape of disability theory and these theories' competing priorities. I argued that these theories seem to share common goals and desiderata which include that a theory should be: descriptively accurate, politically motivating, result in good outcomes for disabled persons, and be sensitive to a wide range of experiences of disability. In this chapter I want to consider how AT fits into disability theory, and how disability theory can be accommodating of AT since AT, and tech more generally is such an important part of life. My secondary goal in this chapter is to advance a techno-inclusive model of disability by drawing on elements from existing disability models. This techno inclusive model will then be developed in further detail in Chapter 5.

I will begin by re-iterating the desiderata I have provided above. Then, I will establish that the AT landscape cannot be holistically included in the current dominant social and medical models of disability. While bio-psycho-social models can be accommodating of AT, they do not give us good direction on how to focus and agitate politically in regards to AT. I will, however, suggest that the Human Variation Model of Disability can give us good guidance for crafting a techno-inclusive model, and that in fact, incorporating a Human Variation perspective in a

techno-inclusive model gives us additional benefits from a perspective that seeks to improve designer/policymaker/gatekeeper attitudes as to what the purpose and goal of AT should be. Finally, I will consider whether or not the existing technological model of disability that is proposed by Ladner sufficiently fulfills my desiderata, and I will argue that it functions more as a descriptive model of the current landscape rather than a prescriptive model of disability which tells us how to act moving forward. In my closing statements, I will then suggest that to create a substantive whole techno-inclusive model of disability, it is imperative to first consider the testimony of disabled persons.²⁷

3.1 Disability Desiderata: Integrating AT

In the previous chapter, I came to the conclusion that the following were desiderata for disability theories. The first is that the theory should be descriptively accurate to the experience of disability. This means that the theory should tell us what disability is and who fits into that category. Next, a theory should be politically motivating. There should therefore be some desire from disabled persons and those in their sphere such as family, friends, and caregivers to advocate for some political action. In this way, a theory should give people a reason to act as a group, reflect on their identity and goals as a group, and work as a community towards those goals. It should also help in an explanatory way to share these ideas and goals with others (e.g. voters, policymakers, members of other communities, etc.). These goals are generally intended to result in good outcomes. This leads us to the third criteria, which is that the theory of disability

²⁷ In this chapter, I take it as self-evident that the testimony of disabled persons is key to having a rounded conception of disability, and to have an understanding of how AT is thought of in the disabled community. I will be advancing arguments as to why that is the case (and dealing with counterarguments as to why someone might think it is not the case) in the next chapter.

should actually lead to good outcomes for disabled folks by materially improving their lives. In particular, I think it is important that it improve their lives in a way that they themselves testify that it has improved their lives. Finally, a theory of disability should be attentive to the wide range of experiences of disability, as the disabled population is highly heterogeneous. This means we need to accommodate a wide range of experiences of disability from sensory impairments like blindness or deafness, to mobility impairments, to chronic conditions like diabetes or fibromyalgia, to learning disorders, to mental health and other neurodivergences and even to those who may only be perceived as disabled (such as individuals with disfigurements that do not medically impair them). Let us now examine what these desiderata mean in light of the important role AT plays in the lives of disabled folks.

In regards to what disability is, AT gives us strong evidence that disability is more than simple impairment as the medical model asserts. Where technology changes, so too does the impact and experience of disability. In the first chapter, we saw examples of technology profoundly affecting the severity of disability such as how telephones increased barriers for those with auditory impairments, and computer complexity increased barriers for those with visual impairments (Wise, 2012, 171). These technologies also diminished barriers, especially in the workplace, that allowed disabled folks with higher education to participate, even if the diminishment of barriers was not the goal of these technologies (Roulstone, 2016, 92). Therefore the same technology can be assistive for one group or person, while exacerbating barriers for another group or person. Disability is also affected by what AT in particular individuals have access to or are pressured to use. If someone is a child with congenital disabilities, their use of AT may be dictated by their parents or other caregivers. If someone is an adult their use of AT

may be contingent on a particular diagnosis that gives them access to funding under various insurance programs, or their access to financial support or engineering acumen. In particular, requiring diagnoses may reinforce rigid rules surrounding who counts as disabled, and what counts as a disability. Therefore, we might see a feedback loop effect, where one particular model's (usually the medical model's) definition of what a disability is affects who can access AT, and then since AT is bound up in identity and disability, we loop back around and causally in society we may identify those using particular types (especially readily visible types) of AT as being disabled, making them more subject to potential discrimination which increases experiences of disability.

Aside from the impact on opportunities, activities, and sense of their self as a disabled person, there are also examples of individuals' sense of self changing as a result of integrating technology into their conception of their disability and person. For example, Mullins and Harbisson self-identify as "cyborgs," and Harbisson talks about how his sense of self including his sensory perception, dreams and more, are impacted by his relationship with the AT he uses (Harbisson, 2012). Other self-identified cyborgs report similar relationships with their AT (Sargent, 2016). Disability is then meaningfully changed by technology. Regardless of whether or not a disabled person decides to use AT, their experience of their disability will be influenced by the technologies available to them. Furthermore, they may choose to integrate the AT they use into their sense of identity.

As far as political motivation goes, we have seen a few issues relating to AT thus far which require government support and motivation. Governments (and therefore voters, lobbyists, and other political advocates in indirect ways) create legal standards and protections

(such as accessibility requirements) for disabled folks, and they may also provide income supports, or supports specific to medical interventions as is the case in Canada. In the absence of greatly increased income supports, it will be necessary to provide additional financial or in-kind support to enable disabled persons to access non-medicalized AT (and in some cases medicalized AT as well).²⁸ Additionally, as we saw in both of the previous chapters, another key issue related to tech that requires political motivation and activism is the need for enforced accessibility standards. These standards do not necessarily make technology assistive on their own, but, if as some authors have argued, universal design is how we accommodate the needs both of disabled persons and align with the current tech landscape which is rapidly evolving, then the technology that is created under such guidelines has the potential to become AT when used by folks with a disability for reasons related to the disability, even if they are mainstream tech. The incidence rate of tech becoming AT will likely increase under such a scheme since the user base of tech will broaden. This is what we see in the increased multi-tool nature of cellphones. Some disability theorists of course might argue that this is more of the same, and that accessibility requirements under a human rights legal approach have failed (Scotch and Schriener, 2001, 101; 1997, 154), which is why particular attention needs to be paid to regulating technology, and to ensuring these regulations have appropriate enforcement mechanisms. Alternatively, we could see actions such as those recommended by Seelman relating to orphan technologies, where companies are financially incentivized to either specifically support AT, or to ensure universal design (therefore eliminating or at the very least, severely diminishing the need for orphan AT) (Seelman, 2005). Finally, the ubiquity of technology and the ways in which

²⁸ As will be demonstrated in later chapters.

technology is integrated into all aspects of our life makes it an important rallying point to make sure disabled folks are afforded full citizenship and the ability to participate in political and social life, as well as to labour.

The criterion of political motivation is, of course, intimately connected to the criterion of having good outcomes for disabled folks. Disability theories and their impact on politics should be measured. Being politically motivating is insufficient if that motivation and activism does not actually lead to real change. This is what Scotch and Schriener point out in their criticism of a human rights approach to disability. With technology this means that our advocacy should ensure that disabled folks have access to technologies that are desired. In the previous chapter, we saw the outcome of a variety of studies related to AT, even if findings are sparse and more data collection is necessary. Nonetheless, this data tells us several important things about how disability theories should integrate AT in ways that are likely to lead to good outcomes. First, it is important that the use and advertisement of AT does not play into ableist narratives that assume it is always the goal of the disabled person to be “rehabilitated ‘back to normal,’” or which “unknowingly reproduce conceptual dichotomies between able-bodied and disabled, and normal and deviant” (Phelan et. al. 2014, 2073). Furthermore, we have data that tells us that the following are key for the continued use of AT. So, inasmuch as continued use of AT can be considered a good outcome, we know these criteria help with good outcomes. These criteria are disabled consumer involvement in the selection process, professional support in the continued use of technology, and the ability for individuals to “re-invent” their devices, allowing for bespoke “additions or modifications to their devices to meet their unique needs” (Reimer-Reiss

and Wacker, 2000, 45)²⁹. Therefore, it is key that manufacturers of AT do not create barriers to the re-invention of devices. To further measure good outcomes in objective ways, we can consider other metrics which will require resources and further study. These potential ways of measuring the good outcomes of AT could include things like the effect of AT on employability, income, life expectancy, or savings on caregiver or medical costs for individuals who use AT. In the next chapter, I will consider testimony as to what disabled individuals subjectively report to be good outcomes in regard to AT.

Finally, we want to be attentive to the broad, heterogeneous nature of disability and have AT reflect that heterogeneity. While perhaps the most perfect AT solution to this issue would be to ensure bespoke AT for any disabled person who desires it, alongside providing universally designed mainstream tech. Unfortunately, the first part of that solution seems obviously not feasible or scalable, as there persists a high correlation between disability and poverty (Goodley, 2011, 43-47). Universal design principles give us some hope, but orphan or bespoke technology too will also be necessary, as many disability theorists note that universal design by itself cannot be a panacea, especially when it comes to environments, and so if technology is going to compensate for those environments it will have to compensate in different ways for different disabled persons. Shakespeare gives the example of universal design in city architecture, where “blind people may find that kerb [sic] cuts which liberate wheelchair users make it difficult for

²⁹ While I will not discuss it in this thesis, this point raises challenges for current monopolistic industry tendencies to prevent repairs to devices under the guise of copyright and software patenting. I am unaware as to whether or not these tendencies have invaded the AT space specifically but they have certainly invaded the tech space more generally. A key example of this phenomenon is John Deere tractors, which the company argues are only licensed by users, not owned, and therefore users (who have bought these devices) are forced into paying overpriced fees for proprietary parts and software. Apple is another notorious example of pushing laws and regulations that make modifying devices or software difficult and/or illegal. (Wiens, 2015)

them to differentiate pavement from road, and leave them vulnerable to walking into the path of a vehicle” (Shakespeare, 2006, 46)³⁰. In the far future we might imagine a utopia coming about in which a solution is designed that accommodates all users regardless of their abilities (perhaps a world in which cars are technologically prevented from hitting unwitting pedestrians), even in light of conflicting impairment needs. However, such a solution is impracticable at the current moment, and I am concerned with what real-world changes we can enact in policy to ensure a good AT scheme now. In the current moment, universal design is not possible for all technologies or tasks (both because we do not have the technological acumen and because as mentioned in the previous chapter, people at times have conflicting needs). Scotch and Shriner give the example that operating a transit bus or flying an airplane necessarily requires “a certain level of visual acuity” at least until technology changes such that vision is no longer integral for these tasks (Scotch and Schriner, 2001, 104). Even in largely universally designed systems there may remain a mismatch between “individual attributes and the requirements of even universally designed systems” and this is when customized solutions are necessary (Scotch and Schriner, 2001, 105). In light of scarce resources though, customization may need to be an offered solution only in cases where universal or orphan AT are unavailable (or in the potential case where bespoke solutions are cheaper, such as may be possible with 3D printing).³¹ Logistically as well as financially though, it would be difficult to ensure bespoke AT for all disabled persons. Finally, to meet the desiderata of accommodating a wide range of disabilities, we must

³⁰ Although this is constantly evolving, and more universal solutions may be found. For instance, it is becoming more common to add bumps to sidewalks around curb cuts, so as to signal to blind people that the road is ahead, while simultaneously providing the cut for people with mobility needs. (Sidewalk bumps, 2017).

³¹ Even if in a world of limitless resources this might be a desired outcome. In future chapters we will see that many disabled people express a preference to be able to use the same products as nondisabled persons.

accommodate not just the heterogeneous nature of disability which makes universal design at times difficult, but also the heterogeneous attitudes that disabled persons have towards their disability and towards assistive technology. That facet of this fourth desiderata will also be discussed in the next chapter on testimony.

To conclude this section then, I will summarize what we should look for in a disability theory, given the importance of the AT landscape to the experience of disability. First, a disability theory should have a way of describing the complex interaction between impairment, technology, task, and environment. Second, a disability theory should motivate disabled persons along with their families, friends, caregivers, and perhaps even the general citizenry to ask governments to implement a regulatory scheme to encourage or require the development of tech that adheres to principles of universal design, and that provides funding and support to disabled individuals who wish to acquire AT.³² It should also encourage employers to accommodate the use of AT and promote flexible employment schemes to take advantage of the full breadth of accommodation that technology offers. Third, a techno-inclusive theory of disability should encourage measurement of the impact of AT on the lives of disabled folks, and elevate the testimony of disabled persons as it relates to their use or non use of AT. Finally, the theory should promote a multiplicity of AT solutions, including mainstream, bespoke, and orphan, where they are respectively needed, and should accommodate a variety of disabled attitudes towards AT, which will be expanded upon in the next chapter.

³² Just as a medical model motivates further research into cures, and a social model motivates more stringent human rights protections or environmental modifications.

3.2 Considering Models of Disability in Light of AT Desiderata

Now that we have desiderata specific to AT, we can begin to evaluate existing disability theories in light of that desiderata. In this section I will argue that the major players in disability theory that currently influence politics and medicine are not currently up to the task of integrating the concerns of AT. I will suggest that there are elements from several theories that we can draw on, in particular the Human Variation Model of disability since that model also gives us access to ideas that theorists have pointed to as a path forward for AT. I will consider whether or not Ladner's technological theory of disability is a superior offering, but will suggest that it is less promising than drawing elements from more holistic models of disability because it does not make prescriptive claims about disability that show us how to move forward and improve the AT landscape going forward in the way other models do.

3.2.1 The Medical Model

First, let us turn to the medical model. As covered in the previous chapter, the medical model remains influential on medical and political systems in terms of their policies and in the attitudes of professionals who interface with disabled persons. The implicit claims that are made by proponents this model are that disability is an individual problem or misfortune, and that the best way to address disability is to seek to bring disabled persons up to some norm, such as "species-typical" functioning (Amundson, 1999, 45)³³. Under this model, impairments are measured and treated by medical professionals. As was asserted in the first chapter, AT that is medicalized does tend to fit neatly under this model. As was demonstrated in the study from

³³³³ Whether or not they adhere to this model consciously or deliberately.

Phelan et. al, and writing by Silvers, the assumption that is made by developers and marketers of AT is that AT is to be used to bring an individual up to some level of species typical functioning, that this is desirable for disabled persons and their caregivers/families, and that the true purchasers and consumers of AT are the medical professionals who oversee the AT process rather than the disabled person who will be using the device (Silvers, 2010) (Phelan et. al. 2014).

Just because existing, medicalized AT fits neatly under this model though, does not mean that this is an ideal model even for medicalized AT. We might suppose that many or most bespoke and orphan AT require the involvement of a medical professional at some point along the process, and that the goal of many of these interventions is a medical goal of treatment or cure (though not always, as some examples of bespoke AT such as Mullin's legs or Project Unicorn are primarily for aesthetic benefit and not used for the purpose of mitigating or curing impairment). Nonetheless though, this model fails disabled individuals in a few ways. First of all, the gatekeeping inherent in this model means that individuals who cannot access diagnosis or for whom the diagnosis doesn't line up with traditionally prescribed AT (such as the example Roulstone gives where individuals who desire wheelchairs may not be able get a referral/prescription for them if they don't need them all the time) end up with their needs going unmet ((Roulstone, 2016, 4). Secondly, as will be addressed in later chapters, this system can be very burdensome for disabled persons in terms of the time and effort it takes to navigate, and the support offered for medical interventions can still fall short of true costs.

Aside from these issues, the medical model cannot accommodate AT which does not seek to fix impairment, and excludes mainstream AT which is not mediated through medical systems, and AT is far more vast than just those technologies that are actively medicalized. In

some cases, it might be preferred that mainstream AT is obtained in consultation with a medical professional (one might imagine a case where something marketed as mainstream AT might exacerbate an existing impairment or may not have any effect at all, for instance, a person using traditional headphones at too-high a volume to compensate for hearing loss, therefore exacerbating it, when hearing aids would be better), or in the cases of certain therapeutic or telecare apps there may be a medical professional on the other side³⁴. But, in the cases of smartphone and computer technologies more broadly, innovations like dark mode, persistent mainstream AT like closed captioning, and more, there is simply no medical involvement in an individual's acquisition of the AT. Even if we consider some AT to be within the broader medical ecosystem (similar to hygiene products, over the counter medication, wellness products and marketing), the medical model cannot be the totality of the picture. As will be shown in the next chapter, many disabled persons do not see their AT as aimed at fixing or curing their impairment, which is the ideological construction of the medical model. Nonetheless, medically mediated AT are valuable technologies, and valuable specifically for disabled individuals even if those individuals lack a formal diagnosis or might not themselves identify as disabled (e.g. the elderly). These technologies are sometimes covered under accessibility rules (such as universities providing closed captioning or notes of lectures to individuals who are hearing impaired), or not-for-profit funding schemes, but more often, these technologies are accessed like any other consumer good without involvement from a medical professional.³⁵

³⁴ Though to my knowledge, such services are always privately paid for, and not part of Ontario's regular healthcare system. This is a rapidly emerging realm of services.

³⁵ These systems will be addressed at length in later chapters, and it may be the case that these systems ought to be less medicalized (i.e. dependent on diagnosis of particular impairments) and cover a wider range of AT costs.

I and others have already argued that mainstream technology is valuable in addition to orphan and bespoke technology because pragmatically it creates a larger user base and therefore there is more support for it. Universal design also helps to advance goals of anti-discrimination both by enabling access to a given technology in the first place, and because it means that there are less opportunities to visually identify someone as disabled through their use of technology which could open them up to discrimination. The medical model has the greatest difficulty dealing with this group of technology. Furthermore, the medical model may in fact encourage orphan technologies due to its focus on treatments for particular diagnosis. This is contrary to what Seelman and Wise argue is beneficial if AT is to keep up with the pace of technology more generally (Seelman, 2005; Wise, 2012) and thus ensure that disabled persons are not further disadvantaged by having access only to older technology.

Overall, this means that the medical model fails to fulfill the desiderata. It fails capture the complexity of the interaction between technology and disability because it is conceptualized as all-or-nothing and does not capture the myriad of purposes technology can serve in relation to disability that go beyond considerations of impairment. This lack of attention the breadth of uses of AT is itself a failure of the final desideratum of heterogeneity, and also leads to it being politically less useful as there are no ways to advocate for AT that falls outside of the medical sphere (and it seems self-evidently absurd to consider trying to medicalize all mainstream tech that is potentially used for AT purposes), as well as fails to give us reasons to observe the outcomes of such non-medicalized AT.

3.2.2 The Social Model

Nonetheless, the medicalization of some AT gives us some clues as to why AT also does not fit neatly into social model conceptions of disability whether that be a social barriers or a minority model, since some AT will necessarily be medicalized due to surgical requirements as is the case with Cochlear Implants (CIs) and certain advanced bone-integrated prosthetics. Setting aside these examples though, even AT that is mainstream can act in ways that are contrary to the goals of the social model, or at the very least, that are not explicitly motivated by social models. As was established in the previous chapter, both major social models of disability seek to reduce the environmental barriers that society puts in the way of disabled people. As we saw in the first chapter, while some AT can reduce environmental barriers, some AT can increase it (such as telephones increasing barriers for disabled persons with hearing impairments), and this can function differently for different groups of disabled individuals even when we are talking about the same technology. This makes the task of eliminating environmental barriers via AT not straightforward, as we must consider competing needs given a wide variance in disability. Minority models have the benefit of being able to be used to promote non-discrimination against individuals who use AT that visibly identifies them as disabled (and therefore targets for discrimination), but it seems much more challenging to use such reasoning to promote, for instance, access to free smartphones, when while it might be of the utmost importance for disabled people so that they can access their accessibility related apps, having such a device is necessary for essentially everyone. Therefore, it can be hard to distinguish between the AT needs of disabled people and the tech needs of people more generally. To use the social model to advocate for such an intervention I think it would be necessary to establish that there was some

additional barrier disabled persons faced that were not faced by abled persons (including poor or other disadvantaged abled persons), and this would be quite difficult.

As we have seen too, the whole AT landscape cannot simply be reduced to mainstream AT that removes barriers, as there will be cases where bespoke or orphan AT is necessary. This tech may at times disincentivize the removal of environmental barriers in favour of technological solutions. One example of this is that rather than promoting closed captioning in all spaces at all times, one can imagine the rise of smartphone accessibility technologies that create individualized voice-to-text outputs disincentivizing the further spread of such captioning. It is generally desirable both for barriers to be removed, and for individuals to have access to individualized solutions when such barriers cannot be removed, or perhaps even if they prefer an individualized solution (or something in the middle, such as a case where individualized solutions might be necessary in rural locations, but not urban ones). Individualized interventions may be harmful in some cases to disabled persons, and in the next chapter we will see criticism from disabled persons on AT like exoskeletons and stair climbing wheelchairs on the basis that they disincentivize wider social change like the acceptance of different ways of being and moving, and the implementation of more accessible spaces with ramps, automatic doors, etc. This is an important criticism that the social model raises, but there will be cases where such orphan or bespoke AT is not actively harmful, and where such AT will be desired by disabled persons. Some might be a grey zone, such as CI. Even, if everyone could learn ASL, some deaf³⁶ folks might prefer to have CI. Even if mental health concerns were not a barrier to employment,

³⁶ I use the lowercase deaf here to indicate that it seems likely such persons would not identify with Deaf culture.

some individuals might desire to have individualized apps to help them connect with counsellors and manage their care. Others though, seem incredibly unlikely to be contributing to environmental barriers and in fact help promote disability pride such as Project Unicorn and Mullins, and yet, still seem unable to be motivated under a social model view. These AT considerations nicely illustrates the critiques that bio-psycho-social model proponents level against social model advocates. Therefore, it is a problem that there is nothing in the social model which gives us political motivation to advocate for disabled persons to receive such AT where it is desired or is, perhaps, the only reasonable solution.

The social model then fails to meet the AT desiderata in two primary ways. First, because it does not consider the breadth of ways that individuals might conceptualize their disability and desire AT to navigate environmental barriers. We have seen that tech itself can exacerbate disabilities, perhaps even to the level of looking causative from a social model standpoint, and it seems both unlikely and undesirable to think about eradicating technologies like telephones or computers, so bespoke or orphan AT will always be necessary as a patch to the environmental barriers these technologies cause, and to the original environmental barrier of nature itself. Second, and relatedly, it cannot provide political motivation to promote access to bespoke or orphan AT, though it can give us valuable criticism of some bespoke or orphan AT which might be harmful and best to discontinue or not research in the future, more of which will be examined in the next chapter. Importantly though, the social model reminds us that this criticism is important and that we cannot support only AT which is bespoke or orphan, and must work to include barrier-removing, universally designed, mainstream AT.

3.2.3 The Bio-Psycho-Social Model in Comparison to the Human Variation Model

As discussed in Chapter 2 (48-52), the bio-psycho-social model beneficially tells us that disability is a complex interaction between impairment, environment, and social location. Still, although the bio-psycho-social model can help us to understand the weaknesses of the social model of disability, especially with regard to AT, this is not enough to make it the best fit for the basis of a techno-inclusive model of disability. It does ask us to be critical of solutions which attempt to address only one of these elements, or which privileges one of these elements over the other, and is skeptical that universal design by itself can be a panacea. However, I argue its combination of various elements from the social and medical model unfortunately makes the bio-psycho-social model ineffective at measuring the outcomes and advocating politically for certain types of AT over others. Furthermore, I argue that it is ill-suited for encouraging the kind of policy change that I believe is necessary to un-medicalize financial support for AT that can be un-medicalized and therefore distributed to a wider range of disabled people who may benefit from it, whether or not they are diagnosed or identify as disabled³⁷. These claims will be argued for later in the thesis in the sections dealing with policy. The kind of emphasis that the bio-psycho-social model places on diagnosed bodily impairment, namely, an emphasis which accepts the ableist conceit that one needs to identify “as abnormal to get services and benefits” (Shakespeare, 2006, 72) and which imagines technology as “a response to special needs, not an inclusive and non-discriminatory universal provision” (Shakespeare, 2006, 47) does not seem like the best path forward as this continues a history of charity and demarcation of one group as

³⁷ For example, the elderly, who could still greatly benefit from AT.

other and needing more than a base group.³⁸ While it might initially seem that we need to distinguish between disabled “special needs” and nondisabled needs to politically motivate protections for disabled persons, this is not the case. I argue that branding disabled needs as “special” enables the current state of affairs where disabled needs are considered after the fact and separately from other standards, requiring further motivation for accommodating disabled needs than if disabled needs were simply seen as part of human needs. Nonetheless, the bio-psycho-social model lends us insight as it shows that a wide range of disabled needs in regard to AT can be considered, and that what we conceive as both medical and social interventions can be valuable, and more of those needs can be covered under this model than the medical or social model alone.

Finally, the Human Variation Model (as described in Chapter 2, 54-55) gives us a strong path forward when it comes to integrating AT into our disability theory desiderata. This model has two key benefits over the bio-psycho-social model while still being able to accommodate a wide range of disabled needs and preferences. These two benefits are: first, that it can give us direction as to how to prioritize AT needs, and motivate them without picking out disability as a special category (and therefore easily relegated to the position of an afterthought); and second, that the main thrust of this model allows us to think more broadly and creatively about AT in ways that scholars argue would lead to better outcomes for disabled persons. The core of the Human Variation Model is that “the problems faced by people with disabilities might be seen as

³⁸ As opposed to noting that we all have different needs, and that even within the disability community there are different levels of need, none of which can be accurately understood on the basis of a particular designation. Other issues with the designation of normal vs. abnormal were covered in Chapter 2 (pg. 33-34).

the consequence of the failure of social institutions (and their physical and cultural manifestations) that can be attributed to the institutions' having been constructed to deal with a narrower range of variation than is in fact present in any given population" (Scotch and Schriener, 155, 1997). This perspective does a few key things in regards to AT. First, it explicitly talks about the ways in which social institutions design our environment. This, by extrapolation allows us to view the current technological landscape as being *designed*, and also notes that it has been designed incorrectly, because it does not consider the full range of human abilities and methods of completing tasks³⁹. Therefore, it accommodates a view of disability which addresses both bodily realities by pointing out the range of human abilities, but also like the social model emphasizes that mismatch between abilities and the constructed environment⁴⁰. From there, we can look for solutions as to how to accommodate that range of human experiences, and we are responsible for the solutions because regardless of impairment, the fact is that we might have designed our systems environments better⁴¹, and this gives us good reason to support users of AT. This perspective allows us greater latitude to support individuals using AT who may not identify explicitly as being disabled. The bio-psycho-social model of disability, while broad and nuanced in its understand of disability, still relies on the specific identification of disability to motivate support (Shakespeare, 2006, 64-65, 72, 75) and thinks that "disability is *always* an interaction between individual and structural factors" (emphasis mine) (Shakespeare, 2006, 55)

³⁹ I'm thinking here of technology which privileges some bodies over others because it makes assumptions of how bodies move in the world. For instance, cars which privilege people with four limbs, when it is perfectly possible for someone to drive fully without four limbs.

⁴⁰ Unlike the social model though, the Human Variation Model leaves space for non-environmental solutions to an environmental/capacity mismatch

⁴¹ In terms of technology, we might have designed telephones, computers, cars, etc. with disability in mind in the first place. In terms of social environment, we might have created workplace standards and norms that were already accommodating of disability.

The benefits of the bio-psycho-social model including its nuanced understanding of the complex interplay of the individual and the environment, and the need for differentiated supports regardless of diagnosis are shared by the Human Variation Model.

The Human Variation model, in contrast to the bio-psycho-social model, allows us to remove diagnosis as a requirement for access to support for AT. This has benefits for various groups, in particular, people with diagnosable conditions who aren't yet diagnosed (as diagnosis is often a very burdensome process,⁴² and individuals may not realize they *can* be diagnosed⁴³), or people who do not want to be diagnosed or identify as disabled because they do not see themselves as disabled (e.g. Deaf folks, elderly) but would still benefit from AT. Some might argue that removing a demarcation for disability might decrease political motivation and limit the ability to identify where particular need is I do not think this is the case. In fact, I think that if folks were more cognizant of the fact that “no whites will become black; few straights will become gay; but every normal person can become disabled” (Davis, 2002, 4) then there would be more incentive on the part of the general populous to support disability friendly policies. Third, while it is not certain that this model would necessarily result in good outcomes (this would need to be studied), it does take a new approach, and would seem to have good outcomes for disabled persons who find the severity of their disability is policed and who therefore struggle to access AT. For instance, Roulstone notes that wheelchair availability is becoming “increasingly problematic” since “some disabled people are refused access to wheelchairs due to

⁴² I take it as being common knowledge that even in countries like Canada with free healthcare, there is still a significant time and mental burden that comes with navigating systems, getting referrals, appointments with specialists, etc. to receive a diagnosis.

⁴³ I am thinking of many adult women who may have ADHD or Autism who often go undiagnosed because they are unaware they might meet the conditions.

medical conceptions which connect certain impairments with ‘wheelchair need’ and not others,” (Roulstone, 2016, 4). Roulstone further points out that “non-disabled thinking on cars, bikes, and public transport technologies would not conceive these needs in a binary need/does not need manner” (Roulstone, 2016, 4). Incorporating these elements of a Human Variation Model into a techno-inclusive disability would help us move away from that binary. This outcome and attention to the diversity of disabled needs and desires to access different technologies at different times, even for the same impairment is also in alignment with the desiderata of accommodating a wide range of experiences of disability. While the bio-psycho-social model does not correlate AT to particular impairments and therefore does not suffer from that binary, it still holds the binary of abled/disabled which as described above is still problematic.

In addition to fulfilling the desiderata I have set out, elements from the Human Variation model further allow us to emphasize something that Anita Silvers points out as being key to producing better outcomes for disabled persons, and reducing the ableism of the medical model in the development and use of assistive tech. This is the idea that should not merely bring someone up to a particular norm of functioning, but rather, that we should create space for AT to be used to uplift “people’s different functional modes” (Silvers, 2010, 13), and promote values of “functioning as well as possible” over values of “functioning normally”, accepting that functioning “other than” or “better than” new is just as reasonable goal as functioning “like new” (Silvers, 2010, 13).⁴⁴ Where the bio-psycho-social model still focuses on impairment (even if it situates it in a context that is larger than the body), the human variation model focuses on

⁴⁴ This elimination of the dichotomy and standard of “back to normal” is something that is also advocated for by Rehmann-Sutter and Scully, but not in the context of AT specifically.

variation, so while it is not necessarily the cases that the bio-psycho-social model prohibits or discourages functioning differently, this different functioning is an assumption of the human variation model from the get-go. In this way, AT continues to expand and to reflect the diversity of human variation. This model places responsibility for accommodating the vastness of human variation largely on society—governments and workplaces, and asks them to provide AT accommodations on the basis of what is preferred by the disabled person at a particular point in time. While it advocates for universal design, it also recognizes that at some times individualized solutions are necessary. When those individualized solutions are necessary though, this is not presented as a personal problem or failure on the part of the disabled person, but rather as an additional facet that needs accommodation because our systems have been designed in an inadequate way (Scotch and Schriener, 156, 1997).

In this section I have analyzed various disability models and discussed the ways in which they fulfill or do not fulfill the desiderata of a techno-inclusive model. I have argued that the Human Variation model in particular provides many of those desiderata as well as other benefits. Some of these desiderata are also fulfilled in part by the other models as well. However, given the incompleteness of that desiderata without the inclusion of disabled testimony, a more complete techno-inclusive model of disability cannot be advanced at this point. A fuller techno-inclusive model will be advanced in Chapter 5.

3.3 Why Not an Existing Technological Model of Disability?

Of course, Ladner puts forward another model of disability that is presented as being focused on AT, so before proceeding we should consider whether or not this provides a better basis for a techno-inclusive model of disability. I think that while Ladner brings important

considerations to the AT discussion and models of disability, their view does not have the completeness to satisfy the desiderata the same way that previously discussed models do.

In “Accessible Technology and Models of Disability” Ladner puts forward a number of what he calls “models” of disability with regard to AT. These models include: Medical Model, Rehabilitation Model, Special Education Model, Legal Model, and Social Model.⁴⁵ These models are not really models of disability in the sense that I advocated for in the previous chapter, as they are primarily descriptive rather than prescriptive, and their fulfillment of the desiderata is incomplete as they are not interested in addressing disability holistically. Rather, these models are meant to be representative of the realms of life in which disabled people can find access to AT, and the ways in which that access is meted out. For example, Ladner suggests that under the “Medical Model,” AT is conceptualized as treatment and/or (partial) cure and is accessed via prescriptions, and paid for by insurance. Since Ladner is looking at the US context, this treatment is expensive (Ladner, 2011, 26). Under the Rehabilitation Model, AT is needed for “employment and everyday life.” It is sometimes accessed and paid for through the employer, but also at times paid for by the disabled person (Ladner, 2011, 26). Under the Special Education Model, AT might be provided to some disabled children, specifically for the purposes of education (Ladner, 2011, 26-27). Under the legal model, AT related to legal access is provided free of charge, and disability legislation enshrines certain rights related to AT such as non-discrimination for the visible use of AT because this legislation is meant to ensure that disabled persons are treated equally with other citizens (Ladner, 2011, 27). Finally, under the Social

⁴⁵ The medical and social models here are *not* synonymous with the medical and social models I have previously discussed.

Model, for disabled folks to participate in the diversity of life access to various spaces is needed and that access often comes through the use of AT. Under this model AT is often paid for by the disabled persons unless otherwise mandated by law (Ladner uses the example of Closed Captioning being one such mandated AT) (Ladner, 2011, 27).

Ladner's "models" can help us categorize the realms of life in which AT is used and desired but ultimately these categories are underdeveloped and do not give enough attention to mainstream and bespoke ATs which are currently inadequately covered by government legislation and which I will argue in later sections need to be guided in ways that are appropriate to the method of access categorizations that I have proposed as opposed to the realm of life categorization that Ladner uses. Furthermore, I argue that the realm of life distinction Ladner uses makes it too easy to focus on "just the basics" i.e. work, basic necessities, education and not broader things like social participation or hobbies. Even though these facets are covered under the "social model," because of the lack of prescriptive elements we are not given an impetus to increase support in this area under Ladner's model. A system that allows a focus on AT in some realms of life but not others I believe is discriminatory against disabled people, because a selected focus would cut off some important realms of life, and furthermore, we have at least some practical evidence to believe that AT that is restricted to such realms leads to worse AT. One such concrete piece of evidence comes to us from wheelchairs, as many of the improvements in wheelchair design which have bettered the life of disabled persons came from sport wheelchair designs and the use of wheelchairs in sport (Roulstone, 2016, 188). Additionally, as we will see in the next chapter, disabled persons desire AT in all realms of their life, and not to simply be treated as potential workers, or their AT treated as a means to

increased economic productivity (either in actual work potential or in decreased hours of labor required for their care either by themselves or their caregivers).

While there is some possibility that we might extend Ladner's view to be more complete, given the descriptive nature of his project, there simply seems insufficient grounding on which to build a more robust technological theory. Ladner's view risks over-emphasizing the purposes for which disabled persons use AT, and has the potential of minimizing the important social realm which we have seen is key to the improvement of AT, and which is self-evidently important if disabled persons are to be able to live comparable lives to abled persons. Instead, I will propose in future chapters that the elements Ladner introduces are useful when thinking about the various realms of life in which individuals use AT, and can be used in the application of a techno-inclusive model to ensure the breadth of existing systems is captured.

3.4 Conclusion

This sketch of the desirable qualities and suggestion of a promising for a basis of a techno-inclusive model of disability is then, still incomplete as we do not yet have the perspectives of disabled persons themselves and what they wish to be the new status quo as it relates to AT. The importance of having this perspective is something I have taken to be self-evident throughout this section, and I have gestured to particular gaps in the implementation of an techno-inclusive theory of disability that remain unless we gather the perspectives of disabled users of AT, but will argue for in the next chapter. These gaps, in particular, apply to the "good outcomes" desiderata as well as the desiderata of accommodating the heterogeneity of disabled persons, inasmuch as that heterogeneity is reflected not just in impairments themselves, but also in the attitudes of disabled persons towards their disability and towards AT.

Despite these gaps though, in this section I have put forward a set of revised desiderata for a techno-inclusive model of disability, have shown how dominant disability models fail to accommodate the complexity of the AT landscape, and have suggested the Human Variation Model has many elements which make it a strong primary contributor to a techno-inclusive model of disability, alongside considerations from other views. First, I made proposals as to how the desiderata of a model of disability apply to the AT landscape. Then, I considered how each of the major disability models are able to accommodate those desiderata. I suggested that although there are beneficial elements to various models, our current desiderata can be drawn from the Human Variation Model. I also suggested that the Human Variation Model can go beyond the desiderata to allow for and encourage a more beneficial conception of AT that opens up possibilities for disabled people that go beyond traditional conceptions held by medical professionals and engineers as to what AT is meant to provide. I considered Ladner's technological model of disability as an alternative but ultimately shelved it as being too descriptive and insufficient at directing policy when it comes to increased access to a wide range of AT for disabled persons, although it will be useful when considering the current policy landscape in later chapters.

The techno-inclusive theory that I have begun to sketch will be developed further in the next two chapters using the perspectives and testimony of disabled persons. Then, it will be used in subsequent sections to advance policy goals related to the access and funding of AT in Ontario. The work I have done in this chapter not only highlights the importance of integrating AT into a theory of disability given the importance and ubiquity of AT, but also, I believe, highlights broader failures on the parts of theorists and governments to integrate everyday

technology into our social institutions (i.e. medical systems, social assistance supports). I hope that this broader issue and question is taken up by others going forward.

Chapter 4: Disabled Testimony

In the previous chapter I examined disability theories in light of the desiderata that AT raise. However, we could not fully define the desiderata and therefore could not fully evaluate this model without the testimony and perspectives of disabled persons. Therefore, in this chapter I want to take a step back and provide a space for that testimony and those perspectives to answer the two fundamental questions relating to AT desiderata that remained: 1) What kinds of different attitudes towards AT are there in the disabled community (heterogeneity)? and 2) What is a good outcome in regards to AT as far as disabled people are concerned (good outcomes)? To that end, I will begin first by providing some arguments as to *why* it is absolutely imperative to elevate disabled testimony and disabled voices, including the “Nothing About Us Without Us” movement, and the historical harm done when the testimony of disabled people is ignored, as well as the discriminatory nature of ignoring their testimony. Then I will examine testimony from disabled activists and laypersons related to the two questions I mentioned above. Finally, I will synthesize this testimony into some key takeaways and desiderata regarding AT and show that despite differing attitudes, shared criteria can still be established. I will then use that shared criteria in the next chapter to complete a techno-inclusive model of disability which incorporates disabled perspectives and concerns.

Before moving on to the focus of this chapter, however, I would like to note that this is not the first time that disabled voices have featured prominently in this thesis. Although the singular focus of this chapter is disabled voices, they have been here all along. In the first chapter on technology I included testimony from disabled cyborg activists Mullins and

Harbisson (29-30). Similarly, Reaume is cited there as an AT user and proponent (27, 31). The voices of others are aggregated in the study on the continuation of use of AT by Reimer-Reiss and Wacker. Disabled activists are also featured in the second chapter on disability theories. Without the inclusion of disabled voices, and the elevation of those voices, we would not have social models of disability. Similarly, Shakespeare and Kafer, proponents of the bio-psycho-social model, are disabled themselves.⁴⁶ Here my intention is not to diminish the importance of these voices throughout, but to add to the chorus and look specifically at attitudes towards assistive technology to answer the questions I have posed above.

4.1 The Importance of Disabled Testimony

There are two key and interrelated reasons for my elevation of disabled testimony.⁴⁷ The first is that disabled testimony represents testimony that comes from a place of epistemic privilege (Fricker, 1999) that comes from the embodied experience of being disabled and which abled persons cannot access.⁴⁸ The second reason is that historically, abled persons and ableism in society has been such that the testimony of disabled persons has *not* been respected, and this has led to the infantilization and minimization of disabled persons and their autonomy and has

⁴⁶ This list is also not meant to be exhaustive. Although I am aware of the biographic details of many of the writers that I cite, others are more private about their personal life circumstances and social positioning. It should not be a requirement of disability scholarship that individuals need to out themselves as disabled, especially given the academy's continued, if not hostility, then indifference towards disabled persons and their adaptive needs.

⁴⁷ While I will be advancing these arguments in this section, I firmly believe that it should not be necessary to provide justification for the idea that we should believe disabled people about their own lives, and that we should consider folks who hold disabled identities as unparalleled sources of knowledge. Nonetheless, these are the demands of my discipline.

⁴⁸ The exact reason for and distribution of epistemic privilege and expertise is discussed and debated more at length in the literature, but for my purposes it is sufficient to establish that such privilege exists and that by virtue of their experiences as disabled persons, many disabled persons and many more disabled persons have this privilege and knowledge than nondisabled persons, and their expertise as such is epistemologically valuable over and above the knowledge produced by nondisabled/dominant group persons.

as a result caused real harm to disabled persons. The dismissal of disabled testimony is a major contributor to ableist attitudes such as the idea that it is “better to be dead” than disabled (Basnett, 2001, 453-454). Later in this chapter, it will be shown via testimony that similar harms are done with some AT.

First, let us address the question of epistemic privilege. Epistemic privilege is an idea that comes to us from feminist standpoint theory. This theory argues that those with more marginalized “standpoints” or social positions, tend to be better knowers on matters related to their social positioning and are valuable knowledge resources because they are aware of their own position as marginalized, as well as aware of the dominant position and mindset, (Harding, 54, 1993). The specific knowledge that is gained about what it is like to be and live as a person with a marginalized identity as a result of being marginalized and living in that standpoint is knowledge that is easily overlooked or dismissed by those in more dominant positions (Harding, 55, 1993). Although this is classically applied to White vs. Black and feminine vs. masculine positions, it can also be applied to abled vs. disabled positions. This lines up very strongly with demands from the “Nothing About Us Without Us” disability rights movement, as documented in the seminal and similarly titled book by James Charlton. This movement advances the need for policymakers to “incorporate people with disabilities into the decision-making process and to recognize that the experiential knowledge of these people is pivotal in making decisions that affect their lives,” (Charlton, 1998). This is the epistemic *benefit* of involving disabled testimony in disability theory and policy. In particular, for this project I will show through testimony later that the types and ways in which AT are developed and accessed will be benefitted by the inclusion of disabled voices and perspectives in the design process.

The second reason to include disabled testimony and voices is the risk of epistemic and moral harm when testimony is dismissed or silenced. As with epistemic privilege, there is a robust epistemological literature documenting various epistemic harms, but here I will focus on just those raised in Scully's "From 'She would say That, Wouldn't She?' to 'Does She Take Sugar?' Epistemic Injustice and Disability." This article focuses specifically on the epistemic harms done to disabled folks when their testimony is dismissed or is not asked for in the first place. In this article, Scully uses the experiences of Susan, a deaf hearing aid user, who is continually dismissed when she reports broken induction loops which are meant to provide sound to her hearing aids in places like theatres and cinemas to cut down on background noise (Scully, 2018, 106). Scully points specifically at the testimonial injustice that is done to the disabled community by abled persons who publicly or privately dismiss testimony from disabled persons on their experiences of their disability and of the ableism they experience (Scully, 2018, 108). This testimonial injustice is not limited to disabled persons' experiences out in the world, like Susan with her hearing aids, but also extends to nondisabled persons' (including many healthcare providers) negative perceptions of disability which is in stark contrast to the high quality of life disabled persons generally report (Scully, 2018, 109-110). Basnett speaks to this attitude from the perspective of a physician who later becomes disabled, and notes the prevalence of "better-off-dead mentality" in physicians, i.e. the belief on the part of physicians that disabled people would be better off if they were dead (Basnett, 2001, 453-454). These attitudes, which stem directly from discounting disabled persons testimony about their quality of life, inform policy decision-making over the allocation of scarce health resources. These policies are then based on metrics which assume a disabled life is one of fundamentally less value than an

abled life, leading disabled people to face a “double jeopardy” of care where individuals who are suffering are also deprived of treatment on the basis of their suffering (even if they might have a high quality of life before or while seeking care) (Basnett, 2001, 456-457)⁴⁹. In short, when we do not listen to or believe disabled people, we assume their lives are without value. In assuming so, we then treat them as though they do not have value and diminish the quality and length of their lives.

This discounting of disabled perspectives also creates hermeneutical injustice “which involves excluding the knowledge of stigmatized groups from the collective epistemic resources”. This harm can create situations where disabled persons don’t have access to knowledge that might make their lives better such as expertise on how to most efficiently use a wheelchair (Scully, 2018, 112). These injustices can also overwhelm disabled person’s abilities to be autonomous and act for themselves, such as when disabled persons are assumed to have what Scully calls “*global epistemic incapacity*.” This term relates to a common experience disabled folks have where “a nondisabled person directs a question not a disabled person herself but at her companion, clearly believing that, say, a mobility impairment renders her incapable of knowing or communicating how sweet she likes her tea,” (Scully, 2018, 116). In short, it is common for people, including medical professionals to assume that disabled people, because of their disability, are impaired with respect to their decision-making capabilities, even if their disability has nothing to do with decision-making. This leads them to discounting disabled testimony and choices. It is well accepted that it is morally harmful to deprive agents of the ability to exercise

⁴⁹ Further discussion of healthcare rationing such as QALY will begin with Chapter 6 as part of the application of the techno-inclusive model of disability.

their autonomy when they are moral agents with clear capacity to reason— which is the case with many, many disabled people. It has therefore been demonstrated that there are clear epistemic benefits to the inclusion of disabled testimony, and clear epistemic and moral harms to disabled persons when their testimony is not respected.

4.2 Deriving Desiderata from Testimony

At the end of the last chapter, two main questions relating to AT desiderata remained. First, “What kinds of different attitudes towards AT are there in the disabled community?”; and second, “What is a good outcome in regards to AT as far as disabled people are concerned?” To this end I will be looking at testimony from disabled activists on their attitudes towards AT, and cure more broadly. I will also be looking at data from laypersons on Twitter who have engaged in the #DisabilityDongle hashtag. Before moving on to address the questions above, I will first introduce this data in brief.

The #DisabilityDongle hashtag seems to have originated at the 2019 AIGA (the professional association for design) conference on April 4th, 2019. Liz Jackson (@elizejackson) was quoted on Twitter by Flavia Stoian (@FlaviaStoian) as having made this statement in a presentation: “A well intended and elegant, yet useless solution to a problem we never knew we had. Disability Dongles are more frequently conceived of and created in design schools and IDEO,” (@FlaviaStoian, 2019). Jackson then commented below, #DisabilityDongle, and a movement was born. Jackson and others see the proliferation of #DisabilityDongles as being attributable to things like hackathons, student projects, design competitions, social media, and view it as a “sadly expanding genre” (@Suzybie, 2021). AT such as stair climbing wheelchairs, sensors on harnesses meant to alert blind folks to objects around them, sensors on shoes meant

to alert blind folks to objects around them, glasses to encourage autistic children to make eye contact, muzzles for children with Tourette's to prevent ticks, watches that display text in braille, and gloves meant to translate signing into text or speech are all mentioned in the tweets as examples of "Disability Dongles," (Appendix A). Aside from Jackson's activism work on this topic on Twitter and beyond, the conversation around #DisabilityDongle includes 189 tweet statements from 105 distinct, public users (Appendix A). This data was gathered through a Twitter API and includes only publicly available tweets (Appendix A). These tweets were made in the timeframe between the origination of the term on April 4th 2019 and data collection on May 22nd 2021 (Appendix A). The following sections will include examples from the data, as well as excerpts from Jackson's work and work others have done to expand and refine the concept of a "DisabilityDongle."

4.3 Testimony

Obviously, it is impossible to be exhaustive in cataloging the range of attitudes that disabled people can have towards assistive technology, especially as such attitudes may be constantly shifting as individuals' needs, desires, relationships, access to AT, and so on, similarly shift. Nonetheless, here I will attempt to detail the myriad and heterogeneous attitudes towards AT that exist, and show that ultimately, there are threads of agreement throughout various criticisms of and stated desired for AT even if disagreement on details remain. As we saw in Chapter 1, individuals such as Mullins who uses prosthetic legs, and Harbisson who uses a bespoke "eyeborg" to see colour, relate strongly their AT, incorporating AT into their sense of self and personhood, not identifying merely as disabled, but also as cyborgs (Sargent, 2016). They are hopeful for a cyborg future in which everyone has access to bodily-integrated

technology, and in which such technology allows individuals to be more comfortable with disability (Sargent, 2016). Similarly, participants in Reimer-Reiss and Wacker's study indicate that their attitudes towards AT may shift depending on how AT is presented to them, where consumers are more likely to continue use of AT where there is an ability for them to "re-invent" devices, using "additions or modifications" and where they have professional support, and "their opinions are taken into consideration in the selection process" (Reimer-Reiss and Wacker, 2000, 45).

Here I will look at further testimony from Clare, Reaume, and the #DisabilityDongle community to explore what other attitudes exist. Clare's *Brilliant Imperfection: Grappling with Cure* resists both a singular definition of cure and a single attitude towards it. AT falls under the umbrella of cure that Clare discusses in examples such as cochlear implants, which while they "don't meet the benchmark of cure," as they "neither eradicate hearing loss from the world at large nor restore individual deaf people to 'normal hearing,'" are nonetheless marketed and sold as "effective and necessary treatment that approaches cure," (Clare, 2017, 91-92). Cochlear implants are also resisted by Deaf persons on the basis that they do present cure in a way that minimizes Deaf culture and experiences (Clare, 2017, 91-92). Other examples he presents, such as the "weighted cuffs" he wore as a child for his cerebral palsy that he found deeply physically uncomfortable (Clare, 2017, 38), also seem similar to the #DisabilityDongle of eyeglasses which prompt autistic children to practice making eye contact, or the muzzle which suppresses Tourette's tics.

However, other AT seems more to fall under the umbrella of what he calls "treatment" or "adaptation," such as the typewriter he uses (Clare, 2017, 38). These AT are discussed in a

much more positive light, especially in the context of “Zoe’s Race,” which is a fundraiser for accessible housing retrofits, which is inclusive both in its process, where participants are invited to walk, roll, etc. and where the benefits are distributed based on need rather than diagnostic category, and in fact, mentions no particular diagnoses (Clare, 2017, 90). Finally, wheelchairs are powerfully described in the poem “Rolling” where Clare recounts how wheelchair users (and in particular, powerchair users) leave “walkies” “in the dust every time,” and how “when manual chair users become/ tired or have difficulty with a steep incline” they do not ask the “walkies” for help, but rather hitch to their “power/chair-using friends” (Clare, 2017, 99). The poem closes with the thought that “I don’t mean that rolling is better than walking; just that/walking has long been overrated,” (Clare, 2017, 99).

Above, we see that attitudes towards AT can be variable depending on the AT itself, as well as the user’s own experiences. This tension is reflected in more general attitudes towards treatment and cure. While treatment is not cure, “diagnosis, treatment, management, rehabilitation and prevention” are all intimately connected with cure. None of these are “cure itself” but neither are they fully distinct either from cure or from each other (Clare, 2017, 71). While Clare does not fully explain how each of these things is connected, the important connection that I argue can be drawn for the purposes of this project is the ableist attitudes that underly all of the elements, namely, that individuals would be better off being nondisabled, and if that is not possible then bringing them as close to normalcy and ablebodiedness as possible is the goal. This goal then becomes a guiding ideology and value system, even where ablebodiedness cannot be achieved. Diagnosis then medicalizes impairment and designates it as

a problem.⁵⁰ Treatment and rehabilitation aim to eliminate or reduce the problem that been identified through diagnosis. Prevention and management seek to prevent further problems, or to mitigate and minimize the current problem.

All of these elements make that goal possible and work towards it. This makes AT where it aims towards compulsory ablebodiedness, especially in the medical context, potentially as messy as cure itself. While one individual might welcome one intervention another may be skeptical or hostile towards the medical establishment's upholding of socially coercive forces (e.g. masculinity, misogyny) that encourage the individual to change rather than working towards changing the world (Clare, 2017, 180-181). To illustrate this, Clare uses the example of how he welcomed his top surgery, and his friend welcomed her gastric bypass, but each disagreed with the other's choices. This seems analogous to attitudes towards the use of some assistive devices, as will be shown in the data later.

The ableism inherent in cure as a guiding value and related aspects of cure are harmful, Clare argues, because they justify ableist rhetoric and allow charities to “shamelessly use pity, tragedy, and the belief that we would all be better off without disability” (Clare, 2017, 13). Similarly, diagnosis which allows access to cure, treatment, and in some cases AT is harmful because it often leads to “shame”, a propensity for institutionalization, when it delegitimizes

⁵⁰ This is not to say that diagnosis is always wholly negative. Many individuals find a lot of comfort in acquiring a diagnosis that explains their experiences, rather the medicalization of diagnosis and the way it focuses on removing the disease that has been diagnosed, and opens up individuals to pathologization, infantilization, and institutionalization is problematic. Furthermore, treating “symptoms,” or however we want to describe the “bad stuff” of disability or anything else seems possible without diagnosis, since we have seen that diagnosis does not really reveal anything important about how best to serve a persons' needs to recognize them as persons. Diagnosis could be potentially good in some world where the former benefits came without the latter drawbacks, but that world is not our current one.

experiences of pain, or when diagnosis is created for the purpose of profit (Clare, 2017, 41, 74-75). Cure as a value then tends to orient AT narrowly towards the goal of bringing people as close to normalcy or ablebodiedness as possible when it could be so much more expansive. Where ablebodiedness requires an overall functioning in a narrow so-called “normal range” in “species-typical” ways, we can imagine infinite ways to function with a disabled body that is enhanced or altered via AT. For instance, speech and writing are expected “species-typical” communication. Some disabled people enhance this by using sign language, but with technology a whole range of communication mediated by technology is possible. This is just one example. Therefore, a narrow, cure-based value scheme and prescription with regard to AT is to be avoided to avoid negative responses and attitudes towards AT amongst disabled people. Instead, all options must be explored to accommodate disabled heterogeneity: AT which offers different functioning, AT which enhances, and AT which cures when that is desired and where such an offering does impose a value proposition that this is the best course of action and that disability is something lesser-than. This also accommodates the fact that attitudes around AT may not necessarily be bound up in what AT is itself, but in how it is marketed, who benefits monetarily from its use, what coercive forces there might be encouraging folks to take up or to not take up AT (such as how AT is provided and funded), and how all these things contribute to ableism in society more generally. This gives us a framework for teasing apart *why* attitudes towards AT differ, and also, where they might at a fundamental level converge.

This is well reflected in Reaume’s autobiographical article “What Do You Do When Your Disability Keeps You from Writing? What I Learned When I Launched a Brute Force Hack on my Brain.” The assistive devices she mentions in this article include: the F.lux App (for

blue light minimization), an anti-glare screen protector, hiking poles, colour tinting glasses (which were made into bespoke AT through the addition of tape in the middle to prevent her eyes “overly fusing”), dark mode, high contrast mode, a text-to-voice app, Freewrites, a Remarkable table, an eInk monitor, and a GPS hiking app (Reaume, 2020).

These AT devices Reaume credits as “open[ing] up my life” but she also does not shy away from criticism that the reason why many of these devices are necessary in the first place is because screen-based technologies are currently hostile to people with visual processing disorders. She questions why accessible features cannot be baked into technology from the start— such as being able to buy a laptop that simply comes with an eInk screen, or Remarkable being designed in such a way that it can be easily used with a standard keyboard and word processors. She also questions why some apps have not taken-up accessibility modes such as dark mode, and notes that she is unable to use important social networking tools like Facebook, or engage in online dating because these apps do not support the AT that is necessary for her to be able to use them without inducing brain fog and pain (Reaume, 2020). Another major issue is the cost of many of these interventions, which is compounded by the fact that often Reaume had to purchase AT before she even knew if it would work for her. The total cost for the AT devices mentioned in the article alone, not including the physiotherapist appointments or vision therapist appointments which were integral to knowing about and accessing some of the AT came to a total of \$2,790 (Reaume, 2020). Of course, in the grand scheme of AT this is not even so exorbitant, with some power wheelchairs costing up to \$18,000 (Mobility Medical Supply, 2021). Nonetheless, these are costs which are prohibitive for many disabled persons, especially if

they are unable to work or rely on government assistance (the maximum assistance in 2018 in Ontario through ODSP was \$1,169/month) (Trick, 2018).⁵¹

Ultimately, Reaume says she has “a bunch of very expensive imperfect workarounds that I’m usually too tired to use at the end of the day” (Reaume, 2020). She pleads with the tech industry to stop disabling people in their rush to get products to market, and instead think about persons with disabilities as “there is no such thing as standard bodyminds. Human variation is broad. You need to design for that in your software and hardware,” (Reaume, 2020). In essence, Reaume is calling for tech designers to recognize the wide range of human capacities that exist in both disabled and nondisabled folks to ensure that the products they produce accommodate that range and are not themselves disabling or contributory to disability.

4.4 #DisabilityDongle, Sentiments from Social Media

These testimonies from Clare and Reaume above are the testimonies of activists, of writers, of disabled people who are in the public eye and who make calls to action to make things better. Of course, not all disabled persons are inclined or able to be such figures, and their voices are also important. To that end, I have analyzed all tweets using the #DisabilityDongle hashtag that was introduced above.⁵² Of course, given the nature of the hashtag many of the statements made are critical ones, but clear themes emerged as to what factors made something

⁵¹ So, to afford the AT that Reaume uses a person on ODSP would need at least three month’s worth of funding with no other housing, food, etc. related expenses. The cost of AT and the role of Ontario’s assistive programs in the AT landscape will be explored more at length in Chapters 6-8. Reaume is based in Canada, but not Ontario. However, the Ontario context will be the focus of later application chapters, which is why I use its social assistance program here.

⁵² Jackson’s tweets were excluded from the analysis as Jackson’s views are clearly represented in other texts written by her that are referenced here, and I did not want to skew the data of the hashtag towards the originator’s opinions, as it is expected that she is more engaged in the hashtag than any other Twitter user.

a #DisabilityDongle, and there were cases where #DisabilityDongles were recognized as such but still desired by disabled folks. Here, I will look at Jackson’s preliminary work to lay out the concept and issues raised by the #DisabilityDongle, and then provide my data analysis and key details from individual tweets.

As mentioned previously, Jackson originated the term #DisabilityDongle at a conference in April 2019. As a follow up, Jackson wrote and spoke on #DisabilityDongles in a variety of outlets. Jackson notes some shared elements of these technologies, such as that they are “pitched as inspirational” (implicitly presuming that disability is a tragedy). These dongles are largely created by nondisabled persons, organizations, and institutions who don’t understand the current landscape of AT or the needs of disabled persons and don’t do adequate work to understand how these devices can be unsafe, overly expensive, or place burdens on disabled people rather than on those creating inaccessible spaces (s.e. smith, 2019). This means that disability dongles can result in further marginalization and stigmatization, and risk “blue-washing” i.e. the appearance of being accommodating to disabled persons, without actually working towards their real needs, or in some cases actually rolling back protections for their real needs (CBC Radio, 2020).

The ideas and concerns raised by Jackson in creating the term “Disability Dongle” seem to be shared with other disabled laypersons on Twitter. Approximately, 29% of tweets using the hashtag #DisabilityDongle identified some piece of AT as a disability dongle and/or critiqued some particular disability dongle (Appendix A).⁵³ This category also contains much of the

⁵³ This represents the second largest grouping of data. The largest group was “information sharing and community building” which represented 42% of the tweets. As explained in APPENDIX A, the identification of

reasoning as to why #DisabilityDongles are undesirable as well as “calling out” various products as #DisabilityDongles. Many products were called out repeatedly. Tweets in this category were very pessimistic and expressed sentiments of “who is this even good for?” “will this even work?”. There was by and large a resistance to narratives of solving tragedy used in marketing materials (Appendix A). Frequent critiques of disability dongles included the high cost of devices, and fear that devices would continue to put the burden on “each individual #disabled person [to] adapt @ their cost.” (@AccEase 2020), as well as the related idea that the problem the dongle purports to solve is not the real problem people with disabilities face/not a problem at all. Along that final line, some questioned too, what goals the dongles were aiming to meet. For instance, glasses to encourage eye contact in autistic children were questioned on the basis that making eye contact is potentially “based on [the] goal of [an] able milestone not on the child” (@Samspearevans, 2020).

However, this is one portion of the data, and although it shows that there is derision and skepticism of some AT, this cannot be taken as the totality of disabled attitudes towards AT or even towards Disability Dongles. Another category, the category of “Is this a disability dongle?/This isn’t a disability dongle” represented 7% of tweets (Appendix A). It demonstrates that it may not always be easy even for disabled persons to identify all disability dongles. Things that were questioned as being potential #DisabilityDongles were either not answered by the community, or were designated as NOT being Disability Dongles. However, that does not mean

something as a #DisabilityDongle and specific critiques of disability dongles were lumped together because the term is meant to be inherently pejorative.

they are beyond critique. For example, @VarunChandak_ brings up a new “inclusive deodorant” which is suitable for folks with limited arm mobility, compared to the usual twisting, turning, and pushing required by deodorant. Chandak praises the existence of this important implement, but critiques its special design and inability to be used with all deodorants, noting that while it is a good move forward “We, the people with disabilities, are after all the original life hackers. We figure a way out.... people with disabilities don’t always want “special” products. We just want the regular, everyday products to be accessible” (@VarunChandak_, 2021). Similarly, items could be not #DisabilityDongles but still be problematic in their messaging or marketing, such as an advertisement for a pregnancy test for blind folks that doesn’t require visual cues. The Tweet and article in which the product was advertised used no alternative text for their images, which raises the question of who the marketing is even for, if the designated user group cannot consume it (@MrSulaimanKhan, 2021).

Additionally, there were two examples (2% of tweets) of individuals who recognized certain tech as a Disability Dongle, but nonetheless, desired them. @DeaffHistorian, notes that while sign-to-text gloves are largely denigrated as being a #DisabilityDongle and they recognize that label is justified, they nonetheless desire such a product to come to market, and have been dreaming of it for twenty years. This is because of their particular context where they have nerve pain in their hands that is such that they can sign, but cannot type without pain. They think that this dongle can be valuable and also be improved by involving disabled persons in the design process (@DeafHistorian, 2020). Other desires for #DisabilityDongles may be mistakenly identifying such things as dongles, or may be a niche, but still worthwhile product, such as this

daughter who is looking for a #DisabilityDongle to help her father navigate a hospital during COVID while in a mask as a sip + puff wheelchair user who does not want to be pushed by a caregiver (@epcoffman, 2020).

4.5 Synthesizing Attitudes & Good Outcomes in regards to AT

Ultimately, while the details of the attitudes on particular ATs remain varied, and in some ways we might have to let AT reflect Clare's sentiments on cure and let it "be the contradictory mess it is", there are shared elements that can be agreed upon (Clare, 2017 183). Where consensus can be determined, it seems to be that AT is desired when: 1) it does meaningfully improve the lives of disabled people 2) in ways that do not additionally place burdens (financial, social) on them to overcome their disability 3) or risk diminishing the importance of environmental and social changes and 4) the product is not marketed in a way which plays into ableist narratives around pity and tragedy. However, different disabled people will identify different things as meaningfully improving their lives (1), and others may accept other failures in regards to 2-4 if it benefits them personally. In addition to what is to be avoided, it seems that what is in particular desired is universally designed AT which allows disabled persons to use the same technologies as nondisabled persons.

Similarly, the idea of a "good outcome" for any one individual is hard to determine, but we can say some global things about what a good outcome looks like. A good AT, as noted by Reimer-Reiss and Wacker, is one that disabled people want to continue using. It should also be something that improves their life in a meaningful way either by making a task/activity easier or more efficient, or allowing the opportunity to complete a new task/activity that was previously

inaccessible to them. However, if an AT contributes to ableist narratives and erects new barriers, or prevents the eradication of existing barriers, this seems to be harmful in the long run. Even if it is not immediately harmful for the disabled person themselves and their place in society, steps backward for any disability seem likely to present eventual ripple effects, and represent a significant risk. For example, a figure who might resist criteria 2-4 is Christopher Reeve. Reeve is a complicated and generally disliked figure in the disability space, due to his championing of curatory endeavors like stem cell therapies and reportedly spent more than 270,000 Euros every year on therapies and treatments while accepting and benefiting from donated AT (Shakespeare, 112, 2006). Weighing these harms is a challenge, and folks may disagree on how to do it, but it is agreeable that it needs to be done. While it seems difficult, especially given the heterogeneous nature of disability to strictly prohibit technologies which violate 2-4, we can still say that the research, development, and acquisition of such technologies ought not be publicly funded (and perhaps even that the charitable status of organizations which pursue such technologies might be revoked). Such measures also seem more reasonable given that, it seems likely that everyone could be satisfied if in every case there was an AT that could simultaneously provide the assistance that a user desired from it, that also did not contribute to or reinforce ableist mindsets around disability, and that was reasonably accessible (i.e. the individual was aware of such an intervention, was able to access it without diagnosis and/or diagnosis was easy to obtain, and they did not need to pay more for it than they are financially able to). However, at the current time it is unrealistic to expect or require all AT to fully satisfy that description, but we can set such a standard as an evolving goal.

Overall, there remains the possibility of irreconcilable conflict between what is a good outcome for a disabled individual, and what is a good outcome for the disabled community as a whole. A good outcome for a disabled individual might contribute to ableism and therefore be bad for the disabled community as a whole. But conversely, ensuring good outcomes for the disabled community might prohibit the use of AT that would result in good outcomes for individuals, especially given our current non-ideal world and the slow march of social change which might mean individuals do not realize the good outcomes of said group change given long timelines. It therefore seems unconscionable to recommend the wholesale banning of disability dongles, but nonetheless I think along the lines of my earlier statement that we can say that governments and not-for-profits should not be in the position of promoting disability dongles or supporting their use except perhaps in rare cases where other AT is not available. We can say that where resources are scarce AT that is not a Disability Dongle should be prioritized.

When evaluating any particular AT or emerging AT, we do have some guidance to help us and this can serve as a shared criteria. Some of the #DisabilityDongle tweets (5%) were focused on theory building around #DisabilityDongle (Appendix A) and one from @Touretteshero presented a blog post which provided questions that can be asked of AT to determine if AT is a “Disability Dongle” or “Disability-Centred Design.” These questions include:

- “1) Is the product created by a design team that includes people with lived experience of the barriers the product addresses?
- 2) How many people with lived experience have identified a need for this product?
- 3) Have the disabled people who’ve contributed to this product been paid or credited for their input?
- 4) Have people who might use this product said that it’s unhelpful?
- 5) Could this product be used to justify systemic barriers?
- 6) Are you confident the product will work in the real world?

- 7) Is the product likely to be prohibitively expensive?
- 8) Are users central to the messaging associated with this product?"

(Tourettes Hero, 2020)

These questions are aimed primarily at designers and marketers of AT, but if those individuals can answer these questions in a satisfactory way, or if the answers can be discerned by disability theorists, policy makers, and healthcare professionals, they also seem fruitful in guiding the beneficial use and support of AT. For example, it seems easy to gain consensus that products which are created by a design team that include people with lived experiences of the barriers (1) the product addresses are desirable, and that even if a product might be desirable without this criteria being met, it would be better if this criteria were met and if disabled persons were included in the process for all the testimonial reasons given at the beginning of this chapter. Similarly, it seems inarguable that disabled people should be compensated for their input (3) and that it should work in the real world (6). Prohibitively expensive (7) is obviously undesirable, and that has been clearly stated in testimony, but it seems impracticable to ban such products in our current capitalist, consumerist society. So we might agree that such products are undesirable, and that cheaper products are better, but disagree as to whether or not we might want to move towards a system where accessibility can no longer be bought in the form of prohibitively expensive AT.⁵⁴ Finally, in this chapter I have also provided strong evidence that messaging associated with the product (8) should not be ableist, and I take this to be user-

⁵⁴ Expense is also related to policy, as governments can subsidize expensive products. However, this has its own considerations which will be discussed in later chapters.

centered since the user base for AT will necessarily be disabled people who are harmed by ableist rhetoric.

Other questions may have more disagreement. While we can agree that at least one person with lived experience should identify a need for an AT product (2), it's less clear how many need to identify such a need before it should be widely supported (especially by governments allocating scarce medical resources). Similarly, one person saying a product is unhelpful (4) may not be enough to justify eliminating its use if it is especially valuable for another. The justification of systemic barriers (5) may be one such reason for finding a product unhelpful, and should strive to be avoided, but in some cases needs might conflict or the removal of barriers might simply be too demanding in terms of financial costs or impositions on others, such as if we required every person learn ASL to accommodate Deaf persons (something we don't require with any other linguistic minority), or requiring the re-building of entire European cities to eliminate stairs. It is also important to note that while AT may allow systemic barriers to continue to exist, the non-existence of AT is no guarantee that those systemic barriers would be otherwise removed, and AT is (often) not responsible for the barriers in the first place.

The final shared consensus that is not addressed by this list is the desire for universal design. However, it seems clear that where universal design is possible that is often preferred for some of the reasons above. Universal design works in the real world, it is often the cheapest intervention for disabled people (in that it does not place additional burdens on disabled folks above and beyond what nondisabled folks face). In other places though, we can see the list further guiding universal design in ensuring marketing is not ableist (and perhaps, further, that it does not exclude disabled persons from marketing materials in terms of representation and

access), that disabled persons are part of the universal design process in a meaningful way, compensated for their efforts, and able to financially access products they help to design and market.

4.6 Desiderata Revisited

Despite the heterogeneous nature of disability, and the resulting diversity in testimony, it seems that we do nonetheless end up with some guidance as to what the desiderata for a techno-inclusive model of disability should look like. To accommodate the heterogeneous nature of disability and ensure good outcomes for a model of disability we must respect both the common ground that has been uncovered and the heterogeneous attitudes of disabled persons towards AT and protect against the harmful outcomes of AT that have been flagged through their testimony. Therefore, in addition to the desiderata raised in the last section, a model of disability that is techno-inclusive should be able to handle the following.

In relation to the first point on the heterogeneous attitudes, a model should not be prescriptive as to what intervention might be desired for any particular disabled person. A desire for AT, even AT that might be overall harmful to the disability movement and push for the elimination of environmental barriers may be reasonable in some cases,⁵⁵ but it will be obligatory to still mitigate potential harms posed by the proliferation of Disability Dongle style AT. Mitigation should be done in accordance with the guidance discussed above. Conversely, it is not enough to take a single instance of disability testimony of a device being positive for a single

⁵⁵ Such as for @DeafHistorian, where environmental barrier removal seems impossible (we do not demand that all individuals learn all languages), as other text-to-voice alternatives are painful. Which cases are reasonable will be taken up further in chapters 6-8 where the reasonableness of governmental support for various interventions will be considered.

user or even a group of users as evidence that a device is beyond critique from other members or groups in the disability community. It is entirely possible that a device might be helpful for as many people as consider it harmful or unhelpful. This is to be expected. It is unreasonable to critique individuals' needs, and may be inadvisable to critique their desires even if they are suspected to come from internalized ableism, but devices themselves can be critiqued, especially on the criteria I have provided that seem widely agreeable. Additional resource-distribution based critiques may be reasonable, and will be further addressed in later chapters.

In relation to the second point on ensuring good outcomes from AT, a model must both prevent harm and promote good. However, it may not be possible to simultaneously promote all goods and prevent all harms, especially since I have demonstrated that these things may be in conflict. Like all consequentialist calculi, the exact balance in each situation as to the trade offs of goods and harms (especially when balancing group interests against individual interests) are impossible to make, let alone predict. What can be said though is that in the testimony I have analyzed it was demonstrated that harms can happen both by not listening to disabled voices on a macro-level, and on the level of AT itself. Designers and governments must listen to diverse testimonies to be aware of potential issues, and to protect developmental and support resources where those might be scarce, as well as ensuring that support for AT does not come at the expense of the removal of environmental barriers and ableism in design more broadly. Major themes that emerge in testimony tell us that promoting good can involve a few things. Primarily, AT seems to have the best outcomes when disabled people are involved in the selection of their AT, and ideally if they had the ability to trial AT prior to making expensive purchases. Failing that, having better education on the part of healthcare (including rehabilitation) professionals as

to the AT landscape can be helpful, as is connecting individuals with broader disabled communities such that they can access that more robust knowledge network. Support at all steps is crucial. Additionally, in the testimony there was repeated calls for more products that are made with universal design in mind such that disabled persons do not have to buy special products. Special products come with additional costs and more limited choice which minimizes the good that AT can do. Similarly, when products visibly mark individuals as disabled they may be at risk for harm via the discrimination. Universal design can be practiced in accordance with the guidance and shared principles as described at the end of the previous section.

4.7 Conclusion

In this section I have engaged in three major activities. First, I justified the need for and importance of disabled testimony when crafting a model of disability, and in particular, when understanding needs of disabled persons as it applies to AT. Second, I looked at a breadth of disabled testimony including testimony from activists, and laypersons, looking at a variety of uses of technology that was inclusive of mobility, neurological, and learning disabilities. Third, given that testimony I proposed further desiderata of a techno-inclusive model of disability. In the next section, I will conclude my analysis of the various potential disability models and provide a final techno-inclusive model of disability that can then be used to guide policy moving forward.

Chapter 5: A Techno-Inclusive Model of Disability

In the last four chapters I have motivated the need for a techno-inclusive model of disability. I have shown that a techno-inclusive model of disability is necessary given the combination of rapidly proliferating assistive technology (and technology more broadly), and the current lack of attention to assistive technology in disability theory scholarship. Given these needs, in chapter 3 I began to look at what desiderata a techno-inclusive model of disability should include, and suggested various benefits and drawbacks of existing models which could be ported into a techno-inclusive model. However, the story was incomplete without an accounting of disabled testimony and how disabled persons felt about assistive technology. Therefore, in chapter 4, I analyzed various disabled testimony, as well as advanced why such testimony is necessary. I arrived at a few remaining testimonial desiderata related to the diversity of attitudes towards tech amongst disabled people and what constitutes good outcomes in regards to tech for them. In this chapter I will integrate those final desiderata and advance a more complete techno-inclusive model of disability.

In this chapter, I will begin first by orientating the reader to the ultimate goal of the project, which is to provide the necessary framework to help understand the proliferating technology and AT landscape, and then guide policy from a disability-focused perspective. Providing the framework is the goal of this chapter. To that end I will then reiterate the testimonial-related desiderata presented in the last chapter. Once again I will evaluate these desiderata against existing disability models. By drawing elements from various models and discarding problematic aspects of others, I will then present a techno-inclusive model of disability and describe how it fulfills testimonial and other desiderata. I will emphasize this

model's benefits given our current state of affairs, and argue for the benefits of such a model and how such benefits exceed other potential models. In particular, I will argue that a techno-inclusive model illuminates the ways in which technology affect experiences of disability in ways that other models cannot fully conceptualize. This illumination in turn gives us guidance on how to integrate the importance of AT into policy and disability activism. Finally, I will gesture towards my next chapters 6-8 and the specific application of the techno-inclusive model that will be undertaken there in the form of using the model to evaluate the current state of social supports for disabled people in Ontario.

5.1 Applications of a Techno-Inclusive Model of Disability

First, let us turn to the realms in which a techno-inclusive model of disability will be valuable. Although the eventual goal of this project is to apply this model to the Ontario context of assistive technology supports for disabled persons⁵⁶, this is not the only possible application. It is my hope that this model will inform governments more broadly, by illuminating areas in which disability related laws, policies, and/or programs have gaps given the proliferation of technology, by drawing their attention to AT that is outside of the traditional medicalized box, and by emphasizing that AT is ubiquitous, diverse, and so important to the lives of disabled persons. Additionally, outside of human rights codes, governments have tended not to use regulatory power to influence the disability practices of corporations creating technology and AT, and such things have generally been left out of disability theory. However, a techno-

⁵⁶ This will be further unpacked in the next chapter, but this includes legislation that might require the provision of AT, programs which provide direct income to disabled persons, and programs which provide AT to disabled persons.

inclusive model and the resulting potential attitudinal shift towards disability that comes from such a model (along with the experiences that motivate such a model) give us reason to think that corporations should think more carefully about the kind of tech, both AT and non-AT that we make. A techno-inclusive model of disability can tell us how and why they ought to be more careful in making AT, and furthermore can caution against making AT that is less or undesirable for various reasons that were illuminated in Chapter 4 (122-124). It also illuminates the benefits to disabled persons of taking such actions and precautions when it comes to the creation of AT.

Additionally, is my hope that if a model such as the one I will advance in this chapter obtained wider uptake it might result in small or large social shifts in understanding of disability and its hurdles, as other models have. It seems clear that it would make a world of difference to disabled persons if their use of some AT but disdain for other AT was accepted and understood by those in their circle (friends, family, caregivers, etc.). A techno-inclusive model provides reasoning and grounding for the idea that not any and all potential cures, treatments, or therapies need be pursued. Additionally, a techno-inclusive model gives us the context needed to challenge the idea that tech is a “luxury” for disabled folks⁵⁷ but rather an integral accessibility need. This is especially important given general societal attitudes that those who rely on social assistance do not deserve luxuries. Finally, I believe that the way a techno-inclusive model highlights the connection between technology and disability, illuminates the highly contingent nature of nondisabledness and might encourage others to interrogate their needs as it relates to

⁵⁷ Of course, its questionable whether technology is a luxury for anyone at this point, given the integral nature of having at the very least a personal smartphone with internet capabilities.

technology, potentially finding empathy along the way⁵⁸. Some of these goals are loftier than others, and not all will be addressed by this project, but nonetheless, this is the path that an attention to technology in disability theory could lead us down and emphasizes the reasons for which a techno-inclusive model of disability is valuable.

5.2 The Final Desiderata

In the previous chapter, I advanced some final desiderata relating to the testimony of disabled persons. These desiderata included criteria relating to the attitudes of disabled persons towards AT as well as what constitutes a good outcome in regards to AT for disabled persons. While there remain areas of heterogeneity, and any techno-inclusive model must remain sensitive to and accommodating of heterogeneity, there were nonetheless some shared criteria which could be broadly applied.

These criteria result in desiderata that a techno-inclusive model should encourage the following things in regard to AT: 1) aim at universal design where possible, 2) aim to include disabled people in the design process and compensate them for their time, 3) function in the real world, 4) aim at affordability 5) eschew ableism in marketing and related materials. There must remain flexibility in determining when and where such aims might be impracticable, or where the failing of such criteria is outweighed by benefits even if they are only to a singular disabled person, but such an exhaustive discussion of all potential ATs is impossible. Furthermore, a system must be attentive to the potential risks of AT (which may at times be justifiable risks)

⁵⁸ One should of course, not simply care about the needs of disabled people because one might one day become disabled, but that this might be a factor in some people's judgement of societal goals is unfortunately undeniable.

such as the risk of entrenching environmental barriers or supporting only a very small group of disabled persons at the expense of disabled persons more generally. Such potential risks and trade-offs must always be present in the minds of AT creators and supporters, but each individual decision will need to be made based on the particular context of that AT and the group or person it is meant to serve.

5.2.1 The Human Variation Model

First, I will discuss what aspects we can draw from the Human Variation Model that fulfill some of these desiderata and which aspects are lacking. As a refresher, the main tenet of the Human Variation Model is that “the problems faced by people with disabilities might be seen as the consequence of the failure of social institutions (and their physical and cultural manifestations) that can be attributed to the institutions’ having been constructed to deal with a narrower range of variation than is in fact present in any given population” (Scotch and Schriener, 155, 1997). The human variation model is in favor of both environmental and individual accommodations, and emphasizes that different accommodations may be desired even across individuals with the same impairment. This places the focus on desired accommodation over diagnosis, and the onus for providing accommodation is placed on society and businesses rather than on disabled individuals.

The Human Variation model focuses on accommodation over diagnosis because it recognizes that multiple individuals with the same diagnosis might need different accommodations. For instance, while one person with a mobility impairment might need a wheelchair accessible workplace while another might prefer the accommodation of working from home. This accommodation preference could be because of particular nuances in the

individuals' experience of their impairment, because of their environment and the transportation options that are available to them, or because of additional impairments, conditions, or other factors in their lives. As Clare points out, knowing a diagnosis does not actually meaningfully result in knowing what a person with that diagnosis needs (Clare, 2017, 41). The Human Variation model is additionally not interested in diagnosis because diagnosis implies there is something meaningfully different between an impaired person and a non-impaired person, where the Human Variation model holds that *all* people are simply on a spectrum of human diversity, and that our systems should accommodate all of that diversity.⁵⁹

As a result, the Human Variation Model easily fulfills a few of our final desiderata. First, let us turn our attention to the desiderata of universal design. Universal design is in some ways an environmental accommodation. It is not perfectly an environmental accommodation if the device that is universally designed is not universally available, but in that the tech itself is a kind of environment (a digital environment) then we can see universal designs being environmental solutions to institutions that are designed in ways that don't accommodate a full range of human variation, and to technological innovations like telephones, early computers, and more that did the same⁶⁰. AT does not solve all environmental barriers, nor can all environmental barriers be solved in ways which allow for universal design (such as Shakespeare's example of curb cuts being necessary for those who use wheelchairs, but potentially dangerous for those who use walking canes) (Shakespeare, 2006, 46). The Human Variation model can accommodate this

⁵⁹ Diagnosis can of course also imply a spectrum, but then the criticism remains that any diagnosis with a sufficiently broad spectrum will not directly lead to knowledge about what accommodations are required (especially since even specific diagnoses are insufficient to determine accommodation needs)

⁶⁰ The impact of broad societal technological innovations on experiences of disability was covered in Chapter 1 (Pg. 15-16)

issue in cases where there are individualized ATs that can accommodate for the lack of potential universal design.⁶¹ However, sometimes solutions will be outside of the scope of a techno-inclusive model of disability and require solutions that are non-AT in nature. It is not my intention to propose that all the problems of disability can be solved with AT, as real environmental change will also need to occur. For instance, a social environmental barriers model of disability might suggest that the design of cities need to be meaningfully changed to protect pedestrians of all kinds from cars and make public transportation in city cores more accessible. These additional measures would not be incompatible with a Human Variation or techno-inclusive model of disability, but rather would complement them in realms where these models do not meaningfully apply. This conceptual gap then is simply a limitation of a focus on technology that is necessary to this project.

Other desiderata are also easily accommodated by the Human Variation model. The desiderata of having AT that functions in the real world seems easily subsumed under this model (since the goal of the model is to have all individuals function in the world). The onus of accommodations being on businesses or society does not necessarily ensure globally affordable AT but it does encourage AT that is low cost or free to the user even if it might still be expensive for some social insurance scheme or for businesses' use for their employees. Alternatively, given the cost-saving nature of widespread demand and centralized buying power, the scheme a Human Variation Model encourages which puts the onus on businesses, governments, and is accommodating of a preference for universal design is likely to have the

⁶¹ Some of these might end up being Disability Dongles such as a stair climbing wheelchair that did not have issues with curbs, or sensors for people with vision impairments that could differentiate road from sidewalk

benefit of pushing costs to disabled consumers down. Either or both of these options likely fulfills the spirit of disabled persons' preferences in regard to the cost of AT.

The Human Variation Model though, does not fulfill the desiderata of eschewing ableism in marketing materials, and including disabled persons in the design process. These failures mean that the Human Variation Model certainly cannot on its own stand as a techno-inclusive model of disability. It should be noted that the Human Variation model is not incompatible with these desiderata, it is simply that alone it cannot fully justify them.

When it comes to eschewing ableism in marketing materials, we might make a case that ableism is not useful in marketing materials under a human variation model because the whole idea of such a model is that any individual might be outside of our inadequately constructed norms of variation, but this argument is tenuous at best. The Human Variation model does acknowledge that all individuals are within a range of naturally occurring diversity. However, that does not imply that all individuals within that range are to be tied to the same narratives. Similarly, it does not have the conceptual tools to directly recommend prohibiting harmful ableist narratives, as the main concern is with access to accommodations, and accommodations can theoretically be provided even if they are provided for the wrong reasons or with toxic narratives in the background promoting useful accommodations. A mandate for accommodations and a culture of ableism are theoretically separable and it would be possible to enforce accommodations via policy without working on changing the culture. However, continual one-off accommodations can reinforce aspects of ableism such as the divide between disabled and nondisabled as well as reinforce the view that disabled people are receiving “special treatment” when they are provided with accommodations. So, while the elimination of ableism is

marketing materials for AT is not incompatible with a Human Variation Model, the fact that it is not mandated by the model is a gap. It is clear that the harmful effects of ableism contribute to making the goals of the Human Variation Model more difficult to accomplish and that ableism more broadly is in conflict with the worldview of disability that the Human Variation Model espouses.

Similarly, as it stands the Human Variation model is not quite enough on its own to justify the mandate of involvement of disabled persons in the AT design process. A Human Variation Model of course encourages all employers to employ all kinds of workers, and to accommodate the full spectrum of human variation that those workers might fall along. However, this is not enough to justify the stronger claim that disabled individuals need to be involved at all points in the AT design process, as this claim is based on standpoint epistemology and the empirical realities of flawed AT that users face when they are not involved in the design process as discussed in Chapter 4 (102-104). The awareness and specific knowledge of the true range of human variation and the needs that variation implies is, as mentioned previously, not incompatible with a Human Variation Model, but is not demanded by the model in the way this desideratum requires.

5.2.2 The Medical Model

The medical model and its confinement to concerns of treatment and individual solutions by contrast, cannot meet the demands of the desiderata raised in testimony. It can accommodate criteria in some cases as the medical system already has a robust system for approving many medical devices. Additionally, the oversight of certified professionals such as occupational therapists, physiotherapists, etc. will ensure AT is practically useful in the aggregate,

if not necessarily for each individual. However, the aim of cure that is implicit in the medical model leaves out mainstream technologies, as mainstream technologies often help *all* people function in new ways, or allow disabled people to function in different ways (this is especially the case with apps where there may be myriad customizable options for accessibility). This means that the medical model and its apparatus of the medical system are not involved in the approval of mainstream technologies the way that they often are for orphan and occasionally bespoke. Similarly, insurance systems and the value of efficiency in the medical system will somewhat ensure affordability where such things are covered, however, as will be emphasized in the next section, many of these schemes are inadequate and so cost under the current medical system (if not necessarily the medical model as a whole) is still an issue. Unfortunately, the medical model cannot justify and might even eschew universal design as the acceptance of a need for universal design aligns with more social models—placing disability in something external to the disabled person rather than internal to them. Additionally, the medical model nor does it have any principles which provide impetus for the inclusion of disabled persons. Ableism itself is baked into the medical system and its narrative of disability being an individual tragedy and something to be ‘fixed’.

5.2.3 The Social Model

The social model also provides us with significant guidance given the desiderata currently under scrutiny, particularly the social barriers model. The social barriers model is of course, in favor of universal design. Similarly, things like costs of AT and ableism in AT marketing can be seen as social barriers, as they contribute to the exclusion of disabled AT users from broader society. This gives us motivation to advocate for lower costs and to prohibit ableism in

marketing. Given that the social movement is also associated with broad, systemic change, and disability pride (Goodley, 2016), the social model is at the very least compatible with the mandate to include disabled persons in the AT design process. Furthermore, the “Nothing About Us Without Us,” slogans that are associated with the social movement (and were discussed in the previous chapter) indicate that the social model would even more strongly support the criterium disabled inclusion in the design process. The social model, however, might have less to say about AT functioning in *this* world, as a strong tenet of the model is to change this world in favor of a less ableist one. This ideal philosophical bent makes it less useful in the unideal interim of our current moment where it is important to simultaneously promote AT partially as a method to minimizing or eliminating ableism and as a stopgap measure to minimize the effects of ableism and disability in an ableist society. The ideal orientation of the social model might therefore be less accommodating of some AT which works functionally in this world, but which only serves a small population of disabled people or which allows for environmental barriers, therefore diminishing the flexibility a techno-inclusive model could offer given still-existent heterogeneity in attitudes towards AT. Another drawback to this model given our current world, is that the social model might take the stronger position on the necessity of universal design over individual solutions regardless of individual desires, which might hold us to a higher standard than is practicable. Nevertheless, the social model has significant merits.

5.2.4 The Bio-psycho-social model

The bio-psycho-social model has no apparent preference for universal design vs. individual solutions, but does recognize both might be appropriate depending on the individual and situation. As Shakespeare puts it, this model holds “no prior assumptions that one approach

is automatically preferable in all cases” instead, this model involves the recognition that “judgements about how to improve individual situations are complex and should be based on evidence, not ideology,” (Shakespeare, 2006 62). The bio-psycho-social model’s acceptance of our current world order, and entrenchment in the complexities of that order ensures that AT would be practical in real-world settings. It also seems like this model would allow us to focus on oppression in the case of including disabled people in the design process of AT and eschewing ableism in marketing materials, but it’s unclear where that leaves us on the question of universal design and affordability. In a common-sense way, of course every consumer would prefer if products were more affordable, but this model does not necessarily give us additional reasoning to push towards this if some individuals are able to pay more. Furthermore, as emphasized in some of the testimony in Chapter 4, it does appear that some AT is required because technology itself can be disabling, and this model’s inability to prioritize between individual or social solutions does not lend itself to collective solutions around universal design which seem to be integral in preventing further disabling tech moves in the future.

5.3 What is a Techno-Inclusive Model of Disability

While none of our models are perfectly suited to fulfilling all the desiderata of a techno-inclusive model of disability, we can combine elements of the Human Variation Model and the Social Model to get to the elements we need for a techno-inclusive model. As was demonstrated in Chapter 3, while all models have facets to contribute to the overall understanding of a techno-inclusive model, the Human Variation model is able to provide many of the non-testimonial desiderata such as: accounting for the complex interaction between impairment, technology, task, and environment, motivating persons around the regulation of AT regardless of whether

that tech is mainstream, bespoke, or orphan, encouraging further research into the impacts of AT and promoting a multiplicity of AT solutions. In this chapter I have further analyzed how the various models meet or fail many of the important desiderata raised in testimony such as a preference but not a requirement for universal design, a preference for more affordable AT, and a need for real-world functionality, although it does not quite give us the justification we need to include disabled persons in the design process and eschew ableism in marketing materials. A Techno-Inclusive Model of Disability can draw strongly on the Human Variation Model alongside a Social Model (as well as being informed by the potential benefits and drawbacks of other models, as has been done above). Furthermore, the valuable additional benefits of beginning with a Human Variation perspective as outlined in Chapter 3 remain the same. These benefits include a flexibility of the model to advocate for accommodations which include functioning “other than” or “better than” new (Silvers, 2010, 13). Using this model as a strong component of a techno-inclusive model also allows for and potentially encourages a further increased range of human variation if we consider variation to be not just the individual human capacities but also individual capacities in conjunction with various tech and AT. The fulfillment of important desiderata, and the additional benefits taken together will comprise the techno-inclusive model which is both more (because the techno-inclusive model more completely captures the phenomena of AT) and less (because the techno-inclusive model cannot be extended to realms that are unconnected to technology) than its other disability model counterparts.

To get to a techno-inclusive model of disability we must integrate these various strategies, as well as situate the model in the current literature and socio-political landscape. As

described in the previous section if we draw on the Social Model for the purposes of describing the harm that ableism in marketing materials causes, and ensuring the inclusion of disabled people in AT design process, we can fulfill the final testimonial-driven desiderata. After we have these combined desiderata we see that there are some additional benefits to a techno-inclusive model.

First, I argue that the study of AT uncovers some of the ways in which ableism is emergent from the mistaken belief that individual persons are flawed if they need accommodations to thrive in our society and institutions. Given the examples in previous chapters, such as the ways in which the severity of disability can be exacerbated by changing societal norms that are the result of technology (e.g. phones vs. letters, computers and text messaging vs. telephones), and how ubiquitous technology can both create (e.g. screen-reading disabilities) and alleviate disabilities (e.g. text-to-voice, closed captioning) it is clear that our societies are built and designed. The design of our societies and institutions result in different, unequal consequences for different kinds of people across different characteristics and attributes. In particular, some designs have particularly negative consequences for individuals with certain kinds of bodyminds, and result in or at least partially constitute disability. In being designed, they could be designed otherwise, and a larger range of human variation could have been chosen to be accommodated in said design. In this way, we can see that ableism is emergent from the mistaken belief that it is individual persons who do not fit our institutions, rather than institutions not being accommodating of the natural range of human diversity. When it comes to technology, ableism rears its head when disabled people are unable to use ubiquitous technologies because those technologies are not adequately designed for their needs, and the

creators of those technologies say that disabled people's needs are too difficult to be accommodated. This often leads also to situations where separate technologies are made for disability and the technology marketing narrative becomes about overcoming disability rather than about living one's life the same way nondisabled people are expected to do and displayed as doing in the marketing of mainstream technologies. These ableist beliefs and constructions are of course, mistaken, because abled folks are designing and using technology to make navigating and acting within their environment easier, as well as to create new things. Eliminating ableism in design and marketing rhetoric therefore helps us tell a more accurate story about society and technology's role in society, while at the same time aligning with the explanatory power of the human variation model. The techno-inclusive model therefore both uses and reinforces the human variation model.

Second, I argue that if those who were "difficult" to accommodate in technological usership or technologically mediated settings were included in the design process we might see a frame of mind shift towards a perspective of human variation. Given the ubiquity of technology, the use of especially mainstream AT is unremarkable, but as we have seen more mainstream technology could and ought to be AT via universal design. Including disabled persons in design is the best way to ensure universal design. When design becomes universal, disabled persons can be more integrated into society as more of their needs will be seamlessly accommodated, in the same way that nondisabled needs are accommodated. This has the potential to engender a shift towards recognizing that the needs of disabled people are not "special" at all, but something that deserved to be, and could have been accommodated all along.

5.4 Differentiating the Techno-Inclusive Model of Disability

A techno-inclusive model of disability is distinct from existing disability models, including the Human Variation Model and Social Model which it draws heavily upon because the techno-inclusive model is not a holistic model of disability, as the primary concerns of such a model are the specific intersections of technology with disability. Still, as society becomes increasingly technological and as more and more AT is invented, this becomes an increasingly important aspect of the disabled experience. AT will never replace other important accommodations like medication, surgery, various therapies (occupational, physio, mental health), nor will it by itself solve the disabling nature of ableism and the exclusion that disabled individuals face in social situations due to stigma. However, these medications, surgeries, and therapies may end up being mediated through AT (such as alarm reminders, surgery to install AT, and virtual appointments) and AT might help alleviate some of the physical barriers or augment resiliency if we think of things like mental health apps or chatbots. A techno-inclusive model also brings our attention to the previously under-interrogated way in which technology, including mainstream technology, affects experiences of disability. In particular, it illuminates this grey space that other disability models cannot neatly accommodate. In describing a techno-inclusive model of disability we both describe this important facet of disabled life, and gain guidance on how to integrate it into our existing systems.

5.5 Delineating a Techno-Inclusive Model of Disability

To summarize, let us again go through the desiderata one by one and how the techno-inclusive model addresses them. My techno-inclusive model aims to be descriptively accurate by focusing on the AT tools that disabled persons use to navigate our world. By integrating AT into

our understanding of disability we have a better idea of what tools disabled persons need, what accommodations are available to them, and what kind of digital spaces are key in our current society. Understanding the landscape of mainstream, bespoke, and orphan technologies as well as the various realms in which they intersect with disabled lives gives us a better idea of what being a disabled person in the 2020s is actually *like*. A techno-inclusive model is politically motivating around ensuring access to required AT, helping to broaden and improve AT options, and ensuring that AT options are baked into mainstream technology via universal design. This model is sensitive to a wide range of experiences and types of disabilities by noting the diversity in the ways and types of AT that individuals use, and how they feel about design, access, and support for different kinds of AT. It differentiates between which experiences and desires are universal and which differ from person to person. This also goes for desiring good outcomes for disabled persons. Under a techno-inclusive model, what constitutes a good outcome might vary from person to person but there are certain universals that should be adhered to so as to improve outcomes (as described in Chapter 4 106-109). Furthermore, this model gives us impetus to further study AT experiences with emerging and existent tech to get an empirical idea of what outcomes are. By advancing these positions, a techno-inclusive model of disability can inform this facet of disability theory and disability policy that has been previously neglected.

5.6 Benefits of a Techno-Inclusive Model

A techno-inclusive model of disability is especially useful in a few ways, some of which have already been iterated. These benefits include simplistic things such as providing increased access to existing AT as well as the more complex goal of improving AT moving forward. However, there are broader social benefits and benefits to the conception of disability.

Unlike other models, including the human variation model, a techno-inclusive model in centering technology reveals many of the historical contingencies of the status of disability such as the rapid evolution of technology, and the movement of AT from the fringes in the form of bespoke and orphan technology to the mainstream or mainstream adjacent (such as specifically designed orphan or bespoke AT that piggyback on mainstream tech like cellphones in the form of apps). A techno-inclusive model does not just give guidance for disability policy more generally in the form of advocating for human or workplace rights, but rather provides specific principles which can be used to guide policy specifically in the AT space. Furthermore, a focus on AT provides a grounding for guiding mainstream technology going forward, which provides an opportunity to integrate disabled needs in mainstream areas going forward.

A techno-inclusive model also provides benefits to the conception of disability more broadly. Since AT exists both inside and outside of the medical realm, and requires the support of governments⁶², this can provide us with the motivation to overhaul outdated policies which do not consider the costs and needs of non-medical equipment. Additionally, these practical considerations of AT existing in mainstream and bespoke realms as well as the more traditional medicalized and orphaned realms means that diagnosis for the purpose of prescribing such devices becomes impracticable. The practical considerations of policy and diagnosis in relation to AT will be addressed in the following chapters. In the meantime, it is enough to say that the focus that the techno-inclusive model provides on accommodation means that individuals

⁶² Government specifically support orphan tech through social support systems, and other AT indirectly through income support programs (as will be described in the next chapter). They also create regulations under which all technology is designed and therefore tacitly support some technologies but not other.

should get what they need regardless of diagnosis or medical expertise on the wide range of AT that is out there. The alternative to starting with accommodation is starting with diagnosis, and as we have seen, this is not useful because it is not tailored to individual situations, and even individuals who share a diagnosis could have radically different needs. Therefore, a techno-inclusive model of disability has the potential benefit of lessening the stigma of and general focus on diagnosis, as well as directing individuals to disabled communities which hold valuable knowledge around AT.

Finally, the integration of disabled needs into mainstream tech can lead us to interrogate the tenuous and transparent border between ability and disability. In a particularly rosy world, it might also lead governments and societies to more clearly reckon the ways in which technology is integral to us all in the digital world that we have built. Although some of us might have more or different needs from one another, we all have needs, and those needs deserve to be met. A techno-inclusive model of disability makes this apparent. There is no space that is more clearly constructed by humans than digital spaces, and the focus on the ways in which digital spaces and AT are or are not constructed to navigate those spaces uncovers parallels in other realms of life. Digital spaces are not just those spaces that exist purely digitally, but also gatherings that are organized primarily online, physical spaces with digital-interactive components, physical spaces that are represented digitally (e.g. virtual museum tours), digital check ins to physical spaces, etc. all of which are becoming more and more common in the wake of COVID-19, although this was already what we were trending towards. A techno-inclusive model of disability allows us the opportunity to reimagine disability in this rapidly shifting world and to ensure that the future experiences of disabled people are more positive than what exists right now. In creating and

shaping a new digital world, we have the opportunity to create space and accommodation for disabled people in that world in a way that is substantive and meaningful.

5.7 Future Use Cases

As mentioned throughout, there are myriad applications for a techno-inclusive model of disability. On the small scale, it could be used by individual designers and companies to help guide values in AT design. It might also inform angel investors in technology start-ups or who sponsor hackathons which were identified as one source of #DisabilityDongles in that data. On the medium scale it could inform school curriculums and engineering design ethics, as well as the missions of various not-for-profits who support disabled individuals as a type of best-practice protocol. On the larger scale, it can be used by governments to inform policy related to such things, and I will be proceeding through one such example in the next few chapters. While it is not well-suited to human rights work generally, (since it is difficult to mandate access to technology in general let alone such a broad range of technologies), it can be used to enhance and interpret existing frameworks, as it encourages us to understand AT to be an integral part of disabled experiences. In turn, human rights might encourage certain AT designs to help make disability less visible⁶³ as a method of preventing discrimination, and ensure access to AT via accommodation requirements. It is my hope that some of these applications will be taken up in future projects.

⁶³ Should that be desirable. There are, I'm sure many arguments both in favor of more visible disability and also abilities to more easily conceal disability to prevent discrimination and unconscious bias.

5.8 Conclusion

In conclusion, in this chapter I have, after re-iterating the testimonial desiderata relating to a techno-inclusive model of disability, evaluated other competing disability models. Through this analysis and by drawing strongly on the Human Variation and Social Models of disability, I have presented a more complete techno-inclusive model of disability. I have described the techno-inclusive model in regards to how it fulfills all the desiderata previously presented in Chapters 3 and 4. In doing so, I have referenced more specific guidance that has emerged in the discussions of the previous two chapters, focusing here on the broad strokes of what the techno-inclusive model tells about disability and what we should do for disabled people. I have additionally established some benefits of using a techno-inclusive model going forward and gestured as to some potential future use cases of a techno-inclusive model to be done in future work. Now I will turn to one particular case example and use my techno-inclusive model to analyze the current social support scheme that exists for disabled persons in Ontario, Canada. This will occur over the next chapters and could be used as a template for applications of the model going forward.

Chapter 6: The Ontario Policy Context

The ultimate goal of this project is to provide a techno-inclusive model of disability which can be used to direct policy. Thus far, I have looked at the current state of AT, disability theory, and using these things alongside disabled testimony I have proposed a techno-inclusive model of disability. Therefore, in this and the next chapters I will be providing just one example of how the application of this model might be done. In this chapter, I will be looking at disability policy as it relates to assistive technology in my jurisdiction of Ontario, Canada⁶⁴. First, I will begin with the overarching legislation that enforces human rights and accommodations for disabled people but do not themselves provide financial support. Then I will examine primary disability supports which can be used for AT and are provided by the Federal and Provincial government to those who meet the criteria of disability for each given program. Then I will examine secondary disability supports for AT which include supports available in hospitals and schools as well as in the community, and the tertiary support potentially available via private or employer provided health insurance. Ultimately, this discussion will allow me to synthesize the supports that exist for disabled people in Ontario, Canada as it relates to assistive technology, as well as identify the main areas of critique that will then be unpacked in the next two chapters. This discussion is not meant to be fully exhaustive, as one of the areas for critique is that these programs are horrifically fragmented as well as difficult to learn about and navigate. However, I believe this overview will give a strong demonstration of the kinds of supports that exist as well

⁶⁴ I am doing this for two reasons, first because I am familiar with the context and second because it is an opportunity to engage with public and concrete philosophy in the place where I am completing my degree and have the opportunity to influence policy via missives to local political representatives of whom I am a constituent.

as provide an overall picture of the system that disabled individuals are expected to navigate to obtain support and accommodations.

6.1 Governing Disability Legislation

Disability policy in Ontario is largely directed by the Ontario government, because disability policy is largely held under the umbrella of health policy, and the Canadian constitution is such that healthcare is a matter of provincial jurisdiction. However, the government of Canada does enshrine the rights of people with disabilities in the Charter of Rights and Freedoms⁶⁵, as well as the Canada Human Rights Act. Additionally, at the federal level the Accessible Canada Act seeks to remove barriers in realms like,

“employment; the built environment (buildings and public spaces); information and communication technologies; communication, other than information and communication technologies; the procurement of goods, services and facilities; the design and delivery of programs and services, and; transportation (airlines, as well as rail, road and marine transportation providers that cross provincial or international borders).”

It specifies that “Communication, as a priority area, includes the use of: American Sign Language; Quebec Sign Language (Langue des signes québécoise), and; Indigenous sign languages.” This act however, only applies to areas under federal jurisdiction, and only asks that departments prepare accessibility plans and be subject to a complaints system wherein users can report accessibility issues to a commissioner (Accessible Canada Act, 2019). Similarly, the Canada Human Rights act applies as a governing document to “the legislative authority of

⁶⁵ s. 15 “(1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability. (2) Subsection (1) does not preclude any law, program or activity that has as its object the amelioration of conditions of disadvantaged individuals or groups including those that are disadvantaged because of race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.” (Canadian Charter of Rights and Freedoms, 1982).

Parliament,” (Canada Human Rights Act, 1985), and the Charter of Rights and Freedoms applies to both federal and provincial governmental actions as it is enshrined in the constitution and was assented to by the provinces.

This federal legislation which guides disability policy via legal avenues is mirrored at the provincial level with the Accessibility for Ontarians with Disabilities Act (AODA). The AODA is a governing document which sets out and enforces accessibility standards. The current legislative goal is that all “goods, services, facilities, accommodation, employment, buildings, structures and premises” will be accessible “on or before January 1, 2025” (AODA, 2005, S1). The barriers this act seeks to remove to ensure accessibility include physical, architectural, information or communication, attitudinal, technological, policy, and practice barriers (AODA, 2005, S2). This act does not apply to private individuals (e.g. private homeowners need not make their residences accessible, individuals not acting in a business capacity may hold negative attitudes towards disabled people and act in a discriminatory manner by choosing not to be friends with them or invite them to events etc.) but does apply to all goods, services, and facilities, as well as to any organization that is an employer, provides accommodations, owns or operates a building, structure or premise, or engages in business activities (AODA, 2005, S6.3). The disabled community which the act serves includes individuals with:

- “(a) any degree of physical disability, infirmity, malformation or disfigurement that is caused by bodily injury, birth defect or illness and, without limiting the generality of the foregoing, includes diabetes mellitus, epilepsy, a brain injury, any degree of paralysis, amputation, lack of physical co-ordination, blindness or visual impediment, deafness or hearing impediment, muteness or speech impediment, or physical reliance on a guide dog or other animal or on a wheelchair or other remedial appliance or device,
- (b) a condition of mental impairment or a developmental disability,
- (c) a learning disability, or a dysfunction in one or more of the processes involved in understanding or using symbols or spoken language,
- (d) a mental disorder, or

(e) an injury or disability for which benefits were claimed or received under the insurance plan established under the Workplace Safety and Insurance Act, 1997; (“handicap”) (AODA, 2005, S1.2)”

Notably, this means that anyone who uses assistive technology is considered by this act to be disabled under (a) “physical reliance on a guide dog or other animal or on a wheelchair or other remedial appliance or device”. This Act enables directors to order compliance with accessibility standards, and prescribe fees or other penalties. The accessibility standards are set out in a separate document under the act, the Integrated Accessibility Standards.

The Integrated Accessibility Standards set out standards in five areas: information and communications, employment, transportation, the design of public spaces, and customer service (O. Reg. 165/16, s. 1.). Not all businesses and organizations must follow all standards. These standards provide examples of accessibility needs, but do not limit accessibility needs to the examples provided (e.g. “‘accessible formats’ may include, but are not limited to, large print, recorded audio and electronic formats, braille and other formats usable by persons with disabilities”). However, many of these standards are waived where they are “not practicable.” What the standard or definition for “not practicable” is, however, is not described. Furthermore, many of these standards are only for newly constructed or redeveloped spaces.

The AODA is interpreted and enforced by the Ontario Human Rights Commission (OHRC). This commission requires employers, unions, housing and service providers to provide reasonable accommodation. This accommodating can include inclusive/universal design, including ensuring that when new structures are created or old structures are revised that no new barriers are “knowingly” created. While not all accommodations under the OHRC are assistive technology, some are such as modifying workstations, or providing multiple ways of

contacting a service (Ontario Human Rights Commission, Duty to Accommodate). The OHRC uses “undue hardship” as a similar limitation though on these duties to accommodate disabled employees. It is similarly unclear in terms of what *is* undue hardship, although some things like customer preferences, employee morale, and business inconvenience are specifically described as *not* being “undue hardship” (OHRC, 9. Undue Hardship). The violation of rights under the code are also no guarantee of action, however, as violations must go through a legal process if a victim is seeking restitution. It is these legal processes which over time can give clues at to what may be considered “undue hardship” and this standard is therefore open to change over time given the evolution of legal arguments, precedents used, and as new challenges and situations are brought forward to the courts. This is in some ways positive, because it allows for nuanced deliberation and to consider situations on a case-by-case basis, but it can be negative as well as it means disabled persons may feel uneasy pursuing a legal remedy with an uncertain outcome given the burdens of the legal process.

These legislative mechanics are the only policy which might guide the creation or access to mainstream AT, as universally that tech is left out of other programs. The only exception to this is the ODSP and Federal Tax Credit which provide general financial support which might subsidize indirectly the purchase of mainstream AT, both of which will be addressed in the next section.

6.2 Primary Disability Supports

6.2.1 Federal Supports

I am identifying primary disability supports in relation to AT as those programs that actively provide some kind of support which provide or otherwise enable individuals to access

AT which are government-provided. While these primary supports may be limited in their scope of coverage or in what diagnoses they cover, they are still more global than the secondary supports I will discuss later, as they are not provided by secondary levels of bureaucracy like the school or hospital system, or administered by not-for-profits.

Once again, the main primary supports will be found at the provincial level. However, there are two notable federal initiatives specifically targeted to disabled people which could be or are aimed at AT. First, the federal government provides the Federal Disability Tax Credit (DTC). To be eligible, a form must be filled out by a medical practitioner (prescribed by the kind of disability that is claimed, medical doctors and nurse practitioners could testify as to all kinds of disabilities listed) who certifies “a severe and prolonged impairment and must describe its effects.” Maximum credits in 2020 were \$8,576 for persons 18+ and \$5,003 for persons under 18. Eligibility for the Federal Disability Tax Credit also entitles persons to use a Registered Disability Savings Plan which are primarily for parents to save for the long term financial security of a disabled person, and funds might presumably be used at some point for AT (Disability Tax Credit, 2021).

Second, while not policy itself, the Public Health Agency of Canada released “Go for It! A guide to choosing and using assistive devices” in 2002 which was reprinted in 2005, 2007, and 2008 and this guide is still actively available and promoted on the Health Canada website. The guide recognizes many important aspects of AT such as that the disabled individual is best positioned to know what kind of accommodation they require, that AT is broad category, and that AT can be used to function either in alignment with abled norms or can be used to find new ways of being and interacting with the world. Some examples of AT

used by “Ms. Canada” in the document include: grab bars, a bath seat, canes, a kitchen trolley, a tilting mirror, a cordless phone, a cushion, and many other items which can be purchased at pharmacies or similar, without the involvement of a healthcare professional. However, despite this promising framing, the “Next Steps” to “be prepared” when obtaining an AT device include caveats like “budget limits and costs often come into play”, “vendors are not philanthropic; they want to earn money, so beware the ‘sales pitch’” and “funding programs are limited and assistive devices can often be expensive,” (Go For It!, 2008). The existence of this document and its promotion on various federal pages presumably also indicates that disabled individuals might be encouraged to use general funds such as their tax credit for mainstream AT. However, this document is evidence of a clear gap between an understood need for various kinds of AT and policies which might make AT financially accessible for disabled individuals. The types of AT described in the document are very broad, and the strategies of determining what kind of AT might be beneficial are admirable, but this does no good if a person cannot financially access the AT devices (or their installation) or does not know that these kinds of interventions are possible when provincial programs are acknowledged to be severely limited in what they cover.

6.2.2 Provincial Disability Supports

The provincial programs covering disability-related matters are much more exhaustive since under the Canadian constitution, provinces are responsible for social assistance programs and healthcare. Since the vast majority of disability supports require diagnosis, they are intimately connected to the larger umbrella of healthcare, which is paid for by the Ontario Health Insurance Program (OHIP). These disability related programs include things such as the Ontario

Disability Support Program (ODSP), the Assistive Devices Programs (ADP), and more. At this point, I will discuss a myriad of these programs and how they relate to the support of disabled people accessing AT in Ontario.

6.2.2.1 OHIP

While OHIP is meant to provide what Canada claims to be ‘universal healthcare’ it does not have any provisions for assistive technology. It covers the majority of healthcare that is received in-hospital, or immediately after discharge from a hospital including specialists like physio and occupational therapists. In the community it covers visits to healthcare professionals, primarily doctors and nurses, although there is partial coverage for some podiatry, optometry, and physiotherapy services. Notably, OHIP specifically excludes coverage for eyeglasses and contact lenses, as well as coverage for hearing aid evaluation⁶⁶ (alongside other notable, but not AT focused care such as dental, and mental healthcare). The visits to healthcare providers for diagnosis, though, are often integral for obtaining support in other programs.

Insured services under OHIP include:

Insured Services

11.2 (1) The following services are insured services for the purposes of the Act:

1. Prescribed services of hospitals and health facilities rendered under such conditions and limitations as may be prescribed.
2. Prescribed medically necessary services rendered by physicians under such conditions and limitations as may be prescribed.

⁶⁶ Although, as will be discussed later, hearing aids themselves are partially covered under the ADP.

3. Prescribed health care services rendered by prescribed practitioners under such conditions and limitations as may be prescribed. 1996, c. 1, Sched. H, s. 8.” (Health Insurance Act, R.S.O. 1990, c. H6)

This is also relevant in later sections, as we will see that in hospital settings there may also be supports for some kinds of AT, or for learning how to use AT with the guidance of healthcare professionals, and these are possible under OHIP. However, those services are separated out as secondary supports since they are obtained only in the hospital setting.

6.2.2.2 Ontario Disability Support Program (ODSP)

While the AODA is meant to handle accessibility on the parts of businesses and spaces, it does not directly put goods in the hands of disabled people. While employers are mandated to create accessibility protocols and implement accommodations procedures, the AODA does not provide goods like AT to those employers, nor does it prescribe particular AT which employers should provide. Instead this is meant to be a negotiation on a case-by-case basis with a limit of practicability as discussed in the previous section. Similarly, the AODA does not set out social support schemes (that is the purview of the Ontario Disability Support Program). So, let us now turn to the Ontario Disability Support Program (ODSP).

The ODSP primarily provides income supports for disabled people. These income supports are not guaranteed as the “benefits” that are listed under “Your Rights” are only “if you are eligible,” (ODSP Website 2021). The eligibility criteria laid out states that you must

“have a substantial mental or physical impairment that is continuous or recurrent, and is expected to last one year or more **and**

- your impairment directly results in a substantial restriction in your ability to work, care for yourself, or take part in community life **and**
- your impairment, its duration and restrictions have been verified by an approved health care professional.”

Otherwise, you must be a member of a prescribed class, which is an eclectic list containing persons like pension recipients, individuals eligible for funding under other programs, and individuals living in care facilities, among others, (Eligibility for ODSP Income Support, 2018) (Prescribed Classes, 2018).

Becoming eligible for ODSP entitles recipients to a “basic needs” amount of income support. Depending on the marital status of the disabled person and number of dependents, the “basic needs” amount ranges from \$672-\$1739 per month. Additional funding can be acquired if individuals are deemed eligible for programs for special diet needs, have additional dependents, have an accredited service animal, live in the far North, or where both the individual and their spouse are disabled (although where both individuals are disabled, they do receive less than they would if each applied and lived individually to account for “economies” that come with shared living). (ODSP, Income Support 6.1 Basic Needs Calculation). Individuals on these programs can earn up to \$200/month in paid employment before income support is reduced. After the \$200 threshold, 50% of employment earnings are clawed back, with exceptions for full-time students (ODSP, Information Sheet, Accessed 2021). This income support could presumably be used for AT. However, given that the average cost to rent a bachelor’s apartment in Ontario as of September 2021 was \$1080 (averaging high COL jurisdictions like Toronto alongside low COL jurisdictions like North Bay), there is little, if any left over for pricey AT after other necessities of life are taken into account (CMHC, Rental Market Statistics Summary, 2021). This forces disabled people into making difficult decisions where they must choose between things like shelter, food, and

acquiring technology that might enable them to live a life beyond a level of mere subsistence (if that).

As far as specific funding for AT goes, the ODSP will enhance OHIP vision supports by providing assistance with the cost of eyeglasses and repairs in addition to biannual examinations. Recipients of ODSP may also be able to get assistance with medical supplies such as syringes, surgical dressings, incontinence supplies, transportation costs, and diabetic supplies. These requests must be affirmed via the submission of a form by a medical professional (family doctor, RN, or enterostomal therapist). The financial level of these programs is dependent on need and type of assistance, and in some cases they are financially supported by non-governmental agencies (e.g. Diabetes Canada, a registered charity, provides 75% of the support for diabetic supplies) (ODSP 9.12). Individuals who need devices are also eligible for assistance with the cost of hearing aids and mobility devices.

To remain eligible for income supports, ODSP recipients have the responsibilities of: attending periodic interviews, keeping receipts and statements for various expenses, reporting any income including from other government sources, and reporting on any life changes like starting school, travel, hospitalization, or moving. Simultaneously, disabled persons on ODSP must pursue other sources of income including child support benefits, CPP, EI, WSIB, and supports from a sponsor (if the disabled person is a sponsored immigrant). Their families are also bound by the program and family members who are 18+ and nondisabled must be working, looking for work, caregiving, a full-time student, or ill/injured. These are obviously significant administrative burdens which are placed on disabled persons, on top of the requirement of diagnosis.

ODSP's "Extended Health Benefits" can also be used at times by individuals who no longer qualify for income supports but who still face high health costs or who qualify under grandfathered programs. These benefits include programs relevant to assistive devices like dental, vision and hearing, mandatory special needs such as diabetic supplies, and the consumer co-payment for the Assistive Devices Program (ADP), as well as the cost of assessment for the ADP program, and the cost of batteries and repairs for mobility devices (ODSP 9.10 Extended Health Benefits).

The ODSP program is also intimately connected to the Ontario Works program⁶⁷ which seeks to help disabled individuals find work via upskilling, counselling, education, and other job search assistance. Individuals may start out in either ODSP or Ontario Works, depending on whether or not they can successfully prove their disability keeps them from working, and may move between the two if their ability to work changes. To access benefits, participants in Ontario Works and their spouses must sign an agreement which is binding and sets out individualized activities which must be done such as looking for work, reporting income, and whatever else is negotiated with their caseworker. The Ontario Works program also supports basic needs, along with specific costs related to drugs, dental, eyeglasses, diabetes, moving, and employment, but this support is contingent on job-seeking activities. Individuals may transfer from the Ontario Works program to ODSP when a substantial difficulty in ability to work has been established, (Ontario Works, Policy Directives, 2021)

⁶⁷ Ontario Works, like ODSP is a program which provides temporary financial and employment assistance for those in need. Those who access Ontario Works need not meet the requirement of having a disability prescribed under the Ontario Disability Support Program Act (Government of Ontario, Social Assistance)

6.2.2.3 The Assistive Devices Program (ADP)

As seen in the discussion above, the ADP is the main program by which disabled individuals gain direct access to AT. The program covers AT like “basic upper and lower-limb prosthetic(s)”, (ADP, Breast Prostheses and Artificial Limbs), “manual wheelchairs, power wheelchairs, and power scooters” (ADP, Mobility Aids), “writing aids e.g. portable or stationary computers to be used with assistive technology,” (ADP, Communication Aids), “Perkins and other manual brailers for writing,” “audio player for reading books” (ADP, Visual Aids). This is not an exhaustive list. Many of these technologies are “orphan” technologies that are targeted specifically to people with disabilities that do not have a large market and risk being orphaned, like prosthetics and brailers, some though are mainstream like the audio player or the computer. This medicalizes mainstream technology in particular instances, but still requires them to be purchased through ADP approved providers. It is unlikely that any of these devices are bespoke. However, sometimes these devices can be customized with off-the-shelf add-ons like bag holders, cushions, etc. or computer devices might come preloaded with specific content or with a specific operation method (e.g. voice activated, toe-touch, mouth blow), and might have different options for a particular size-fit (Brown, 2021). Individuals could of course modify them after their acquisition so long as that did not risk voiding the warranties.

The ADP itself generally funds 75% of the costs of these equipment and supplies, with the other 25% being borne by program recipients, although the government does list various non-profits which may assist with that 25% portion. 100% of the costs are covered

for ODSP, Ontario Works, and Assistance for Children with Severe Disabilities recipients. Recipients must generally apply for the program with the assistance of a healthcare provider that is registered with ADP, and buy the device from a business registered with the ADP. Regulations do vary from device to device though, (for instance, ADP off the bat covers 100% of the price of an insulin pump, compared to the 75% standard for other AT like hearing and mobility aids). Another notable exception is that the ADP does not cover individuals who became disabled through work (these are covered under the Workplace Safety Insurance Board) or military service (these are covered by Veterans' Affairs)⁶⁸ (Assistive Devices Program, 2021).⁶⁹

Finally, the ADP specifically DOES NOT cover all items. They list these items under various umbrellas such as mobility aids, hearing aids and other devices, visual aids, diabetes equipment and supplies, respiratory equipment and supplies, respiratory equipment and supplies, artificial eyes and facial prosthetics, orthotic braces, compression garments, and lymphedema pumps, prosthetic breasts and limbs, enteral-feeding pumps and ostomy supplies, as well as a myriad of “miscellany,” (Government of Ontario, Assistive Devices Program, 2021). Navigating this list to figure out exclusions therefore requires reading the whole list or knowing for sure which umbrella the assistive tech you desire might be housed under. The complete list of what is not covered is available on the ADP website, and while

⁶⁸ I will not cover the specifics of these programs, since they are the exception rather than the rule. Furthermore, I will be discussing why this piecemeal system is unhelpful and confusing, and advocating for a consolidation of services.

⁶⁹ I will not be going into detail about these programs due to the necessity of limiting the scope of this project. However, the caveats and exceptions which lead down into these other programs illustrate the complicated network which divides disabled people based on the source of their disabling experience, and separates those with congenital vs. acquired disabilities.

some or many items under a particular class may not be covered, others might be. For instance, under diabetes, the list only specifies that continuous glucose monitors and related supplies are not covered. Additionally, the ADP specifically does not cover repair costs for equipment. Although in some cases, batteries and repairs may be covered under ODSP's 9.13 Mobility Devices Batteries and Repairs which requires a special application/approval separate from the ADP program, (Assistive Devices Program, 2021). Ultimately, this means that a person looking to get support for a device under the ADP will need to determine what device they need either before they approach a professional or in concert with a professional who handles that kind of device, check against the list of exclusions, find a vendor for the device they want, apply for the device, be approved, and cover 25% of the cost or find other support for that portion of the cost.⁷⁰

6.2.2.4 Miscellaneous Other Governmental Supports

Some classes of disabled persons may also have access to additional supports. This includes individuals who live in long-term care or are 65+. Autistic persons can receive supports through the Ontario Autism Program (OAP), which can include support for technology recommended by a regulated health professional or certified behaviour analyst (Ontario Autism Program 2021)⁷¹. Other programs include Passport funding for adults with developmental disabilities, which is a discretionary funding program that can be used for a myriad of things. In April 2020 it was amended to allow for the expensing of sensory items,

⁷⁰ I talk later about the burdens this and other programs create, but for one recent example where the ADP fell seriously short is the story of Shawn Brush, who waited 2+ years for a new chair due to the burden of contributing to the cost of an electric wheelchair, alongside the difficulty of having the expense of the chair approved. (Hristova, 2022)

⁷¹ This program is widely criticized for its inadequacy and multiple years-long waitlist.

technology (including laptops, e-readers, remote monitoring devices, etc.) and items for home-based recreation. These changes were in response to the COVID-19 crisis and would not have previously been funded (Ontario Autism Program, News and program updates, 2021).

Parents of children with severe disabilities may also be able to get financial support through the Assistance for Children with Severe Disabilities Program (ACSD). Low and moderate-income families can get between \$25-\$500/month for disability related costs. This support can be used for assessments for assistive devices, or the consumer contribution portion of device costs, as well as costs of barriers and repairs for mobility devices, and hearing aids and vision care including eyeglasses. The exact income cut off for the program is not available on the governmental program page itself but Peel region lists the cut off as being \$66,000 annually for a family of four (Child Development Resource Connection Peel, Special Needs). During COVID-19, this program was expanded to cover potential AT devices like laptops, tablets, e-readers and remote monitoring/medical alert services and devices that were not previously covered. More non-AT services were also covered during COVID-19. Similarly, prior to COVID-19 the “Special Services at Home” program did not cover the cost of any AT but now provides funding for the same potential AT as the ACSD program on a temporary basis until the end of the pandemic and the “return of regular business once the government provides notice,” (Covid-19: Temporary changes to children with special needs programs).

Finally, children’s treatment centers are accessible for children and youth 18 and under if they have physical or developmental disabilities, or communication disorders. These centers provide access to physiotherapy, occupational therapy and speech and language therapy. These

service providers can at times provide or help prescribe special equipment, presumably inclusive of some AT (Children’s rehabilitation services, 2021)

6.2.3 Concluding Thoughts on Primary Governmental Supports

These myriad standards fracture the disabled community based on their diagnosis and make it difficult to share information and experiences. This creates difficulty in knowledge sharing, and diminishes the disability community’s ability to support one another and strive for collective action. For users, this fragmentation makes it difficult for a person to determine their eligibility let alone how to obtain AT that might be covered. The patchwork nature of even these primary support systems makes it difficult for a person with a diagnosis to know what is available to them, let alone a person who may not yet have a diagnosis. Furthermore, it relies on evaluations and applications at every step, meaning individuals may need to reproduce much of that work if they apply for multiple programs. In some cases a copy of evaluations and assessments may be sufficient, and some of it is integrated under ODSP, but this is not a guarantee. The reason for this is likely well-intentioned. As will be discussed in the next chapter, social supports must generally balance needs against a scarcity of resources to ensure that those resources go to those who are more in need. However, this system simultaneously sets up a situation where a disabled person or caregiver must engage in a lot of work of their own, but must also be “disabled enough” or disabled AND poor enough to qualify. Although this system is self-evidently burdensome for anyone, it seems nigh-insurmountable for those with the additional worries and challenges that come with poverty and severe disability. If those who are most in need cannot easily acquire documentation, or have to face high costs in terms of appointment time and administrative burdens to prove

their need, then they are not actually being served. In my next chapter, I will argue as to how we can balance the needs of efficiency as demanded by a scarcity of resources while still reducing bureaucratic obstacles.

6.3 Secondary Supports

Secondary supports are supports that are outside the main apparatus of government. These supports include supports that might be found inside hospitals and publicly funded schools, as well as supports that are available via not-for-profits. Not-for-profits are included in this list because they are relatively easy to access, are often involved in government support programs, and because they are governed and receive tax breaks under the apparatus of government. The examples in the sections that follow may seem at times overly detailed or conversely lacking when the options and locations of disabled persons looking to access AT may be so disparate. What is provided in what follows is meant to be a sampling to suggest potential trends, although even if these examples are isolated they still have important information to contribute to understanding the state of AT support in Ontario.

6.3.1 Not for Profits

Not for Profits form an important part of the fabric of how AT is accessed and supported in Ontario. Some of the major players include: War Amps, Easter Seals, March of Dimes, Kiwanis, Diabetes Canada, and the Lion's Club. In addition to helping to complement the ADP program by providing funding for the consumer portion of the medicalized AT covered by that program, some of these organizations also work in the disability space in other ways.

March of Dimes has partnered with Telus to offer “Tech for Good”, which is support for AT on phones and tablets. It does not provide phones or tablets, just helps to understand the AT that is available on those devices, and potentially provides financial assistance “to help cover the cost of the assistive technology required to optimize the use of their mobile device.” Telus also offers a discount on a monthly phone plan to participants of the program, although this appears to be a marketing technique for Telus rather than a program on the part of March of Dimes. To participate in the program, participants must also consent to release their information to Telus (March of Dimes, Tech for Good, 2020).⁷²

March of Dimes also administers the Ontario Home and Vehicle Modification Program, which provides support for some assistive devices in the home or in vehicles. Eligible applicants can receive up to \$15,000 as a lifetime maximum (with exceptions for safety risks, change in disability, employment relocations, or changing physical needs of a child) for home modifications and up to \$15,000 every 10 years for vehicle modifications (Home and Vehicle Modification Program, 2018). Both the modifications and the applicant must be deemed eligible. Program funding is limited and prioritized based on the necessity of the modification, with modifications for safety being prioritized first, followed by modifications to prevent hospitalization or allow discharge, avoiding loss of employment or income, and finally supporting development and community activities. The “disability requirements of applicants” is assessed by a Service coordinator and in some cases an occupational therapist to ensure the access needs are genuine. Individuals are only eligible if

⁷² While this is not a main focus of this project, this, along with other burdensome reporting requirements discussed demonstrates that disabled persons must give up their privacy in ways that are not expected of abled people to be able to access the things they need.

the family makes less than \$35,000 annually after allowable deductions. Below that level there is a sliding scale of what percentage the family must pay towards the total cost of modifications. Individuals on ODSP, Ontario Works or Old Age Security do not need to pay any percentage towards the total cost. Eligible modifications include things like environmental controls, the rearrangement of rooms, paving to enable wheelchair movement, and more. Ineligible modifications include the purchase of a home, construction of additional rooms or accessible exits not required by the Ontario Building Code, or therapeutic items or other AT that is covered by the ADP. Similarly for vehicles modifications can include specialized seating in the car, modifications to a garage, or car phones, but specifically do not include the purchase of a vehicle, vehicle repairs, or a monthly cellphone service. Assessments of the modifications “must be completed by an occupational therapist, a rehabilitation engineer, a rehabilitation engineering technician, or rehabilitation technologist of the applicant’s choice,” (Home and Vehicle Modifications Program, Program Guidelines, 2012). So disabled persons themselves must be approved for the program *and* their requested modifications must be approved as two separate hurdles to overcome.

The War Amps provides financial assistance towards the cost of artificial limbs (not means-tested)⁷³ for those 18+. They also assist with advocacy if funding is denied by governmental or private insurance. They will help individuals appeal government or insurance decisions and therefore are an important part of individuals’ ability to access government programs. Additionally, they also provide both everyday and recreational limbs and devices for

⁷³ This means that unlike other programs, this program does not take into account the income of individuals when deciding whether or how much support to provide to them. This reduces barriers because means reporting is often invasive.

children, notably covering 100% of the cost of recreational limbs and devices. For instance, they cover limbs or devices used for “swimming, biking or playing a musical instrument”. This is notable because no provincial program pays for recreational limbs. They also have a “JUMPSTART” program which provides children with multiple amputations funding for computers and assistive devices. The War Amps also have programs to raise awareness on different kinds of limbs and devices available as well as more general sessions on things like body image, learning to drive, etc. (War Amps, Ways we Help, Adult Amputees, 2021). Finally, they have a partnership with the Department of National Defence and Veterans Affairs Canada to assist war amputees and “seriously disabled veterans” to help them navigate their military benefits (War Amps, Ways We Help, War Amputees, 2021). They host a wealth of resources on their website on all kinds of prosthetics.

Easter Seals similarly helps to cover the costs of assistive devices for children under 19 which are funded by the ADP but are not fully covered by the ADP (Easter Seals, Equipment Funding Overview, 2021). They also fund accessibility aids like porch lifts and portable ramps, as well as bath and toileting aids like shower chairs, bars, and grips, as long as the items are authorized by a healthcare professional and two quotes are provided (Easter Seals, Equipment We Fund, 2021).

This not-for-profit patchwork demonstrates that not-for-profits are an integral part of disability funding and access to AT both in terms of how intertwined they are with government systems like the ADP and in terms of how they may be government systems themselves in a sense such as is the case with the Home and Vehicle Modification Program. Despite their involvement in government systems, many also go beyond what government provides by

providing funding for AT that is not covered under any government program but that is nonetheless essential for disabled people both in terms of their basic needs like showering and bathing, and in terms of providing the things that help individuals to flourish, such as AT for recreational needs. However, these organizations, like governmental systems are still at times limited by diagnosis both in terms of what *kinds* of disabilities individuals have, and in terms of needing medical documentation to access supports.

6.3.2 Hospitals

In addition to providing accommodations to patients in line with the AODA, and being a major provider of healthcare under OHIP, hospital systems are often an integral provider of AT in the form of either being a registered ADP prescriber or vendor or in the collaborations that are required with healthcare providers for some kinds of AT. This is not meant to be an exhaustive list of all programs and supports that exist in the hospital system, but rather to demonstrate how provincial policies trickle down in practice, and how the hospital system functions with regard to how AT is accessed.

For instance hospitals are often involved in the care and AT of amputees, as amputees require medical attention, and amputee rehabilitation programs are administered through hospitals. These programs include education regarding ATs like prosthetics (HHS Amputee Rehabilitation Program, 2019). One oversight of this system is that clinicians can at times overlook options. For example, a downtown hospital, clinician, and vendor team may not think to offer an all-terrain walker to a person with a mobility issue unless the disabled person specifically requests that (Brown, Private Correspondence).

Similarly, some AT, such as cochlear implants, require medical oversight in hospitals. Sunnybrook Hospital is the main Ontario hub for cochlear implants (and one of only four hospitals in the province to provide this service) and states that, “Ontario residents who hold a valid health card are eligible for coverage under the Ministry of Health’s plan for surgical care, hospital stay, and audiological support. There are personal costs that are not included, such as batteries, post-warranty repairs, and for upgrades,” (Sunnybrook Hospital, Eligibility for the cochlear implant program, 2021; Health Quality Ontario 2018). This demonstrates that some hospitals provide more access to AT than others, and while some costs may sometimes be covered to travel for treatment, other costs are borne by the individual and these financial and travel-time related barriers create significant hurdles for access. Similarly, hospital research programs like UHN’s KITE program enable certain disabled persons to access more experimental technologies or therapies, but such programs are rare and will also require travel to access with some experimental technologies or therapies only being available to those with the ability to frequently visit the hospital to participate in research (KITE-UHN, About) (Brown, Private Correspondence).

Hospitals may also be hubs for treatments or general education (some of which may be provided by non-healthcare workers like hospital employed social workers). For instance, Hamilton Health Sciences has a range of programs which run the gamut from being free to being thousands of dollars in costs to help support individuals with Autism. Some of these programs include help navigating the support programs which might provide access to AT, like the ADP, (HHS, Autism Services, 2019). These services are fragmented and are not directed at

disabled individuals in general, but rather are geared to particular diagnoses and assume diagnosis is already known.

These are obviously limited examples, and yet they still demonstrate the limited nature of AT access, and suggest additional burdens some disabled persons might have to undertake to obtain treatment, such as needing to travel repeatedly or potentially move to access ongoing out-patient services after the initial surgery at Sunnybrook or one of the three other hospitals to obtain cochlear implants and supported rehabilitation services after their implantation. This suggests a significant urban/rural divide (as with many health services) that may impact the lives of disabled persons and the choices that are available to them when it comes to AT access, and this is on top of the fact that when services are available in hospitals, they may only be available under certain conditions.

6.3.3 Schools

Schools are also an important locus of AT access for those who are enrolled in them. Again, this is not meant to be an illustrative list of all potential supports for AT that exist at every school in Ontario, but rather one example of the supports that disabled learners might expect to have, and to illustrate how provincial policies trickle down to important realms of life like education.

In schools in Ontario in 2020-2021, publicly funded school boards (primary and secondary schools) received \$10,000 per board plus ($\$36.101 \times$ average daily enrollment) to go towards special equipment for “students with special education needs”. This fund also covers the cost of training, equipment set up, maintenance, and repair. These funds are specifically for

non-computer-based equipment, however, the funds are meant to cover software, such as reading intervention software. For boards to purchase this equipment for students, they must submit supporting documentation which includes specifics in a student's independent education plan (IEP) that demonstrates the use of the requested equipment meets their needs, is aligned with the curriculum, and is aligned with the student's program and report card. Requests for equipment must also include professional assessment (in some cases more than one professional) where a student's need is not already documented by private or previous assessments, or where board internal policies might require it. Capital investment AT such as elevators, stair climbers, noise reducing surfaces, and sound systems are not considered to be eligible under the SEA funding. The SEA funding is meant to work in concert with the ADP, but the SEA is required as "ADP will not fund equipment required only for school purposes" (the ADP requires the equipment be necessary for "daily living")⁷⁴. Although equipment is purchased by the school board, if a student moves, the equipment is meant to move between school boards with the student unless impracticable (Special Education Funding Guidelines, Special Equipment Amount (SEA), 2018).

At the post-secondary level, schools are guided by the OHRC, AODA, and the Human Rights Commission. At my university, The University of Waterloo, this means a few things in regards to AT. First, it means that students must have access to approved assistive technology in test and classroom settings (Student Academic Accommodation Guidelines, 2019). Disclosure of diagnosis is not required to access these sorts of accommodations, nor is a specific diagnosis

⁷⁴ Of course, the implication here is the school/education is not an essential part of daily living. This is patently ridiculous and absurdly marginalizing of disabled folks given the necessity and emphasis of schooling in our society.

required, but supporting documentation from a medical/psychological professional “who is qualified to make the diagnosis or statement of functional limitation, and is acting within their scope of practice,” (Student Academic Accommodation Guidelines, 2019)⁷⁵. The Dana Porter Library also hosts an accessible technology center complete with 7 workstations, 3 of which have a computer with some assistive software installed. Students who have approval from Accessibility Services or who have a Library Accessibility Services approval (which does not require a diagnosis or medical documentation, but does require the filling out of a form and a meeting with Library Accessibility Services, and approval from Library Accessibility Services) may borrow some assistive devices such as noise-cancelling headphones and hand-held magnifiers at the Dana Porter library. Other centers on campus also have scattered workspaces available which incorporate AT (Library Accessibility Services, Accessed 2021), but the Dana Porter is the only library with a dedicated accessibility services and an accessible, scent-free study environment in the adaptive technology center. During regular instruction, there is also a technology lab and an adaptive equipment loan program available through Accessibility Services, but both these programs are currently unavailable during modified instruction as a result of COVID-19 (Learning Strategy and Assistive Technology, Accessed 2021). It is not apparent if other programs have replaced these avenues during primarily on-line instruction. As of the Fall 2021 semester presumably there remains an AT shortfall as instruction is majority online but now some is happening in person.

⁷⁵ This means that while a physician or other healthcare provider must provide documentation that a student needs supports, this documentation can simply testify to the support needed rather than the diagnosis (e.g. “This student needs access to closed captioning” vs. “This student is Deaf”)

Although the University of Waterloo is just one example at the post-secondary level, it is sufficient to be illustrative of a few things. First, it illustrates that post-secondary schools do provide some AT access that would be otherwise unavailable to students not enrolled in post-secondary education. Second, it demonstrates that such systems at least sometimes involve the need for documentation, sometimes from a medical professional, still creating some kind of an administrative burden on disabled students. It is difficult to say how comparable the University of Waterloo is to other publicly funded universities, but one would expect all to be around a similar level. The University of Waterloo guarantees access to approved AT in classroom settings, but this says nothing about what is approved (and if a student might need to learn a different AT for lack of approval), nor does it guarantee access in the first place. The AT lending library is clearly a laudable endeavor, but this still seems insufficient given the range of AT that might be required, and assumes a small population of disabled students (only 3 workstations with AT for 42,000 students).

6.4 Tertiary Supports: Private Insurance

Finally, private insurance plays a large role in providing support for AT. This system is very limited but is nonetheless important to remark upon. Globally, this system provides support only for medicalized and/or orphan AT that is obtained through the medical system. This is broader than the government supports that exist, especially in realms like vision impairment, where glasses and contacts are covered only under ODSP. This system is costly on individuals or their families, though the exact cost is difficult to determine and will vary from individual to individual based on assessments and employment situations. Many disabled individuals may find themselves unable to obtain insurance or will obtain insurance at a high cost if they are disabled

at the time of searching for coverage, which bars many with congenital disabilities from these programs. Additionally, most health insurance is obtained via employment, which is notable since the employment rate for disabled persons in Ontario as of 2017 was just 44.5% (StatsCan, Labour force status for adults with disabilities by disability type). Caregiving parents may also find it difficult to balance their caregiving duties alongside employment in regards to insurance if they have children under the relevant age who might be covered by parental insurance. Nonetheless, insurance might help fill some gaps in the system so I will analyze the supports in regards to AT that are provided by the top insurers in Canada: Manulife, Sun Life, and Great-West Life.

The Manulife “Cover Me” has a range of benefits from “Basic” to “Premiere.” These programs both cover some AT with similar lifetime maximums (e.g. wheelchairs have \$5000 lifetime maximum, both cover \$250/year for orthotics). However, in other cases the yearly difference can be quite different, e.g. \$2,500 for prosthetics, \$1,000 for oxygen and equipment (premiere) vs. \$1,000 for prosthetics and \$500 for oxygen and equipment (basic) (Manulife “Cover Me,” Accessed 2021). Similarly, Manulife also has a Flexcare ComboPlus insurance program with a similar range from Starter to Enhanced. There are also different coverage options for those under 65 compared with those over 65. The Starter program, which provides AT like orthotics at a rate of \$225/year, covers \$400 for hearing aids every 4 years, a changeable rate for prosthetics going from \$1k-\$3k over 5 years, and provides \$150/year for vision care like glasses and contacts. The enhanced program similarly provides \$225/year for orthotics, \$400 for hearing aids every 4 years, \$4k/year for prosthetics, \$4k for, “Durable medical equipment

(eg. wheelchairs, ventilators and lifts), and \$250 every 2 years for vision, (Manulife Flexcare ComboPlus, 2021)

SunLife has a slightly less complicated scheme with just one type of health insurance, although still running the gamut of level of insurance from Basic to Enhanced. The basic plan reimburses 60% of expenses up to a \$2,500 annual maximum or \$20,000 lifetime maximum on items like prosthetics, orthopedics, continuous glucose monitors, rental “or purchase at our option, of durable equipment” like wheelchairs & walkers. The Enhanced program covers 100% of expenses up to a \$5,000 annual maximum with some year limits like, orthopedics (limit \$200/year), continuous glucose monitors, rental “or purchase at our option, of durable equipment” like wheelchairs (\$4k lifetime maximum), prosthetics (\$200/year) (SunLife, Personal Health Insurance, 2021)

Great-West Life (now transitioning to CanadaLife) sells insurance only to businesses, not individuals. Great-West Life covers \$300/year for orthopedic needs, and covers the following “medical supplies” when prescribed by a physician: breathing equipment, orthopedic equipment, prosthetic equipment, mobility aids, communication aids (includes hearing aid sup to \$700), among others which are not comprehensively listed (Great-WestLife, Healthcare Benefits, 2021).

All this is to demonstrate that like other disability support systems, the insurance system is difficult to navigate, and plans are very difficult to compare against one another. These systems are still limited by diagnosis, and they are limited in terms of what kinds of expenses they cover and may run out on a yearly or lifetime basis, if they are even accessible in the first place. Unlike many governmental programs which are means-tested and may have people falling through the cracks if they make slightly too much, insurance programs are usually only available

to those who are already the best off either in virtue of employment or in virtue of having money to spend up-front on insurance.

6.5 Issues with the System

The main takeaway from this discussion in this chapter should be that disability supports are badly fragmented. The onus is currently on disabled persons to aggressively pursue support in all different avenues of their lives, navigating multiple complex programs. This is problematic for a few reasons. First, it means that changes in one area might not be reflected in other areas, requiring constant vigilance on the part of disabled persons to ensure that the multiple support systems they may rely on are congruent and that each gets the information they require. This may be especially burdensome for particular disabled people depending on the nature of their disability and their ability to navigate these complex systems (or the ability of their caregivers, if that is the case, leaving more potential for neglect or abuse). This burden in reporting can apply to general information like income, budgets, leases, but can also apply to diagnosis, which is discussed in the next paragraph. The fragmentation also risks missing aspects of disability when a person is multiply disabled and must access systems on the basis of more than one axis, or need an AT device on the basis of the way their multiple disabilities intersect. The fragmentation in this case may also have impacts on their identity and self worth if they must carve themselves up along the lines of their distinct disabilities to access services when they see themselves as a whole disabled person. It also means that some disabilities may see more support than others such as those that are able to access the War Amps programs for recreational AT. This is not to say that additional access to AT is a problem, but the inequity is and it creates a potential hierarchy of disability. Finally, fragmentation is more likely to lead to inefficiencies and

redundancy (which will be addressed in the next chapter). In the case of governmental and non-governmental systems alike this means more money on overhead and less money in the hands of disabled persons.

Additionally, these programs are nearly all reliant on a diagnosis of some kind which must be pursued through a web of healthcare providers, and becomes much more difficult in practice if applicants do not have a family doctor. (CBC, Lack of Family Doctor...). This is in addition to the previous issues that have been raised regarding diagnosis, such as that it might force a disabled person into a medicalized model of disability which is not congruent with their experiences and which forces them into a paradigm of seeking “cure” and rejecting their disability. Furthermore, with AT there remains the question as to whether or not diagnosis is even useful (and if it is not, why are we using the system’s money to provide it, and wasting disabled persons time in obtaining it). After all, when there are so many expressions of a diagnosis, and so many potential interventions a person might want given their experience of their disability, physical environment, goals, and more, a diagnosis is not a good basis in determining what AT will be best for a person.

Furthermore, when these programs can be accessed (in a fragmented manner, usually requiring diagnosis), they provide incomplete financial support whether that is because the financial support is inadequate⁷⁶ or because financial contributions from the beneficiary are required to even access programs in the first place such as is the case with the ADP, or is necessary with regards to obtaining insurance. It is difficult to catalogue all of these programs, and even in some cases to learn about their existence. Individuals who might be eligible in

⁷⁶ This will be addressed and unpacked further in the next chapter

multiple areas will need to fill out multiple applications and face a taxing overhead of time and labour to navigate this system.⁷⁷

Another clear gap in the current social net is the support that exists for AT designed for recreational purposes. It is alarming that even technology which is integral in schools cannot be covered under the ADP because school is not considered an item of “daily living.” With the exception of the War Amps, there were no policies or groups which seemed to assist with AT which did anything more than these activities of daily living, which are clearly interpreted in quite a narrow manner.

Finally, most of these policies with the exception of the federal “Go for it!” and some not-for-profit programs like Tech for Good, and the Easter Seals support, leave out integral mainstream AT. While mainstream AT might be accessed using funding from ODSP, or might be accessed by students through school-issued laptops and tablets (which would be accessed not under a disability umbrella, but rather because this is something all students generally have access to, and these are likely to be limited in other ways as being devices primarily for education and not for socialization, community, hobbies, etc.), mainstream AT seems to be an afterthought. Even though according to the “Go for it!” document mainstream AT interventions may be some of the easiest and cheapest for disabled people to access. It is quite possible that the marginalization of mainstream AT goes hand in hand with the push to medicalize disability.

⁷⁷ The patchwork of systems may well in part be due to historic or legacy systems, as well as political machinations which are beyond the scope of this project to address, and would be largely speculation on the part of myself as neither political science nor history are my areas of specialization. Nonetheless, what is clear is that regardless of the original reason(s) that the system is as it is, currently the fragmented nature and need for diagnosis is overly burdensome for disabled persons looking to access AT. See Maurutto, Paula. "Charity and public welfare in history: A look at Ontario, 1830-1950." *The Philanthropist* 19.3 (2004): 159-167. for such an examination further in the past.

After all if “cure” is as easy as getting a new I-Phone (and it’s not, but it might be seen as such), then perhaps the system would have to reckon a little more the ways in which disability is constructed and contingent, as well as related to poverty. An increased focus on mainstream AT both opens up the possibility of decreased medicalization in the disability field, and a move towards providing disabled individuals with a plurality of equally plausible choices as to how they would like to live their lives rather than a single cure and return to “normalcy”.

6.6 Conclusion

In conclusion, in this chapter I have delineated some of the myriad supports that exist for disabled people when it comes to accessing assistive technology. I have covered legal policies which may provide access to AT under anti-discrimination and human rights frameworks, especially in the workplace, social support policies which I have termed primary supports that are provided through governmental bodies, secondary supports such as those provided through not-for-profits, schools, and hospitals which work in concert with governmental programs, and the tertiary support of insurance. I have also provided a brief, preliminary overview of the issues with this system including the system’s fragmentation, the burdens it places on disabled persons, the emphasis on diagnosis, financial inadequacy, lack of access to “non-essential” AT, and lack of support for mainstream AT.

Overall, I have simply scratched the surface of these programs as they are presented at the very first level of engagement. This overview says nothing of the interactions that disabled people have with caseworkers, application approvers (or deniers, as the case may be), healthcare professionals and healthcare bureaucracies, or of the process of filling out the forms, having meetings to obtain forms, legal battles, and other potential hurdles that are clearly implied by the

various policies and procedures that I have discussed. Nonetheless, this overview gives us a grounding to begin critiquing the current system, as I have done in brief here. In the next chapter these critiques will be more fully realized and placed into context with existing social values and policy pressures, as well as by using a techno-inclusive model of disability as a measure for what the objectives of social support programs should be with regards to AT and what is necessary to ensure the just treatment of disabled people given their AT needs.

Chapter 7: A Multi-faceted Analysis of Ontario Supports for AT

In the previous chapter, I looked at the current state of affairs as it relates to AT access and support in Ontario, Canada. This included support from various levels of government, non-profits, hospitals, schools, and insurers. I briefly discussed some obvious shortcomings of the current system, including the 1) system's fragmentation and resulting burdens it places on disabled persons, 2) the emphasis on diagnosis, 3) financial inadequacy, 4) lack of access to "non-essential" AT, and 5) lack of support for mainstream AT.

In this chapter I will expand on these critiques by analyzing the current state of affairs as it relates to AT support using various frameworks and value systems which are a large part of how governments set funding priorities and allocate funding under healthcare and other systems. These types of value prioritizations are unfortunately necessary given non-infinite resources. With these conflicting values and needs in mind, I will consider whether or not the current system is justified in light of practical constraints despite its shortcomings.

The tools I will be considering include commonly used decision-making methods such as QALY and DALY as well as other Cost-Effective Analyses (CEA) which look at the value of a given treatment for a person or group to determine whether or not such treatments are a good use of resources. I conclude that QALY and DALY are ill-positioned to consider the case of AT, while CEA supports my criticisms of 1) the system's fragmentation, and 5) lack of support for mainstream AT. I will also be looking at the overarching values which infuse Canadian

society and healthcare including the values of equality⁷⁸ and efficiency as identified by Michael Stiglitz, as well as how that fits into a wider framework of a single-payer healthcare system where markets still play a major role. This discussion will show that with the considerations of equality, and true efficiency in mind that the system is unjustifiable under 1), the system's fragmentation, 3) financial inadequacy, and 5), lack of support for mainstream AT. Finally, I will look at the demands of my techno-inclusive model of disability when it comes to support for AT and how the Ontario system currently fails to meet those demands, as well as how these demands fit into a broader framework of where and how individuals need access to AT according to Ladner's considerations for technology. This discussion will emphasize that under this framework, all the criticisms persist, but especially 1) the system's fragmentation, 2) the emphasis on diagnosis, and 4) lack of access to "nonessential" AT. Ultimately, I will suggest that these various analyses show these key issues persist even taking into account the demands of existing policy protocols and values alongside the reality of limited resources. These key issues will then be addressed with potential, partial solutions in the next and final chapter. This chapter situates my criticisms in the context of real-world policy constraints, while my final chapter will propose positive solutions to the issues that have been raised, ensuring that those solutions are congruent with the values and methods presented in this chapter.

⁷⁸ I use the word "equality" throughout because this is the language that Stiglitz uses, although Stiglitz in the view of Rawlsian justice as fairness could be said to be aiming at "equity", i.e. individuals having access to things in accordance with their needs and contributions. I do not, nor do I think Stiglitz means "equality" in the sense of everyone having access to the same things regardless of their needs or contributions.

7.1 Overview of the Current Ontario System in Brief

Given that we have just spent a chapter going over a vast but non-comprehensive overview of the Ontario systems of support when it comes to AT I do not want to restate that all here. However, I do want to pick out some relevant aspects of that system in brief so that they can be kept in mind for the purposes of this analysis, and so a foundation for that analysis can be built. The relevant aspects of the Ontario system aside from the current shortcomings which have already been restated above are several. First, it is clear that system already holds some values such that within the context of disability there is some obligation on the part of the government to support disabled persons who cannot work and/or who face high costs due to their disability, and to some extent this support extends to AT. Second, it is clear that despite the fact that the scope of this support is generally limited to “essentials” used for the basics of life and work, there is some baseline quality of life that is assumed as being worthwhile to bring folks up to, as these essentials do go beyond basic medical essentials of being merely alive. Finally, although governments do not support “non-essential” AT, employers and “non-essential” spaces and activities (e.g. schools, restaurants, gathering places, activities) must comply with accessibility requirements up to the point of undue hardship or impracticability depending on the realm. This indicates that there is some generally accepted benefit to including disabled persons up to that point. Once again, these are the baselines of the Ontario system. These baselines are problematic because they are insufficiently ambitious, and this is illustrated by the critiques I have already levied against it, but it is this baseline from which I will begin my analysis and which I take to already be existing values in the current system. Furthermore, as opposed to the issues which I have identified with this system, I take these attributes to be the minimum

values which are clearly intentional, whereas the issues I have identified may be as the result of historical contingencies or other factors which may or may not be intentional. Let us turn now to the analysis.

7.2 Tools for Analysis

7.2.1 Cost Effective Analysis

The primary cost-effective analysis (CEA) analytic tools used which often come into play in regards to disability are Quality Adjusted Life Years (QALYs) and Disability Adjusted Life Years (DALYs). QALYs and DALYs are used to rank medical procedures according to their impact on the individual receiving treatment. They are the standard used by the WHO and while the specifics of the guidelines have been revised over the years, their use in policymaking remains constant (Bickenbach, 2016, WHO 2012, Nord 2018, Bognar 2020, Davies 2019, Arnesen and Nord 1999, Brock 1995). In Canada, QALYs and DALYs are a part of Canada's Drug and Health Technology Agency's (CADTH) Guidelines for the Economic Evaluation of Health Technologies, a document which guides federal, provincial, and territorial governments in their decision-making when it comes to what health technologies and drugs are covered under publicly-funded care (CADTH Methods and Guidelines, 4th Edition). For this reason, although I will find that QALYs and DALYs are not suited to the task of AT, I will discuss them first before moving on to a more general potential CEA approach.

QALYs and DALYs are used as policymaking tools because we live in a context in which at least some medical resources are scarce (e.g. organs) and because generally speaking we hold intuitions that scarce resources should go to those who would significantly benefit from

them (e.g. we should give an organ to an otherwise-healthy 20 year-old rather than an otherwise-sickly 75 year old) (Brock, 1995, 168-169). The fact that a younger person is more likely to get more benefit from scarce resources is a consequentialist-based argument in favor of allocating scarce resources where the benefits of those resources will be maximized. QALYs and DALYs in particular seek to allocate resources based on the life-years a person can expect to have where those life years are adjusted by quality in the case of QALYs (years lived in perfect health) or disability in the case of DALYs (years of life in perfect health lost) (Arnesen and Nord 1999, 1423). Together, QALYs and DALYs give a total picture of a person's life years. Because each in some sense implies the other, they are not often used concurrently. They tend to be used in slightly different scenarios (e.g. DALYs are more often used in developing countries, while QALYs are more often used in developed countries), and QALYs in general require a bit deeper understanding of quality-of-life issues where DALYs can be used when only population samples are known (Deshmukh et. al., 2013).

DALYs are intended to measure “the global burden of disease.” DALY calculus assigns “each state of health...a disability weighting on a scale from zero (perfect health) or one (death) by an expert panel” and then that number is “multiplied by the number of years lived in that health state and is added to the number of years lost due to that disease. Future burdens are discounted at a rate of 3% per year and.... weighted so that years of life in childhood and old age are counted less.” The precise weightings of a given disability may change in each iteration of the WHO DALY standards (Arnesen and Nord, 1999, 1423). QALYs and DALYs function together. While DALYs measure the burden of disease and the years of life lost, QALYs represent the years of healthy life that are lived. Arnesen and Nord provide the following

illustrative example, “if the utility of deafness is 0.67, the disability weight of deafness is $1 - 0.67 = .33$. Disregarding age weighting and discounting, and assuming life expectancy of 80 years, a deaf man living 50 years represents $0.67 \times 50 = 33.4$ QALYs gained and $0.33 \times 50 + 30 \times 1 = 46.6$ DALYs lost” (Arnesen and Nord, 1999, 1423). Therefore, the system of QALYs and DALYs gives a mathematically consistent way to compare expected patient outcomes and the utility of a given intervention, which is often thought to be “the best available option” as “no healthcare system can solve all problems” (Davies, 2019, 192-193). This system though, has been critiqued on numerous grounds and in particular, has been critiqued as being discriminatory against disabled persons.

QALYs and DALYs are critiqued as being discriminatory against disabled persons on a few grounds including that: disabled people are considered to have a lower quality of life⁷⁹(Brock, 1995), that disability is constructed in such a way that individuals who help to determine QALY and DALY scores are unable to choose simultaneously to treat disabled lives and also treat their lives as equal value to nondisabled lives⁸⁰, do not adequately measure individual utility of life outside of societal usefulness (Arnesen and Nord, 1999), treat disability

⁷⁹ While some disabilities might result in a lower quality of life, and some disabled people may experience a lower quality of life due to ableism, disabilities by themselves do not often lead to a lower quality of life, and we can see that in the empirical testimony from disabled persons which by and large report similar quality of life to nondisabled persons. (Scully 2018) This problem is pernicious though, because while treatments, interventions, or AT may greatly improve quality of life, QALYs & DALYs will still assume the quality of life of a disabled person to be lower than a nondisabled person.

⁸⁰ A common criticism levied against those who critique QALY and medical conceptions of disability in general is that providing treatment for or preventing disability in the first place demonstrates that disability is a bad thing to be avoided and the absence of disability is better. This is a larger question beyond the scope of this project, but for these purposes I will note Asch’s (2003) point that we can acknowledge a cost to becoming disabled without saying that for all time disabled people are lesser than and their lives are less worth living. Similarly, we can provide treatment for disabilities at the macro-level of resource allocation without at the micro-level disadvantaging disabled persons when it comes to treatment simply because they are disabled.

differently from other factors that affect health outcomes like geographic region, or socioeconomic status (Asch, 2001; Bickenbach, 2008), and incorrectly assume that individuals with lower qualities of life have less of an “interest in life itself” than those in perfect health (Nord, 2016, 268). Despite these numerous critiques, QALYs and DALYs continue to be used, and many of the problematic assumptions about disability that underlie their use and calculations remain as of the 2012 “WHO methods and data sources for global burden of disease estimates 2000-2011”. Still others respond to these various criticisms and insist that things like age-weighting have “virtually no effect” (Murray and Lopez, 1996), that despite flaws QALY is the best option available to us and can be reformed (Davies, 2019), or that QALYs merely result in injustice, not discrimination (Bognar, 2020). The full picture of the debate is beyond the scope of this project, but regardless it is clear that should QALYs and DALYs be used for disability related spending policy, it is likely that there will be some negative effect on disabled persons, though the extent to which that negative effect exists is debated. Furthermore, these negative effects seem implicitly accepted by the WHO and the many countries who incorporate QALYs and DALYs into their healthcare decision-making.

However, QALYs and DALYs are ill-positioned for discussion on AT given the state of the debate for two reasons. First, we have considerations about life years itself, and next we have considerations of the quality of life years. In regards to the first, AT occupies the unique position where it is virtually never going to be required to extend the years of someone’s life. There are two potential edge cases we can consider though where AT might positively impact the years of life lived. The first is where an AT intervention increases someone’s quality of life such that their health outcomes are improved. For instance, in old age there are positive correlations between

strong interpersonal relationships and life expectancy (Andrew, 2015, 188), AT that enables those relationships to flourish could then be seen as contributing to raw life years. The second is where AT prevents some life-threatening event, such as telemonitoring AT that is used to alert a healthcare professional of an adverse effect in a patient or AT used as therapy to prevent suicide from depression or AT used to ensure adherence to a pharmacare schedule. Other potential examples here are also possible, but this is AT as a preventative measure, not as a curative one.

Second, we must consider the cases where AT increases quality of life, and the quality of life improvements that come from AT have been clearly demonstrated. However, there remain two issues when it comes to entering this improvement into QALY and DALY calculus. First, we should consider that while AT improves quality of life, a person who did not choose or was unable to use AT to improve their quality of life does not necessarily value their life years as lesser than a user of AT. For example, we can imagine two people with the same disability A) and B). For person A) having a particular AT intervention will greatly improve their quality of life and the AT intervention is desired. For person B) that particular AT intervention will also improve their quality of life, but it is not desired for whatever reason. Person B) should be allowed to make the choice to not use that AT intervention but it does not follow that in choosing not to use the intervention that person B) values their future life-years less than person A), even if their quality of life is lower. Using QALY and DALY to justify AT would therefore risk entrenching notions of cure and would not adequately capture the fact that quality of life is lower often because of reasons of ableism, not health, and that AT is often a tool for overcoming ableist structures. Second, although QALY and DALY consider quality of life improvements, it is unclear how AT would be worked into the calculation. While AT increases

quality-of-life it does so in ways that are not currently considered part of the QALY and DALY calculus. It is rare for AT to be construed as the kind of cure or therapy that would generally affect such calculations (e.g. a blind person who uses a screen reader to great effect is still blind, and this will still mathematically affect their QALY/DALY score). Furthermore, access to AT would necessarily be a precondition for the alteration of calculations, but access to AT is predicated primarily on income, which is not a part of QALY and DALY quality of life calculations currently as is pointed out by Asch and Bickenbach. This means that QALY and DALY are also ill-equipped to consider the quality of life improvements of AT.⁸¹

For the Ontario system this means that if QALYs and DALYs were to be used to inform all AT, this would conflict with the general use of QALYs and DALYs only taking into account issues of “health” (as disability is currently construed as ill-health for QALYs and DALYs), as opposed to broader issues around access, discrimination, and socioeconomic capacity. To use QALYs and DALYs in a very expansive way might advance the interests of disabled persons, but then we return to the problem of choice for disabled people. In addition to the concern about disabled persons being counted as less of a life if they chose not to pursue AT interventions, since QALYs and DALYs are mathematical in nature, they do not seem to provide room for the fact that different AT will positively impact different disabled individuals in different ways, and that quality of life improvements of a given AT intervention will vary even

⁸¹ This conflict may simply reveal that because of the position of AT and the increasing awareness that disability need not be considered under the umbrella of illness-needing-to-be-cured that disability related matters are perhaps best dealt with in a realm which is not healthcare, but that further discussion is beyond the scope of this project.

within a given diagnosis.⁸² Given the inadequacy and complication of QALYs and DALYs when it comes to discussion of AT we should then shift our focus to the demands of a broader CEA.

Despite the relative uselessness of QALYs and DALYs when it comes to questions of AT funding, CEA is a broader category which Bognar suggests may not fall victim to the same criticisms that it does, and does not necessarily use QALY and DALY metrics to define the “benefits” side of the cost-benefit analysis. Where QALYs and DALYs are rigidly committed to a technical method of weighting which seems somewhat intractable when it comes to considering changes to the system, CEA in general may be more flexible. Potential alternatives to QALY and DALY include looking at the “number of cases averted, number of lives saved, the average number of years added to patients’ lives, and so on” (Bognar, 2020, 656). With AT we might use a metric of quality of life improvement, but the main benefit under CEA is that how we reckon benefits is flexible. Bognar notes that any policy system can fall prey to bad actors, but takes the criticisms of QALY, DALY and other CEA systems to be that the current systems have “inevitable but unintended side effect[s]” which are borne by disabled persons (Bognar, 2020 654-655). However, he thinks this critique mistakes the way in which CEA actually works. He notes that CEA is almost never done at the individual level (perhaps for things like organs, or in emergency situations, but not for choosing which patient to give a given intervention as a general course of things). Instead, CEA takes place at a macro level, where cost effectiveness thresholds are set for certain interventions independent of the particular patient an

⁸² This variation is already a problem for QALYs and DALYs as they do not take disabled persons individual self-reports into account.

intervention might serve. This threshold is such that below the threshold, an intervention is considered cost-effective and above the threshold it is not considered cost-effective (Bognar, 2020, 656). The cost of a given intervention is calculated on a cost-benefit basis, where both sides of this equation are averaged out amongst the group of individuals expected to benefit from the intervention and the cost those individuals will take to treat. Bognar writes that these calculations “work with averages...[to] calculate the benefits of what a typical patient can expect,” (Bognar, 2020, 658). Under this system, disabled persons are only disadvantaged if a treatment is only used for their disability and it happens to be expensive and their group is small (Bognar, 2020, 660). This, he says, is not discrimination, but rather a utilitarian calculus that may be a matter of injustice similar to poverty⁸³ (Bognar, 2020, 663).

On its surface, this kind of analysis seems much more reasonable, even if risks of injustice remain. I think this as a method of policy analysis is notable because under Bognar’s formulation, we should see much fewer AT interventions that involve orphan AT, as these are defined by their small-group of use and generally have high costs as a result, and yet, orphan, medicalized AT expenses are much of what is currently (partially) covered. However, as Stingl will point out in the next section— much of what will have the greatest effect for the lowest cost are public health interventions that occur before the general healthcare system even gets involved, and yet these preventative measures are still not represented proportional to their benefit in public health spending. This means that to appropriately use CEA when it comes to

⁸³ For Bognar, discrimination is a narrower subset of injustice where unequal treatment is given “for no justifiable reason.” Bognar believes the justifiable reason for unequal treatment when it comes to disabled people and healthcare is that “health-care priorities must be set in a way that meets the greatest number of health care needs, given their cost” (Bognar, 2020, 662)

AT we must apply it more broadly than it is typically applied. Still, Bognar's considerations give good guidance that we *should* consider funding interventions like mainstream AT because they are relatively cheap and give benefits to a large group of people. As mentioned in the discussion of QALY and DALY the benefits of AT are largely preventative (e.g. grab bars preventing falls and subsequent medical care needs), or to quality of life (e.g. being able to participate or participate more easily in work, social life, and hobbies), rather than to health itself⁸⁴, but inasmuch as these things are already healthcare goals and we have established that they are to some extent, AT, and in particular mainstream AT seems like a good cost-effective intervention under a more general CEA framework. However, this framework would need to consider the fact that small groups of disabled persons may still face the injustice problem raised.

Therefore, under a CEA we have good reason to consider 5) a lack of support for mainstream AT, still an issue for the current system. To bring 5) under the current umbrella of supports, this will require a significant consolidation of existing fragmented systems. While the fragmentation of the system's burdens on disabled people is not necessarily a concern under CEA, the fact that fragmentation may increase the amount healthcare time needed unnecessarily to complete multiple documentations, or increase the number of workers that are needed to acquire any number of diverse interventions a disabled person might need, is an issue under CEA. So we additionally see that 1), the system's fragmentation, is certainly not justified under

⁸⁴ I take the improved functioning gained by AT to be outside of the curative framework of health. Improved functioning may be gained by AT where there is no "ill-health" and while some disabled people may be in ill-health and require healthcare to improve it, AT will not be this kind of treatment, even if we can imagine AT supporting healthcare at times. The openness of AT is also such that "improved functioning" may simply be different, preferred by the individual in question functioning and does not suggest an objective measure outside of what an individual reports their perceived quality of life to be given how the AT improves (or does not improve) their functioning.

CEA, and furthermore, that without 1) CEA may be increased through streamlining as well as an easier and more well supported administration of 5).

7.2.2 Equality & Efficiency

CEA, QALY and DALY are all more specific tools that are used to implement general values and intuitions about what purpose healthcare has and what kinds of methods should be used to distribute and prioritize that healthcare. The underlying values themselves though are important to address as well. Stingl argues that the values underlying our Canadian single-payer healthcare system are the values of equality and efficiency (Stingl, 1996). In particular, he argues that a Rawlsian idea of equality as justice/fairness is what underpins the system. He argues that the value of healthcare is that healthcare is analogous with political liberty, although unlike political liberty, health needs vary and it is harder to guarantee equal health than to guarantee equal “civil liberties” (Stingl, 1996, 71)⁸⁵. Stingl argues though that this shared value that health and political liberty have mean that Canada cannot have a two-tier healthcare system, because paying for healthcare is a huge issue of justice (Stingl, 1996, 72). Of course, he notes that this value exists alongside a potentially competing value of efficiency. In particular, he notes that there have been pushes to eliminate inefficiencies in the healthcare system such as unnecessary tests, or ineffective treatments. In particular, he thinks the desire for efficiency at times comes from a desire to see those who need treatment being treated, rather than having people who don’t need treatment eating up resources, i.e. it comes from a desire for equality. However, he

⁸⁵ Although Stingl calls these “civil liberties” they seem much closer in Rawlsian terms to guaranteeing the fair value of political liberties, or equality of opportunity (Rawls, 2001, 148-150).

cautions that achieving efficiency in a simplistic way, such as by cutting costs and eliminating overtreatment does not necessarily solve problems of inequality or undertreatment of some groups (Stingl, 1996, 73). Therefore, we must be cautious when implementing efficiency as we cannot use a simplistic notion of efficiency as a shortcut for solving issues of equality. We can see this issue and the desire for efficiency to be related to CEA influences. As foreshadowed, Stingl points out that in general, the most efficient intervention for many health-related issues is to address them before they become health issues (e.g. preventing later health problems by ensuring all children have access to adequate nutrition) (Stingl 1996, 73). We also frequently run into the situation where policymakers feel they must temper equality and efficiency against each other because under a simplistic notion the most efficient use of resources might risk excessively unfair health outcomes, as is a common problem with utilitarianism (Stingl, 1996, 74)⁸⁷. For instance, it may be more efficient to treat only those who are already the most well-off and have easy to treat illnesses, as opposed to those who are not well-off and have complex needs, but this would be an issue for equality and justice. This remains a difficult problem to solve, but the interplay of these values remains important to the Canadian healthcare context. However, I argue that a more robust notion of efficiency which takes into account the idea that equality will be more holistically efficient in the long term would be one way to integrate these two values.

⁸⁷ Stingl gives the example that it might be efficient to only offer hip surgery to those under 75, or only provide treatment for “more prevalent conditions at the expense of more serious but less prevalent conditions” (Stingl, 1996, 74). However, it is potentially possible that if we were to consider justice to be efficient, as unjust conditions have all sorts of negative costs, this would not be the case. Arguing at length for a more nuanced understanding of efficiency is beyond the scope of this project, but a techno-inclusive model of disability and its considerations of justice, as well as the considerations raised in the remaining discussion of equality and efficiency do suggest that we must consider efficiency in a much more nuanced way than a simplistic, utilitarian cost/benefit analysis might suggest.

I argue along the same lines as Stingl with two important distinctions. We can further strengthen Stingl's argument by noting that while health is not totally analogous to political liberties, in addition to being like political liberties itself, health is necessary to exercising many political liberties (in Rawlsian terms, it is necessary to guarantee the fair value of political liberties). Political actions like participating in protests, voting, accessing political information, organizing in the community, etc. are often not possible without a certain baseline of functioning. Health is one aspect of functioning, but accessibility is another, and disabled persons may need support either or both in health and functioning to exercise their political liberties. This is especially true when it comes to disability as even if we do not want to consider all of disability a matter of health, because of social or environmental barriers disabled persons may still be prevented from accessing these liberties, which makes the funding of supports for disabled individuals to overcome these barriers (or supports to eliminate these barriers in the first place) imperative.

Additionally, I argue that Stingl makes a descriptive mistake in his reasoning, although in teasing out this mistake, I will show that his prescriptive claims can be made stronger than his initial argument would suggest. Throughout the article, Stingl emphasizes the importance of a single-payer healthcare system to ensure that political liberties cannot either be bought by the rich, or withheld from the poor. I think upon closer examination one is hard-pressed to argue the Ontario or even Canadian system more broadly is truly single-payer given a lack of access for pharmacare, mental health care, dental care, and most importantly for this project— AT. As long as environmental barriers exist, AT will be integral to accessing spaces that enable disabled individuals to exercise their political liberties. Even without environmental barriers constructed

by human society, in places where universal design is impossible, AT of some shape or form will be required by some folks. This means that to get to a true single payer system and therefore a system which ensures the fair value of political liberties, we must fund AT in a single-payer manner.⁸⁸

If we are tempering the value of equality against the value of efficiency it is difficult to tell exactly what is required, and as Stingl points out it is hard to distinguish between what is essential health services and what is not (Stingl, 1996, 72). However, as will be argued later, there are some problematic inconsistencies between what is considered essential in our single-payer healthcare system, and what is considered essential for AT. This discussion therefore also gestures at issue 4). Stingl's identification of Canadian values overall leads to concerns on the basis of 1) since the burdens placed on disabled people as a result of fragmentation risk inequality, and the fragmentation itself risks inefficiency, as well as 5) on the basis of the inefficiency of not supporting broader public health measures in the form of mainstream AT.

Aside from Stingl and CEA, there are other ideas which help us to understand what is truly efficient and which help to inform how we might best get at both equality and efficiency, as well as how equality may help to inform a more robust understanding of efficiency. In "The Role of Markets in the Delivery of Health Services" DeJong and Basnett argue that under some circumstances, multi-payer, or markets within single-payer health systems can be efficient, even

⁸⁸ A careful reader might note that my argument also requires elements like pharmacare, mental health care, and dental care to be similar folded under a single payer umbrella to ensure the fair value of political liberties. While arguing for these is beyond the scope of this project, this is an implication that I fully support. Whether or not AT is more of a priority than these other things is also beyond the scope, as for this project it is sufficient to establish that there is a fairness need for the single-payer support of AT.

and perhaps especially for disabled persons (given the distrust many disabled persons have towards traditional medical establishments) (DeJong and Basnett, 2011, 610) However, for this to be the case, markets must be “managed competition” such that they compete on price and quality, but meet the following criteria. Users of the services must meet the criteria of sponsorship (where the demand side is organized into large groups), providers must be price takers not price makers (no health plan or provider network is dominant enough to set the price of goods and services), there must be a standardized list of benefits and definitions of medical necessity, there must be consumer choice, information must be accessible, financial risks must be accepted by providers, there must be risk adjustment for payment, risk adjustment for quality, a rule-making body that is public or quasi-public, and governance of the system must be predominantly by consumer representatives (DeJong and Basnett, 2001, 623). For disabilities, this means that in particular, disabled people can’t be labeled as a high-risk group and any standardized definition of medical necessity has to address the “functional needs of disabled persons,” (623). This connects back to the intersection of functioning and health. While functioning is not necessarily connected to health, healthcare still occupies an important position in supporting functioning. Places that lack internal markets, or where internal markets are not managed well are both more prone to medical paternalism (624). It is important to note that internal markets can exist in single-payer, multi-payer, or private payer healthcare systems. For the current set up, we can see the system of AT vendors for orphan AT as an internal market (a competitive market contained within a healthcare system) in a multi-payer system (user contributes and government contributes), and the system of mainstream AT as being a private payer system

In regard to the current system, DeJong and Basnett's considerations speak to the benefit of direct wealth transfers for the purposes of buying AT, as a means of evading medical paternalism and enabling disabled persons to access AT markets. This is a benefit of mainstream AT, or bespoke AT that evades traditional medical providers. However, their standards regarding those markets are appropriately high, and this wider market would be harder to manage than the healthcare market, which is where I think mandates for universal design could come in to ensure that universal design is branded a necessary (thus eliminating disability as a special group that can be discriminated against, at least in part). Failing this, AT needs to be included under the umbrella of medical necessity so that AT can be accessed through medical means and medical markets, and this is currently lacking. These considerations will be unpacked further in the next chapter, but for now these considerations are enough to raise issues along the lines of 3) financial inadequacy and 5) lack of support for mainstream AT. Where 3) is not being met in part because of the additional costs disabled persons face due to inadequately managed markets, and 5) is not being met because universal design is not currently mandated in a manner which is sufficiently widespread. This also leads us to understand that efficiency can be found by mandating markets to behave in certain ways, increasing equality and good outcomes for patients.

One final element of clarity we can find around efficiency when it comes to healthcare spending and in particular, funds being available for AT and to disabled persons is around what kinds of means-testing we employ when distributing funds. Means-testing is the process by which programs and supports are only available (either in full or in part) if an individual has less means (I.e. \$\$) either in income, savings, or assets like a house or car, than the threshold. This is

relevant for ODSP as an income-replacement, and for other Ontario programs which are not income supplements but nonetheless means-test as a way of determining eligibility for support for AT. A recent study from the U.S. “The welfare effects of asset means-testing income support” examines the optimal values for means-testing income supports when it comes to looking at assets. Wellschmied notes that systems which look at assets incentivize holding few assets which leaves people “vulnerable to predictable and unpredictable income changes” and can incentivize leaving the labour force (Wellschmied, 2021, 218). He finds that means-testing works optimally balancing efficiency and wellbeing on assets over \$150,000, but abolishing means testing entirely is very close to optimal, in part because so few individuals have assets over \$150,000 and because there are other social incentives against taking part in income support programs (Wellschmied, 2021, 218). The welfare gain of eliminating means testing is mainly⁸⁹ caused by improved savings decisions, and secondarily⁹⁰ comes from improved employment choices (Wellschmied, 2021, 218). Wellschmied found that removing means testing was especially good for the elderly and increased money going into retirement (Wellschmied, 2021, 219). This has bearings on disability since many more elderly folks are or will become disabled. Overall, abolishing means-testing in his study resulted in only a 4% increase in costs, so the total amount given to individuals could go down by 4% or government spending on income supports could go up by 4% (Wellschmied, 2021, 219). This is against a backdrop where the current asset limit in the US is 2-3k USD (2.5k-3.7k CAD).

⁸⁹ Wellschmied attributes two-thirds of the positive benefits to this

⁹⁰ Wellschmied attributes one-third of the positive benefits to this

This is obviously a bit different from the Canadian case where asset limits on ODSP are 40k CAD (50k for couples), and there are provisions for disability specific savings accounts which are exempted from asset considerations (ODSP, Information Sheet, Accessed 2021). Nonetheless, the \$150,000 USD threshold (~190k CAD) proposed by Wellschmied, is still much greater than the current ODSP threshold of 40k. Obviously, there is not a 1:1 ratio of assets to income, but allowing for a modest 2% interest rate, 190k CAD in assets would allow for an additional 3.8k CAD per year in income (almost a 20% increase over current ODSP support levels assuming \$1600/month). This analysis, therefore, gives an incentive both for an eradication of means testing on income supports, and potentially other programs, as well as for a significant increase on the amount of income supports at least to the level that interest on the asset limit that Wellschmied allows. This supports my criticisms of 1) and 3), where the fragmentation and burdensome nature of systems is likely to be inefficient, especially where they are means-tested (and in part the fragmentation of the system allows some parts to be means-tested and others to not be) as well as pointing out that the financial inadequacy of the current system cannot be justified under an idea of efficiency. Additionally, these considerations augment understandings of efficiency in a data-driven way.

7.2.3 Techno-Inclusive Theory of Disability

Now that we have discharged the practical concerns of CEA and efficiency, and assuaged the gods of capitalism under a mindset of scarcity, let us turn to the tools of disability theory, and examine the current Ontario support regime against the actual needs of disabled persons. In previous chapters, I put forward a techno-inclusive theory of disability. This theory notes that disabled persons need many kinds of AT tools, and that these tools will differ from

person to person and not just disability to disability. Furthermore, under a techno-inclusive model diagnosis can be problematic for individuals not wishing to conform to a medical understanding of their disability, or who may not identify as disabled at all and yet nonetheless require AT. Therefore, the kinds of AT made available to individuals will need to be broad. The model demands increased access to AT used for many different realms of life as a matter of justice and requires that further stipulations for universal design are enacted. Furthermore, it encourages the involvement of disabled persons at every step of the AT design and implementation process. Finally, the model requires that the outcomes of AT use be further studied, and used to improve outcomes, where outcomes are partially universally and partially personally determined. To reiterate, more universally good outcomes can generally be achieved by enabling disabled persons to trial and select their own AT, by supporting universal design and minimizing the visibility of AT, and connecting disabled persons and healthcare professionals to the wider network of knowledge that exists in the disabled community.

In regards to the Ontario system, this leads to a few specific recommendations, some of which may be more practicable than others. First, legal protections which require newly built spaces to conform to accessibility guidelines, and businesses, employers etc. to accommodate to a certain threshold should be expanded to include manufacturers of goods, to ensure that goods are up to a minimum universal design standard, and reinforce the criticism of 5).⁹¹ Second, more support for disabled needs is required as currently neither income supports nor direct funding

⁹¹ Principles for universal design and guidelines already exist and have been previously referenced. These could easily be integrated into broader legislation.

for AT is enough to cover the full costs of a variety of AT. To truly accommodate a flexibility in choice of AT either the scope of what AT is funded needs to be greatly expanded or direct income transfers from government sources⁹² need to be greatly increased to accommodate choice of AT. Under a techno-inclusive model this support would also ideally include connecting disabled persons to a wider disability community, and support for programs like assistive devices lending libraries, to enable disabled persons to be able to make informed choices when it comes to their AT (CBC, New Hamilton Library..., 2021). Similarly, to truly provide choice to disabled persons, the fragmentation of the system and its burdens need to be significantly reduce to ensure disabled people are not simply funnelled into a path of least resistance that may not have all the supports they need, or force them to overcome hurdles and navigate a complex system which may be inaccessible depending on their disability or caregiving situation. These together reveal 1) and 3) to still be substantial problems. Additionally, these supports need to be separate from a diagnosis to enable true access for a wide range of disabled persons (whether or not they identify as such) and to allow for a broad range of interventions. This supports the criticism of 2). Finally, distinctions between “essential” and “non-essential” AT under the current system need to be more deeply examined in light of issues of justice. Given the designed nature of our world, it is unfair to risk the exclusion of disabled people from realms like school, community work, political involvement, art-making, and hobbies of all kinds by limiting the kinds of AT that are funded. This kind of limitation is also contradictory because other health services definitions of “essential” are not limited only to what is life-saving. Healthcare systems regularly engage in care like setting broken bones, consulting with patients

⁹² To ensure easy access for all disabled persons

and providing prescriptions for erectile dysfunction, as well as myriad other services that are beyond the scope of essential for living and minimally caring for one's self. It is puzzlingly inconsistent⁹³ that AT is treated differently from these other cases and that “non-essential” AT is excluded from a list of services that dramatically improve quality of life at a potentially very low price point assuming increased support for universal design, taken together this means techno-inclusive model considerations strength the criticisms of 4) a lack of access to “nonessential” AT and 5) a lack of support for mainstream AT. A further discussion of what should constitute essential vs. nonessential AT can be found in the next chapter.

In addition to my techno-inclusive model of disability, Ladner also raises some good techno-specific ideas which might be addressed in policy considerations. The first is ensuring that any policy covers the breadth of use of assistive technology which include use cases in medicine, rehabilitation, education, legal access and equality, and across “the diversity of life⁹⁴” (Ladner, 2011, 27). Ladner also emphasizes that while universal design is admirable, truly universal design is very difficult, so another good choice is to “design to enable people to solve their own accessibility problems wherever possible. A simple example is found in modern screen readers where the user can adjust the speed of the speech,” (Ladner, 2011, 29). Finding these opportunities is much more likely by including disabled people in the design of technology, and supporting “multi-function accessibility devices” (Ladner, 2011, 29-30). These considerations further emphasize the need to challenge currently drawn clear distinctions between essential and

⁹³ In a way in which might be said to hint at institutionalized ableism

⁹⁴ This is the language Ladner uses to describe the social model, and I believe is intended to be a catch all of “anything a disabled person might want to do that is not covered by the other categories.”

non-essential, especially should AT be approved and funded directly rather than by unrestricted money transfers. In this case, AT in all the realms that Ladner describes should be supported. It also provides additional context and nuance for potential mandates for universal design 5) and accessibility of “non-essential” AT 4).

7.3 Key Issues Confirmed

The analysis shows that regardless of what framework we examine the current system of support as it related to AT, there are shortcomings and inconsistencies. Of course, as we have seen, the design and implementation of support must be a balance between different competing values and factors. At the beginning of this chapter and in the last chapter, some key issues were identified, including: the fragmentation of the current system, the burdens it places on disabled persons, the emphasis on diagnosis, financial inadequacy, lack of access to “non-essential” AT, and lack of support for mainstream AT. As we have seen, the fragmentation and burdens on disabled people, inasmuch as those burdens are related to things like means-testing and discriminating between the essential vs. non-essential nature cannot be justified even under cost-effective frameworks. Inasmuch as these burdens are related to the orphan/medicalized vs. mainstream/universal design division, they cannot be justified either under cost-effective analysis, ideal markets or a techno-inclusive theory of disability. The emphasis on diagnosis is perhaps justified under the value of the existing policy systems and philosophy of the social system in Ontario, but the issues with diagnosis have been laid out more at length in previous discussions of the techno-inclusive theory. The financial inadequacy of the current system is laid bare by careful examination of cost efficiency analysis and the potential benefits and low costs of universally designed AT. The inadequacy of income supports is also supported by considerations

of the maximally efficient level of income testing when it comes to wellbeing. In addition, I have emphasized that there is an inconsistency in distinguishing between essential and non-essential AT when there is room for quality-of-life improvements in other areas of healthcare, and many AT which are classified as non-essential are cost-effective and important for values of equality, as well as for rectifying the issues of injustice that come about through our world that is designed in ways that interferes with disabled persons' liberties and well-being. Finally, the lack of support for mainstream AT first allows corporations to ignore disabled people as a market, potentially exacerbating issues of injustice and continuing or creating new barriers for disabled people, and the lack of support for mainstream AT is cost-ineffective when we look at the relatively low cost of mainstream AT. Furthermore, if mainstream AT was further mandated and supported, we would likely see costs decrease further⁹⁵.

7.4 Conclusion

Given that even under a charitable framework which takes into account the costs and existing values which pressure and underlie our current systems, supports for AT still fall short. It is clear that more must be done and changes must be made. Here I have detailed a sampling of various systems and values which do or should inform AT as it relates to a larger system of healthcare and social supports for disability. I have analyzed the current regime with reference to these influences, and described the shortcomings with reference to the analytical tools of cost

⁹⁵ At least for disability, even if this made the developing and manufacturing process more expensive and costs rose slightly for everyone else. This would have the benefit though of distributing the costs of disability across a wider market who can also benefit (similar to how mothers with babies in strollers benefit from ramp architectures or individuals with text-based learning preferences benefit from closed captioning). However, it's also hard to say when costs of a given product rise if it is really due to increased costs or rather a need on the part of corporations to see profits continually rise.

efficiency analysis, equality, and efficiency, and a techno-inclusive model of disability. Therefore, in the next and final chapter I will suggest some partial and preliminary measures that should be taken to bring the system more in alignment with the current state of AT, are inclusive of these considerations, and which above all prioritize the interests of disabled persons.

Chapter 8: AT Recommendations for the Ontario Policy Context

In the previous two chapters I have first described the Ontario policy context as it pertains to support for AT, and second, described the shortcomings of said policies including the shortcomings in light of cost-efficiency analysis, Canadian healthcare values like equality and efficiency, and on the basis of a techno-inclusive model of disability. In this chapter, I will use these same tools (in particular, a techno-inclusive model of disability) to make some preliminary concrete recommendations as to how the Ontario policy context could be meaningfully changed to better support the needs of disabled people, as well as to better promote equality for disabled persons. The techno-inclusive model is particularly important to this analysis because it calls attention to the ways in which technology is simultaneously a barrier to and a means of accessibility (in the form of AT) that is necessary for equality. The inclusion of nuanced disabled voices in their perspectives on technology as drawn out by the techno-inclusive model is an integral benefit of the model when used for evaluating policy.

Although I will gesture to the other concerns, I recognize that others more enmeshed in the economics of healthcare might be better poised to make recommendations on those grounds. Nonetheless, I recognize those grounds are an important part of how policy decisions need to be made and I hope to emphasize with my argumentation both in the previous chapter and in this one, that support for disabled persons and their AT are not in fact so financially burdensome, especially in comparison to other areas of healthcare.

In this chapter I will begin by reiterating the issues with the current system, as well as how each analytical tool supports my critiques. Next, I will outline how these critiques suggest

two broad areas for improvement: improvement in the development of AT, and improvement in the distribution of AT. I will then make suggestions as to how to improve these two areas, and how these improvements will at least partially solve the critiques. These suggestions are:

1. Mandate universal design
2. Provide incentives or mandate disabled involvement in the design of AT (including mainstream AT with universal design), in particular for #DisabilityDongles or publicly funded AT research
3. Change the definition of essential vs. non-essential AT and include some non-essential AT.
4. De-emphasize or eliminate diagnosis in approving funding for AT.
5. Greatly increase funding supports in the form of direct cash transfers while still supporting direct AT where necessary

Finally, I will conclude this project, and suggest a few ways in which this project could be further taken up and expanded.

8.1 Re-iteration of main issues to solve

As a reiteration from Chapter 7, there are 5 main problems with the current Provincial system and the existence of these problems was proven unjustified in Chapter 7 using various methods of analysis including cost-effective analysis, equality and efficiency, and a techno-inclusive model of disability. I take these methods to encompass much of what current moral and practical hurdles public health and AT are subject to. The issues include 1) system's fragmentation and the resulting burdens it places on disabled persons, 2) the emphasis on

diagnosis, 3) financial inadequacy, 4) lack of access to “non-essential” AT, and 5) lack of support for mainstream AT.

In the chapter that follows I will discuss some suggestions for how these issues can be solved. In broad though, I believe that 1) fragmentation, would be greatly alleviated by a centralized system, and it seems the easiest way to have a centralized system is to rely on direct cash transfers to disabled persons. Problem 2) emphasis on diagnosis, similarly requires an overhaul in the method by which funding approval is granted, as well as how AT is accessed. Problem 3) financial inadequacy, is a relatively simple fix in terms of what needs to be done (i.e. increasing payments to disabled persons) although the problems of how to budget for the necessary funding to implement such a program will be left to someone better suited to that kind of analysis. Problem 4) lack of access to “non-essential” AT, may also be solved through direct cash transfers given a high enough level of such transfers, and/or through more support for mainstream AT if that encompasses sufficiently recreational mainstream AT. Finally increased support for mainstream AT needs a combination of financial support to enable the purchase of mainstream AT alongside more regulatory mandates to increase the availability of mainstream AT via universal design. We see then, that these problems all intersect with one another and similarly, my hope is that the solutions outlined in this chapter will similarly help each other, such as an increase in mainstream AT helping to alleviate an emphasis on diagnosis by making AT more cheaply and widely available, including to disabled persons who may be uninterested in either identifying as disabled or obtaining a formal diagnosis. Similarly, implementing a mandate for universal design (solving problem 5) is likely to result in savings due to economies of scale, allowing an easier partial solution to 3), the financial inadequacy of the

current system. These are just a few examples of how a system overhaul can solve multiple issues simultaneously.

The suggestions that will be made in the following chapter are preliminary, and inexact. Obviously, to make such a comprehensive overhaul of a complex system would require the buy-in of many different kinds of experts including those with political, healthcare, economic, not-for-profit, as well as surely other kinds of expertise, importantly in addition to those with lived experience. The suggestions that follow are therefore broad in nature, and the exact specifics would depend on an interdisciplinary effort alongside political buy-in, and more detailed constraints that I can know or imagine as a philosopher (even as an interdisciplinary philosopher). However, it is my hope that my suggestions will motivate these next essential steps to improve the state of AT in Ontario. The generality of these suggestions (although tied to the Ontario context) may also well position them to be used more broadly in other jurisdictions with similar interdisciplinary collaboration. Let us then turn to the two broad solutions: improving the development of AT, and improving the distribution of AT.

8.2 Development of AT

The first general prong of solutions to the current system of AT support in Ontario is to improve the *development* of AT. This general area encompasses two major suggestions to improve AT development. First, a mandate for universal design should be included in regulations, similar to how accessibility of buildings, services, and workplaces is mandated. Manufactured goods that are designed, produced, or consumed in Ontario should have to meet similar standards of

accessibility and use⁹⁶. This therefore ensures that universally designed, mainstream tech is made. Second, incentives (or potentially mandates) should be provided to encourage that mainstream AT be developed in ways that are in accordance with the suggestions made by the techno-inclusive model, such as by ensuring more disabled involvement in the development of AT. In this section I will detail these two suggestions alongside case examples, and justify them with reference to the analytical tools introduced in the previous chapter's critiques.

First, let us examine the suggestion that universal design should be mandated. What I have in mind in suggesting this is a broad mandate similar to the AODA. Unlike the AODA, however, this mandate should not be piecemeal (as current sections of the AODA only apply to certain domains, all sections do not apply to all domains), but rather truly cover all manufactured goods designed or produced for, or consumed by consumer end-users in Ontario. A well-accepted standard of universal design already exists (Universal Design, 2020), and could be used to evaluate current and future goods. These principles would ensure that a product would conform to minimal universal design principles, but would not prohibit the production of a product that might be impossible to design in a universal manner. Similarly, if multiple versions of a product existed at a similar price point which fulfilled different accessibility needs, this plethora of manufactured goods would be acceptable (e.g. if a book was available in eBook (able to change size of font), physical, and audiobook at a similar price point this would fulfill this stipulation, although individuals might still need an e-reader or media playback device to

⁹⁶ I do mean this to be very broad, as although “technology” as we think of it (i.e. computerized) is very important for accessibility, so are manufactured goods that we might not immediately identify as “technology” but which have been discussed throughout this project: things like grab bars, deodorants, shoes, etc.

access the eBook/audiobook respectively). As it seems clear from the experiences of disabled persons in Ontario that the AODA is itself insufficient, I would also recommend a clearer definition of “impracticability” or “undue hardship” alongside similar limiting language and to ensure that such definitions are sufficiently narrow in scope to ensure disabled persons have adequate access to the supports they need. A similar timeline to the AODA could be implemented to ensure such mandates are fair to businesses.

Universal design principles would apply to mainstream manufactured goods (which could also be AT), as opposed to orphan or bespoke AT, since even under universal design principles it is possible that those with complex needs may still require orphan or bespoke AT. It doesn't make sense to talk about universal design in respect to orphan or bespoke AT as those cover the gaps of what universal design cannot solve in respect to mainstream AT. Bespoke AT is inherently custom, and so a universal design would be against the interests of the individual who is commissioning, building, or altering AT for their own specific use. Similarly, although we want to have clearer definitions of “impracticability” or “undue hardship” it does not mean such a line does not exist. Where exactly that line falls is unclear. As will be discussed in the next sections, we need not be as concerned with items that would be considered luxury for even a nondisabled person. The line will therefore need to be determined based on the criteria mentioned in the next section, keeping in mind that the ultimate goal is that all disabled persons should have access to a similar range of goods at a similar price point as nondisabled persons⁹⁷.

⁹⁷ For example, cars and public transit might serve similar roles in urban areas where public transit is made truly accessible, so there would be less of a need for truly universally accessible cars. Nonetheless, we would still want cars to conform to universal design principles (even if this didn't mean that every disabled person could drive). This means that in the next section, a car might still be something covered by direct AT where a disabled

Where universal design cannot ensure this by itself, my other recommendations will come into play.

A case example for a universal design mandate might be the deodorant discussed by Twitter user @VarunChandak_ which can be found on pg. 103. Instead of creating an “inclusive deodorant” that is only available to buy via limited methods, and only available for particular scents, a mandate would require all deodorants to be made using an inclusive design. Supposing that we are also thinking of scent-sensitivity in our universal design and deodorants are often scented, one might think such a mandate would require all deodorants to be scentless, however, I do not think that need be the case. In cases where some aspect of universal design is tricky to integrate into the usual use of a product, all manufactured goods need not conform to universal design so long as there are a sufficient option of universally designed manufactured goods which were of similar price and availability as one which is not universally designed. This could also be helpful in potential cases where access needs might conflict and no single universal solution can be found, similar to the book example above. It is important too that this requirement for universal design is not simply that such products be available somewhere, but rather that these products be available in similar places and broad ways to existing products (i.e. I could go buy it at my local superstore, or online from a convenient place, etc). The mandate for universal design does not just impose duties on manufacturers, but also on.⁹⁸ While it is unclear what form such a

person had no other transport options, but in other contexts, they might only be provided with AT or the funding to buy AT that enabled their public transit use.

⁹⁸ Such a mandate has been proposed in 2009 in Norway as part of their “Universally designed by 2025” program. However, I was unable to ascertain in any English media whether or not this project has continued going forward, or what kinds of legal mechanisms were in place to ensure compliance. (Norway Universally Designed by 2025, 2009).

mandate would ideally take, the intention behind this requirement is to avoid criticism raised in #DisabilityDongle testimony that when accessible versions of common items are created they may be very difficult or in some cases/locations impossible to access (Appendix A). It is clear that accessible devices cannot simply be made, they must also be available for sale in a reasonable manner.⁹⁹ At the very least we can say such access must be available in person and online.

This change is supported by arguments from the techno-inclusive model of disability, and has the potential to improve efficiency. This solution decreases the costs that need to be borne by healthcare and public health institutions, ensuring that AT is not treated as a “special need” that must be accommodated by government systems, but rather as a fundamental necessity for all consumer goods. This has the potential for allowing economies of scales to be leveraged for the benefit of disabled persons, also decreasing the costs they might face (and that governments might need to provide compensation for).¹⁰⁰ In combination with income supports, cost-efficiency analysis is also likely to support this mandate, as it will ensure that dollars from income supports can go further in many cases, as mainstream AT interventions are likely to be significantly cheaper than the cost-efficiency threshold, as such a threshold is often correlated with the much higher cost of healthcare. A mandate for universally designed manufactured goods results in more mainstream AT, which means that AT is available at a lower price-point and without the need for a referral. This solution is also supported under a techno-

⁹⁹ though of course there will always be variations in access and this a broader problem than the scope of this dissertation and applies to things like food deserts as well.

¹⁰⁰ There is the potential here that costs would go up for nondisabled consumers, thus shifting the burden from governments to nondisabled citizens, which is something that might need further consideration. Nonetheless though, this would be a fairer state of affairs for disabled persons.

inclusive model of disability which centers disability as a contingency of the built environment. In forcing goods as well as services and structures within that society to meet a wide range of human needs this lessens some of the injustice of living in a world that is built contrary to the full range of human needs. This change also serves to lessen the reliance on diagnosis and its correlated narrative of cure so that disabled persons may still access things they need without participating in a medicalized dialogue which brands their lives as lesser-than.

My second suggestion in regards to the development of all AT (including AT that is neither mainstream nor universally designed) is that incentives (or potentially mandates if incentives prove insufficient) should be provided by governments to encourage the involvement of disabled persons in the creation of AT. These incentives might take the form of grants or employment support programs to ensure disabled persons can be paid for their expertise. This is especially easy to change/enforce when developers of AT are student researchers or think-tanks at publicly funded universities due to the fact that these places are already subject to fairly extensive governmental intervention. Furthermore, this area is of importance as #DisabilityDongle activism anecdotally claims that many #DisabilityDongles are created as the result of think tanks and other post-secondary activities where students engaging in publicly funded research attempt to solve the problem of disability without actually consulting or researching with the disability community (Appendix A). The push to include disabled perspectives in the creation of AT might also come in the form of inclusion being required for ethics approvals and/or scholarships and grants, as well as to obtain access to other disability-inclusion specific incentive programs. Finally, best efforts should be made to ensure the disability use-case for AT is represented by disabled persons involved in the project in the case

of narrower, orphan AT, and where AT is universal, efforts should be made to involve individuals with a wide range of access needs.

As a case example, we can imagine the government creating a program in which disabled persons could be hired by corporations with the government providing half of their wage (this is similar to programs like Mitacs that exist for students). Disabled persons in this program would be compensated fairly, corporations of all kinds would be incentivized to hire them, and oversight mechanisms of such programs would ensure that the work does indeed focus on matters related to disability and AT. This would provide disabled persons with income and experience, and elevate the status of their ideas as far as corporations are concerned. Hopefully, corporations would see the value of including disabled employees and their perspectives, and design and produce better AT as a result, increasing the options of non-#DisabilityDongle AT available to disabled persons.

Unlike other suggestions, the mandate for universal design and incentives for disabled involvement in design are beyond the scope of the current shortcomings of the Ontario system and instead look at the way AT can more broadly be improved for all theoretical markets, and the ways in which an Ontario (or federal) incentive could lead that improvement. These suggestions of course, also have positive benefits for other subsequent recommendations that will be made. The improvements in the development of AT are, however, meaningfully aligned with values of equality, efficiency, and with the goals of the techno-inclusive model. As shown via testimony from disabled persons and the techno-inclusive model, #DisabilityDongles can be harmful to disabled persons in that they continue to mark disability as a special need, are often prohibitively expensive, and may create unrealistic expectations for disabled people while using

them as a marketing device. As per the suggestions of Tourettes Hero encouraging the inclusion of disabled persons in the design process helps to eliminate #DisabilityDongles, or ensure those that are made will at least be of use to a particular group of disabled persons involved in the design (Tourettes Hero, 2020). This helps to improve equality because the acquisition, ability, or expectation to acquire #DisabilityDongles to compensate for disability will be less or no longer expected—likely improving the state of environmental barriers for disabled persons and resulting in their increased participation in a wider range of activities, including political ones. Similarly, without research dollars going into narrow #DisabilityDongles, it is likely that what is created will be more useful and potentially cheaper due to economies of scale given a likely broader user base for devices (and since price is one concern that goes into disabled persons thoughts around #DisabilityDongles). This improves true efficiency because it both saves on costs and ensures that dollars go towards AT that is more worthwhile for a vulnerable group in need of justice. Finally, including disabled persons and compensating them for their valuable contributions is in alignment with the goals of the techno-inclusive model.

8.3 Distribution of AT

The distribution of AT is slightly more complicated. My first recommendation is that as an overarching structure, some non-essential AT must be included in what is funded, and second, diagnosis needs to be de-emphasized and/or eliminated. This elimination works hand in hand with a recommendation for large, direct cash transfers to persons with disabilities to a much larger group than currently qualifies for governmental support in Ontario to enable them to overcome the “crip tax” that requiring AT imposes and make their own decisions as to what AT to buy. I will propose three potential strategies by which we might accomplish these ends,

leaving it up to the reader, disabled community, and those who come after to decide which might be most feasibly implemented at a given political moment.

8.3.1 “Non-Essential” AT

In the previous chapter, I discussed how the current “non-essential” vs. “essential” line is incorrectly drawn, as many things which would be considered essential in traditional healthcare are not considered essential in AT, namely, quality of life in things like basic functioning (e.g. we would not allow someone’s arm to remain broken because they could work fine with just one, but we do allow people’s prosthetics to break and not repair them), sexual satisfaction (e.g. consulting for an erectile dysfunction prescription), skin conditions with mainly aesthetic ramifications (e.g. prescribing topical medications for acne), and surely there are more examples of this. Additionally, under the current system seemingly essential activities like education are not covered. This requires then that the line between essential and non-essential be re-drawn to bring it in alignment with what is considered essential and non-essential for nondisabled folks.

Of course, we might still concede that even if the current line between “essential” and “non-essential” is poorly drawn there should be some distinction between essential and non-essential due to scarce resources. This does not mean though that no nonessential AT should be covered. Although no nonessential AT is individually, itself, essential, the ability of each disabled person to access a range of nonessential AT is integral for justice and well-being. That is to say, while no nonessential AT can be identified as themselves essential in a vacuum, for a particular disabled person a particular nonessential AT may be reasonably considered to be essential. I argue that society should take reasonable steps to make sure every disabled person has access to

a reasonable range of non-essential AT as a matter of justice and equality. We might imagine non-essential AT to encompass things like AT for putting on makeup, alternative ways of playing videogames, prosthetics or devices for sports or music, and more. Nondisabled people access at least some these activities at very low price points,¹⁰¹ although their options might still be constrained by their financial means. Nonetheless, these activities are an important part of living a full life and participating in the breadth of society. Therefore, it is an issue for justice and equality if disabled people do not have roughly similar access to these activities as nondisabled people. It is therefore important that supports for disabled persons be inclusive of at least some nonessential AT, in addition to moving the bar of what is considered essential or non-essential to be more in alignment with how other healthcare interventions are considered.

It is important to note too that while nonessential AT may be often for the purpose of leisure (or at least non-economic purposes), just as nondisabled people might want to monetize their hobbies, or might pursue careers that started out as hobbies (like professional athletes, musicians, artists), it is important that disabled people be similarly empowered to pursue a range of moneymaking activities that require AT specifically for that activity. It is unclear whether these activities would be “essential” or “nonessential” in the case of work, since other work might be found, but this is another reason to support AT on the nonessential side so as to not have to make that determination and risk preventing disabled people from making the same kinds of work decisions that nondisabled people make.

¹⁰¹ Obviously, not every nondisabled person has expensive hobbies like skiing or boating. However, many or most nondisabled people will have access to free or low-cost sports and hobbies through community centers, schools, or libraries, or there may be free-to-use infrastructure to support sports and hobbies in the community like soccer fields, basketball courts, and skate parks.

When implementing the suggestions that are forthcoming in the next section, we can ensure that levels of support for AT are commensurate with what would be required to have equal opportunities to nondisabled persons, although more research would need to be done to figure out roughly what a nondisabled baseline would be, and what the cost of AT to provide access to a similar amount and variety of activities would generally entail. The goal is AT which provides access to a range of activities. One tool that could be used for this (and used more generally) is the WHO's rapid assistive technology tool (rATA), a population-based survey tool that can map need, demand, supply, and user satisfaction with AT (WHO, 2021). Additionally, with measures to ensure goods are constructed in ways that use universal design as outlined in my first suggestion, it is hopeful that many activities and hobbies would become more accessible and more accessible at a lower price point than is currently the case.

Of course, there may still be cases where ensuring that disabled persons have access to a similar range of nonessential activities and goods as nondisabled people will be very costly. Once again though, it seems to be only what justice requires to ensure that those with high AT costs might still be able to access a similar range of hobbies and activities as non-wealthy nondisabled people or disabled people with lower AT costs. However, I think it is truly impossible to sketch a fair system for how such needs might be appraised, as it would need to be a dialogue with the individual disabled person taking into account their unique situation and goals. It might involve balancing one more expensive AT which enabled them to do the one hobby they truly dream of as opposed to taking two less expensive AT which enabled them to do multiple hobbies. The point here is that we should not police the choices of disabled people any more than we police the choices of nondisabled people, and that they should be empowered

to make the same kinds of choices as to what they want to do for leisure or work. A good place to start working out a system for direct AT support for “nonessential” purposes would be to collaborate with the War Amps, who already fund such AT for amputees and surely have an internal system for consulting and considering such needs. All of the above programs, however, should be administered centrally through the Provincial government¹⁰² to ensure access. While it is wonderful that the War Amps program exists, it is not a good state of affairs that AT access be predicated on the whims of donors, and is only available to amputees rather than disabled persons more broadly. I simply wish to illustrate that there is already expertise in the area of supporting “non-essential” AT, and that this expertise could be accessed in the broadening of the current scope of what is supported via the government.

The incorrectness of the current essential vs. non-essential line was justified in the previous chapter under equality and the techno-inclusive model of disability. The expansion of funding to *still* non-essential goods is justified under similar reasoning. Equality conceptualized as guaranteeing the fair value of political liberties demands that disabled persons be able to participate in a similar range of activities as nondisabled people. While it might be initially unclear how nonessential AT is important for these liberties, when we look at the role of sports, art, and other hobbies in forming community, engaging in political statements and action, and development of a person’s personality, interests, and capacities, the benefits are obvious. Of course, the techno-inclusive model justifies non-essential AT in the same ways it justifies other

¹⁰² As long as social support systems continue to be Provincially run because of legal constitutional reasons. Obviously, a Federal system would be ideal to decrease complexity and ensure access for disabled persons across all of Canada. However, this dissertation is focused on the Ontario context and recognizes constitutional constraints.

AT—by noting that our environment is built to the exclusion of disabled people, that it could have been built otherwise, and that it is an issue of restitution to ensure that despite this injustice disabled persons still have access to the same range of opportunities and goods that nondisabled people have.

It still remains a question exactly how much non-essential AT should be covered, especially as we might consider some non-essential AT to not only be non-essential, but also a luxury, and would be a luxury even for nondisabled people. The goal of the expansion is not to provide access to luxuries, but rather to ensure that disabled people have similar opportunities to nondisabled people. Therefore, what is a luxury might be dependent on context¹⁰³ but where there are programs to help nondisabled people access a particular activity at a low or free price point, there should be equivalent access to AT to enable disabled people to have similar access. In conjunction with the suggestions on the development of AT, it is my hope this would not be unduly burdensome. The value of access to AT here is an instrumental one, as the AT increases access to previously inaccessible, valuable activities. Thus, the ultimate goal is that access.

8.3.2 De-Emphasis on Diagnosis & Increased Funding Supports

In addition to moving the line between essential and non-essential, and to aid in the access to AT that has been discussed, we must also advocate for the minimization or elimination of the use of diagnosis, and ensure the adequacy of financial supports to enable access to a range

¹⁰³ E.g. in Canada there is a program which for \$30 enables children in grade 4 and 5 to ski twice at over 150 ski hills across the country (Snowpass.ca)

of AT for both essential and nonessential purposes. Since these two things go hand-in-hand I will discuss them together. I will propose two avenues by which this might occur, first, through direct support for AT through both direct cash transfers for AT and the direct provision of AT, and second, through a universal basic income, which is an unrestricted and un-means-tested direct cash transfer.

8.3.3 Direct Support for AT

Whether or not this first suggestion of direct support for AT is seen and implemented as a significant alteration and amalgamation to the current ODSP/ADP/Special Needs program for AT or as an entirely new system is both a question of political ease, and a semantic one which it does not seem prudent to devote significant space to discussing given the ultimate, practical goals of this project. It differs from the existing system in a few ways. In alignment with the needs identified above, first, it differs in that it eliminates or minimizes diagnosis. Second, it differs in its level of support by greatly increasing support for a variety of AT. Finally, it does not constrain support specifically for AT to approved vendors of orphan and bespoke AT, but rather gives disabled persons access to broader markets and supports the purchase of mainstream AT, which is connected to the level and variety of support.

The elimination of diagnosis may worry some, as it might provide opportunities for “cheaters” to exploit social support systems. However, this is not necessarily the case, nor is the presence of cheaters a justification for depriving those most in need from the access they require to be full participants in society. There are a number of ways diagnosis might be de-emphasized, which may still require some level of burden to the applicant. This would allow need to be accurately assessed outside of a medicalized model. It is notable too, that the medicalized

diagnosis model has thus far *failed* to accurately assess need via diagnosis, as has been emphasized throughout this dissertation. Under my alternative model, while a specific diagnosis might not be required, we might still require some verification of need. This could potentially be done by a healthcare provider (to ensure access this shouldn't necessarily be a family doctor, but could be an urgent care or emergency doctor, counsellor or similar), or ideally an assessment could be done by a person trained specifically to understand how disabled persons use AT. Such a person would be able to discuss with the person (or family in some circumstances) and figure out what kind of technology would be useful for their specific circumstance and determine what would best fit their needs. This second option would have particular benefits by ensuring a) the person evaluating a need for AT is an AT expert and b) lowering healthcare costs as healthcare providers, and in particular, healthcare specialists' time tends to be very expensive.

As a case example we can imagine that someone identifies a need for AT. Perhaps their eyesight is being strained by a computer, or they find themselves shaky on their feet, or they are struggling to stay organized with the tools normally available to them. They could then make an appointment with an AT expert who could complete an attestation process to confirm their need for AT. This could perhaps be done out of a community center (to eliminate the need for a family doctor and ensure accessibility) with an AT lending library¹⁰⁴ to do some preliminary experimentation as to what AT would meaningfully benefit their life, or as a virtual appointment to ensure accessibility. The AT expert might then be able to recommend something with an e-

¹⁰⁴ such as this lending library <https://www.cbc.ca/news/canada/hamilton/library-hamilton-assistive-devices-1.6279930> (CBC, New Hamilton Library..., 2021)

ink screen or blue light glasses, or grab bars or a walker, or an app¹⁰⁵ designed to help those struggling with organizational skills (perhaps targeted at those with ADHD or Dementia). The person could then go home, trial their AT, and give their feedback. Based on that feedback, a different recommendation could be made, or a funding request could be approved, allowing the person to purchase their own similar AT. Where such a library might be impossible, the attestation process could still be done but without the trial and error. One way to reduce the cost for a such a center might be to allow donations of previously used AT or accept promotional trial AT goods from corporations. Thus, the library could serve three purposes: to provide advice on AT, to provide the ability to trial AT, and to provide attestation of need in an easily accessible way that did not require diagnosis.

The threshold for the AT expert to approve financial support to individuals to go out and purchase their AT in inexpensive cases would be quite low¹⁰⁶, but we can still imagine some cases where expensive, orphan, or bespoke AT is required. Where large sums of money are at issue, it seems more prudent to provide the AT in-kind, or require some proof that financial compensation is used for the desired AT to ensure that cost-efficiency concerns are met and that scarce resources are allocated in a sustainable yet fair manner. In such cases, while the initial process for the applicant would be the same, the AT expert completing attestations might have

¹⁰⁵ One can also imagine a system whereby an app could be loaned out, just as ebooks, audiobooks, videogames, movies, and other digital items are borrowed from libraries.

¹⁰⁶ We could determine a \$ threshold under which a simple attestation might be sufficient vs. where a more detailed attestation would be required. We can imagine this system being analogous to other healthcare systems, such as it being much easier to get a prescription for an antibiotic than an opioids, or much easier to access talk-based mental health services than psychiatric medication. This is not a perfect analogy, of course, since medication comes with more risks than AT, but it still demonstrates how the processes might originate at the same point but still require a higher level of approval for a more expensive AT than a cheaper AT.

more stringent criteria for approving, and in some cases might need to involve other experts to complete the process. This, however, still saves the need for a primary care provider to initiate the referrals, and ensures the first point of contact for the disabled person is still an AT expert. The more stringent attestation requirement is unfortunate because any barriers will result in fewer disabled persons getting the AT they required, but regretfully, it seems unfeasible to pick out those individuals who need greater financial assistance/access to more expensive AT without some evaluative scheme in place to ensure need. While it seems unlikely that mainstream AT might rise to this financial threshold, one can consider cases that violate that rule. For instance, a person living somewhere with a robust public transit infrastructure may not need a car (modified or otherwise) as an accessibility device, but elsewhere a car might be required, especially if the climate was such that some other motorized AT was insufficient. However, the majority of these cases are likely to be orphan or bespoke AT. Nonetheless, the difficulty of predicting these expensive and particular situations means that each will already need to be dealt with on a case-by-case basis. This means that in our considerations the exact kind of AT that is required is less relevant than the specific AT that *is* required for a particular person and their circumstances

The exact cost-efficiency threshold for this kind of expensive, directly supported AT would need to be worked out similar to other healthcare interventions. However, unlike the existing system, AT should be available at cost-efficiency thresholds similar to what exists across other healthcare needs with no means testing. Furthermore, all AT that could be very expensive would need to be able to be requested under this system, not just what is currently classified as “essential”. Before, I distinguished between luxury and non-luxury nonessential AT, and noted

that some AT for more luxury activities need not be covered because of the cost. Here I have in mind specifically that for persons with complex needs, AT that is even non-luxury but also nonessential might still be quite expensive. For example, we can imagine a person with complex needs requiring expensive orphan or bespoke AT to do tasks like going to a free festival in the park, cooking a meal, or playing the ukulele. An important note about direct cash transfers for AT, and direct AT which does not require any calculations regarding thresholds or criteria for support is that this system might still be made more efficient through a minimization of healthcare resources required for approval. Even under this system, diagnosis might be de-emphasized or eliminated in favor of assessments of need, which need not be done by healthcare professionals, and which would likely be better done by disability or AT experts as outlined in the previous section. In some cases though, especially where AT is integrated into the body, medical involvement will still be necessary.

8.3.4 Universal Basic Income

A second approach worth considering is to do away with any attestation entirely and simply implement a universal basic income (UBI) such that the basic income amount was sufficient to cover a generous range of mainstream AT (and then only expensive, orphan or bespoke AT would require additional application). UBI might strike some readers as too politically radical, however, just as our world has been constructed contrary to the needs of disabled persons, it has also been constructed to require a certain level of technology. As internet access is a basic right in Canada (Kupfer 2016), it does not seem so far fetched to say a UBI ought to include an amount such that every person might have a smartphone, although this broader position is beyond the scope of this dissertation. Disabled persons under this scheme

would still be disadvantaged relative to abled persons if they (as is likely) have higher expenses, but it would relieve them of the burdens of navigating a fragmented system and acquiring diagnosis, and so would be more just on that axis. Under such a system, we could also still imagine the existence of an AT lending library as such libraries would still be valuable, but no longer would be used for attesting need (except in exceptional cases where higher support was required) but could still be used to help disabled individuals determine the best AT for them to spend their UBI on. The UBI transfer would simply go to every person and ensure a minimum floor such that disabled persons would be able to access mainstream AT. This floor would likely be significantly above the current ODSP financial support levels of \$672-\$1739 depending on family size and other criteria. The UBI approach addresses both the issue of access to AT, and the more general problem of the correlation between disability and poverty, and compounding effect that poverty has on experiences of disability. There is a risk of injustice if disabled persons continue to have lower real means across the board compared to nondisabled people, but we can imagine a taxation scheme after a UBI such that those already with means are not benefitting additionally. While this means a disabled person might still be disadvantaged relative to a nondisabled person, given the marginal utility of wealth after a certain point, this disadvantage is less morally salient and still is a better state of affairs than what currently exists. Additionally, disabled persons with very expensive AT needs could also still be covered under the higher needs direct AT model.

The benefits of such a model given the current state of affairs include the fact that this model requires the lowest barrier-of-entry and effort from disabled persons to ensure their needs are met. It would allow easy and immediate access especially to mainstream AT, and

would ensure that disabled persons do not need to select between covering their subsistence needs and living their life with the AT required to do so. It would also eliminate the greatest administration burdens, and result in the most streamlined system where there would be no need for additional AT supports beyond the income support in the majority of cases. UBI trials, while limited in their scope, have shown myriad positive benefits in alleviating poverty and improving health and education outcomes. Unfortunately, a sustained, experimental true UBI has yet to be studied anywhere in the world (Hasdell, 2020).

The benefits of such a model over a direct cash transfer for the purposes of AT and direct AT model include a likely lower cost of administration, and ensuring the burden on disabled people to accessing AT is as low as possible since no application at all would be required. It would additionally combine income supports and AT supports such that disabled people would need not go through two systems for these two different needs. Pereira writes quite persuasively about the potential cost-savings (or at least cost-neutrality) of a UBI scheme in Canada given the savings from replacing existing fragmented social support schemes (Pereira, 2017). The drawbacks of such a model when compared to a direct AT model are the potential political resistance to the implementation of a UBI in general let alone at a high enough level to meet the needs of disabled people, as well as the elimination of supports which are specifically designated towards disabled people except for those at the highest levels of need. However, I believe it is important to highlight this as one potential avenue forward.

8.4 Justification

These measures are supported by the techno-inclusive model. The motivation for removing diagnosis is primarily motivated by the techno-inclusive model, though is secondarily

supported by arguments from efficiency. The techno-inclusive model requires the removal of diagnosis for two primary reasons: first, because this model recognizes that diagnosis is not a good indicator of access needs, second, because this model affirms disabled persons' own abilities to determine whether or not diagnosis is something they are able or desire to pursue, and third (relatedly), it helps to shift away from the medical model of disability where that shift is desired by the disabled person. A de-emphasis on diagnosis also improves efficiency by minimizing the time that expensive, limited healthcare personnel need to complete paperwork for the benefit of benefit programs.

The provision of an increased financial support for a broad range of AT is similarly justified under equality and efficiency, and by the techno-inclusive model of disability. Increased financial support is justified under equality because it is clear that disabled persons are already more likely to be impoverished, both because of the higher cost of living that is associated with being disabled, and because unemployment rates are higher amongst disabled people, whether that is due to discrimination by employers or an inability to work in an ableist job market (or an inability to work even with accommodation). Current financial supports are inadequate for food, utilities, and housing, let alone accessing AT (Denley, 2022). It has been established via the techno-inclusive model that in our current society AT is integral for individuals to access a wide range of goods as well as participate in social life, and this is only becoming increasingly the case. Therefore, to ensure disabled people experience some measure of equality when compared to nondisabled people, especially when it comes to the ability to exercise political rights and participate in public life, it is clear that financial support which leaves room for AT is integral.

Increasing financial support without a means-testing was also argued to be efficient in the previous chapter.

8.5 Conclusion

In conclusion, in this chapter I have made 5 recommendations to improve the AT situation in Ontario:

1. Mandate universal design
2. Provide incentives or mandate disabled involvement in the design of AT (including mainstream AT with universal design), in particular for #DisabilityDongles or publicly funded AT research
3. Change the definition of essential vs. non-essential AT and include some non-essential AT.
4. De-emphasize or eliminate diagnosis in approving funding for AT.
5. Greatly increase funding supports in the form of direct cash transfers while still supporting direct AT where necessary

These recommendations have been illustrated using case examples, and justified using practical reasoning regarding cost-efficiency analysis and efficiency as well as by using moral and political reasoning in the form of equality and the techno-inclusive model of disability. It is important to note also, that although throughout I have recognized cost-efficiency as an important concern given the applied and interdisciplinary nature of this project, there remain strong moral reasons which are exemplified through concerns of equality and the techno-inclusive model that cost-efficiency ought not be our primary concern when it comes to supporting disabled persons.

The recommendations I have made here remain preliminary. This work will need to be taken up by policy experts, championed by nondisabled and disabled people alike, priced by economists and particulars will need to be influenced by existing AT supporters and experts. While these recommendations are focused on the Ontario context and seek to streamline the existing fragmented system, some of these recommendations will likely need to be supported at higher levels, especially those which place regulatory constraints on private industry.

This chapter and the previous chapter demonstrate the usefulness of a techno-inclusive model of disability in providing valuable conceptual tools to understand, critique, and suggest reform to systems that are involved in the creation of AT and which support disabled people in acquiring and using AT. Furthermore, they show spaces in which it is important to, via the techno-inclusive model, consider disabled persons lived experience, testimony, and perspective when it comes to designing and implementing social supports. These final chapters are but one case example of how a techno-inclusive model might be applied to understand the shortcomings of policy which has not kept pace with technology, and which does not appropriately situate technology as both an enabler of and a potential path of resistance against ableism and the ableist structure of society. It is my hope that this model will be expanded and applied to other jurisdictions, and used to inform all levels of decision-making when it comes to technology and disability. Let us now turn to a summary of this project as a whole.

Conclusion

Thank you for coming on the journey of this dissertation with me. Over the last eight chapters we have covered a lot of ground so here I will pause to summarize the main positions and argumentative moves that have been invoked along the way, as well as to look forward as to how this work might be meaningfully extended in the future.

9.1 The Project

Overall, I accomplished three primary goals relating to two motivating questions: How does technology complicate commonly accepted models of disability and how can we modify our understandings of one or more of these models to create a model which is inclusive of technological considerations? And, how could such a model be used to ensure that disabled individuals' needs in a technological world are met, and in particular, how could the Ontario policy context be meaningfully influenced by such a model to bring supports for disabled people more in alignment with their needs in our current world?

These goals included first, providing a comprehensive look at the ever-developing AT landscape and engage in a literature review of current disability to see how the current state of affairs does or does not accommodate the concerns and integrate the information that the AT landscape provides. The second goal was to integrate this existing disability theory with the reality of AT and of the lived experiences of disabled people as it relates to AT to develop a techno-inclusive model of disability. The third and applied goal was to then use the techno-inclusive model to evaluate the Ontario policy context and make recommendations for how the system could be more attentive specifically to the AT needs of disabled people.

I argued that a techno-inclusive model of disability was necessary to both accurately describe and illuminate the way that technology contributes to the social construction of disability and to motivate policy changes in relation to AT. I argued that this model gives us a better understanding of what tools disabled persons need, what accommodations are available to them, and what kind of digital spaces are key in our current society. I also argued that a techno-inclusive model requires attention to the testimony of disabled individuals, and helps us to understand the heterogeneity of disabled experiences and therefore the range of good outcomes that we can strive for. Finally, a techno-inclusive model allows us to clearly illustrate a need for accommodations which are neither clearly medical, or environmental/social in nature, and therefore be more attentive to the complexity of what a disabled person experiences in 2022.

After positing this argument and looking at the current state of disability policy in Ontario, I made some recommendations for policy overhaul in light of the techno-inclusive model of disability as well as other guiding principles which traditionally inform the allocation of scarce resources and public health priorities. I recommended that there be changes made both to the design and distribution of AT. In regards to design, I argued for government-mandated universal design, and government incentives for the involvement of disabled persons in the design and marketing of AT. In regards to distribution I argued for an expanded understanding of essential vs. nonessential AT, and for the funding of some nonessential AT, the de-emphasis or elimination of diagnosis as a requirement for the funding of AT, and greatly increased funding supports for AT, potentially in the form of a UBI.

9.2 Looking Forward

Despite the already broad nature of this project, there are of course, many questions that remain. In addition, there are some significant problems with any idea that this might be a complete answer or endpoint. This project and its usefulness are complicated significantly as time passes for two reasons. First, that the disabled community and its views on any and all matters may shift over time and this necessitates a constant back-and-forth, a continual looking-to for guidance to ensure that both the techno-inclusive disability theory itself and that the deeper attitudes towards AT which informed the techno-inclusive theory up to this point do not at any point come into conflict with the current or future needs, attitudes, and lived experiences of disabled people. Second, is that this same transience is at issue when it comes to technology. Indeed, it may be the case that we will need to find new strategies to ensure that philosophy in areas related to technology can be as nimble and quick-to-respond as technology is to change and this project is just one example of where such new strategies or philosophical methods and norms would be useful.

Aside from these challenges and things-to-keep-in-mind for this project moving forward, there remain a number of open questions. Many of these are empirical and interdisciplinary and involve an iterative process of revising policy, gathering data, and using this data to further revise and refine—especially when it comes to the adoption and implementation of a techno-inclusive theory of disability. Even without policy revisions, there is much work that could be done to further amplify the voices of disabled persons when it comes to their experiences with AT. Here, I relied on things like news reports and activists' and writers' first-person accounts of their use of technology, but as far as disabled layperson testimony is concerned, my investigation was

limited to testimony related to #DisabilityDongles specifically. I am sure that more myriad opinions about all kinds of AT are out there and that it would be valuable to collect them and use them to refine a techno-inclusive theory of disability.

Another key but important area of exploration is related to the applied nature of this philosophical project. The goal of applied projects is that reality will inform philosophy and philosophy will inform reality. This is similarly meant to be an iterative, circular process. Therefore, there are still philosophical questions that might be meaningfully explored given the applied work at the end of this project. For instance, as more data is collected on the use of AT, we might meaningfully revise a techno-inclusive model to more accurately reflect the use of AT. Similarly, I think some of the points that I have raised in this thesis, which have come about because of its applied nature, might have implications in other philosophical realms. For instance, the idea that inclusion in the realm of hobbies and art is also important for political enfranchisement. Or, the idea that human needs and capacities are diverse and that that diverseness is not currently adequately recognized¹⁰⁷ might be used in other realms such as ethics or social constructionism to better understand how we ought to behave or how certain categories are constructed. In particular, I think this project could lead to interesting questions about what does, or ought to constitute “health” or “healthcare” as well as further implications for how healthcare might be oriented against other social safety net priorities, especially in Canada where we uphold universal healthcare as a guiding value where other needs (some of which may include health needs, depending on what definition we want to land on) go unmet.

¹⁰⁷ This concept was introduced by Scotch and Schriener, but is further strengthened by my techno-inclusive model of disability

Finally, I think this project has potentially broad implications for technology ethics and the consideration of rights in a technology-driven society. Although this thesis did not directly advocate for the rights of all to access technology, the importance of cellphones, internet access, and other technological objects to living a full life in the 21st century was certainly emphasized in this project, and I believe this has broader ramifications for both the practical and theoretical understanding of rights.

These are important and far-reaching considerations, but do not speak directly to what I believe are the concrete next-steps for this project. When thinking about what those steps are I believe this project needs to become more embedded, and closer to the ground. This project could be meaningfully improved and extended by the interdisciplinary input of more disabled persons (especially those currently working on AT lending library projects), physiotherapists, social workers, and other clinicians who work within the existing system. I also believe this project could be meaningfully brought forward to design-standardization bodies, including the universal design organization. I believe this project could be motivating as a reason to change or adopt new standards of design, even without the institutional stick, especially as the disability community warns of a great wave of disability due to the effects of the COVID-19 pandemic and long-COVID. I believe there is an increasing awareness of the importance of disability accommodation and of the contingency of health, and that this project could be useful in harnessing that zeitgeist to creating a more inclusive world going forward.

9.3 Concluding Remarks

In this project I have challenged myself and my readers to be more creative and considerate and have strived to include a variety of views. There are no easy or simple answers,

but considering complexity with care and seriousness I think is a strong step in the right direction. While I am unsure if the ideas or recommendations in this project will be seen by others than those closest to it, let alone taken up by businesses, manufacturers, and government bodies, I am sure they are superior to the status quo, and I have given many arguments as to why that is the case. We cannot be complacent with the current state of affairs. We cannot continue to let disabled people become more impoverished year-over-year due to inadequate social safety nets which do not match the cost-of-living or take into consideration the evolving AT needs of disabled persons. This call to action is the most important aspect of my philosophical contributions, and the idea of disability theory without an applied aspect, let alone a techno-inclusive model simply does not work.

In this project, (despite my science-fictional leanings) I have attempted to not prescribe a particular vision for the future, but merely to say that the future must be a better one, and in particular that it must be better for those who are especially vulnerable and those who are marginalized, and that we must listen to the voices and testimony of those people and intentionally include and prioritize those voices as we collectively, inevitably, continually craft a future. I have called attention to the way in which the often-invisible ramifications of progress shape the world and challenged those with the power to do so to take control in shaping that future, and compensating for the exclusionary errors of the past. Technology is often created to solve problems, but we must be careful that in solving problems we do not create greater ones, especially for the most vulnerable. Additionally, we must be cautious as we move forward in viewing disability holistically as one of those problems that is to be solved rather than crafting a future which easily and gracefully accommodates difference and which celebrates diversity.

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Appendix

#DisabilityDongle Data

The full disability dongle data sets including raw data, code, and analysis can be found at:

<https://dataverse.scholarsportal.info/dataset.xhtml?persistentId=doi:10.5683/SP3/SUSFQS>

The data is summarized as follows: The #DisabilityDongle hashtag seems to have originated at the 2019 AIGA (the professional association for design) conference on April 4th, 2019. Liz Jackson (@elizejackson) was quoted on Twitter by Flavia Stoian (@FlaviaStoian) as having made this statement in a presentation: “A well intended and elegant, yet useless solution to a problem we never knew we had. Disability Dongles are more frequently conceived of and created in design schools and IDEO.” Jackson then commented below, #DisabilityDongle, and a movement was born. Jackson and others have referenced the proliferation of #DisabilityDongles to things like hackathons, student projects, design competitions, social media, and view it as a “sadly expanding genre” (<https://twitter.com/suzybie/status/1387518995360792577>). Aside from Jackson’s activism work on this topic on Twitter and beyond, the conversation around #Disability Dongle includes 189 tweet statements from 105 distinct, public users.

I categorized these 189 tweets into 7 categories:

Categories

80 (42%) Information sharing & Community Building. These tweets included article-sharing by folks other than the author, quote tweets presented without comment, exhortations to check out #DisabilityDongle or the work of Liz Jackson. Questions to the community about resources or examples were also categorized here. This category also includes casual dialogue and GIFs shared in threads that functioned in community-building rather than critiquing ways. (Green)

55 (29%) Identification of Disability Dongles and Critique of Specific Disability Dongles. Since the idea of a #DisabilityDongle is inherently pejorative, the act of identifying something as a #DisabilityDongle is its own critique. Critiques were sometimes more detailed and nuanced though, stating *why* something was a #DisabilityDongle or why it was harmful. (Pink)

25 (13%) Critiques of ableism or the existence of #DisabilityDongles more generally. These tweets did not call out a particular dongle, but rather discussed them as a class more generally that emerges due to ableism. This category also includes more general critiques of ableism or intersectional

oppression concerns (such as benches designed with spaces to fit wheelchairs that functioned as hostile architecture) (<https://twitter.com/alexhaagaard/status/1391365089186488321>) (Red)

13 (7%) Is this a Disability Dongle?/This isn't a disability dongle. These two categories were combined together because often this question resulted in something being *not* a disability dongle, or the question wasn't answered. Something not being a #DisabilityDongle doesn't mean it's entirely unproblematic though. (Blue)

8 (5%) Disability theory. These tweets engaged in concept building or were original tweets of articles/blog posts by the authors of those posts that were trying to advance the #DisabilityDongle conversation (Yellow)

4 (2%) This group represented cases where Tweets in the thread were private and thus unviewable, or where Tweets had been deleted and were no longer available. Context could not be discerned clearly based on what remained. (Black)

3 (2%) This is a Disability Dongle, but I still want it and it's good for me (Purple)

1 (1%) Critique of #DisabilityDongle movement itself as being burdensome (Dark Green)

(Values add up to more than 100% because of rounding on the percentages)