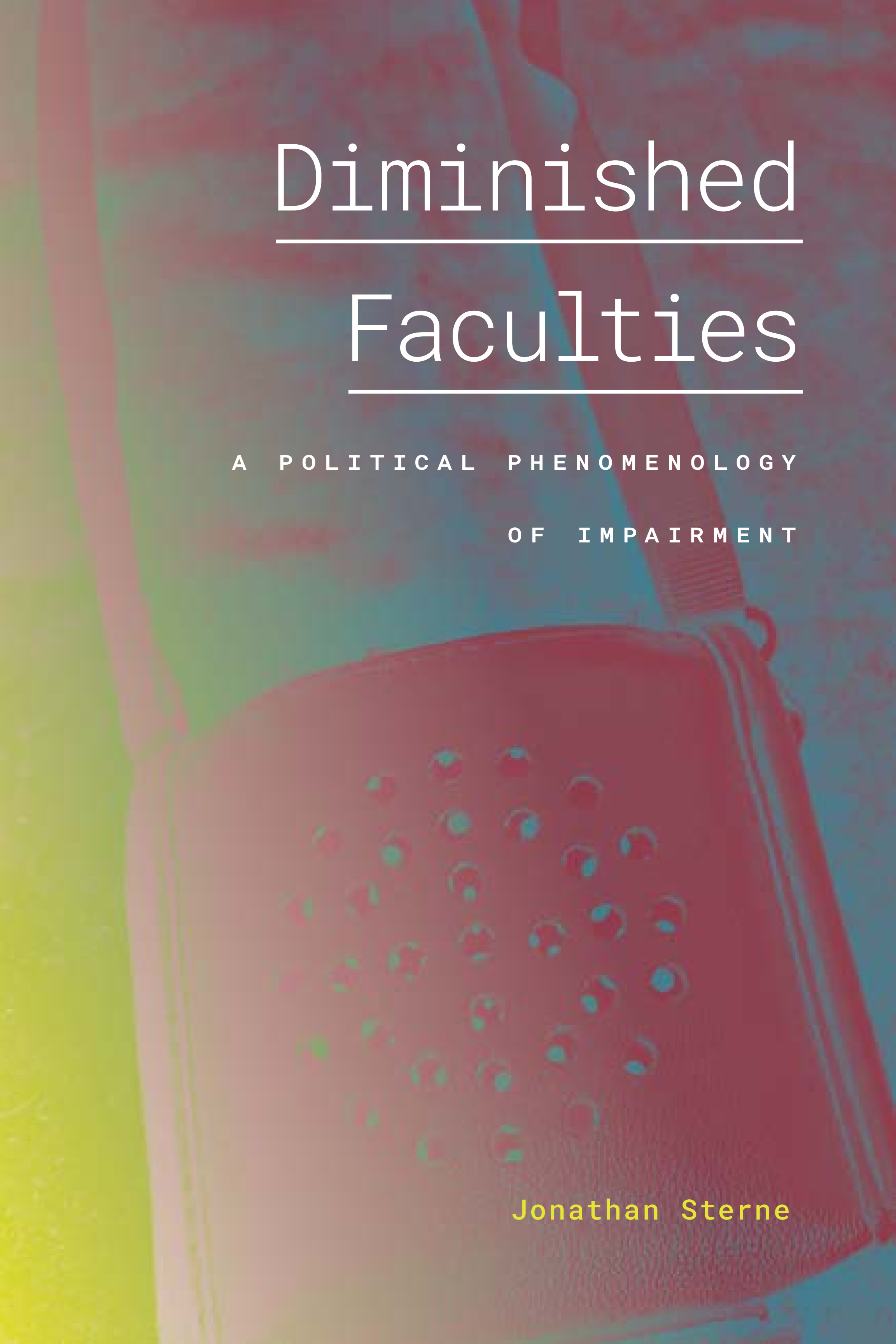


Diminished Faculties

A POLITICAL PHENOMENOLOGY OF IMPAIRMENT

Jonathan Sterne

Diminished
Faculties

Diminished Faculties

A POLITICAL PHENOMENOLOGY OF IMPAIRMENT

Jonathan Sterne

DUKE UNIVERSITY PRESS *Durham and London* 2021

Printed in the United States of America on acid-free paper ∞
Designed by Matthew Tauch
Typeset in Garamond Premier Pro, Roboto, and Roboto Mono
by Copperline Book Services

Library of Congress Cataloging-in-Publication Data
Names: Sterne, Jonathan, [date] author.
Title: Diminished faculties : a political phenomenology of impairment /
Jonathan Sterne.
Description: Durham : Duke University Press, 2021. | Includes bibliographical
references and index.
Identifiers: LCCN 2021013326 (print) | LCCN 2021013327 (ebook)
ISBN 9781478015086 (hardcover)
ISBN 9781478017707 (paperback)
ISBN 9781478022329 (ebook)
Subjects: LCSH: Sociology of disability. | Disabilities—Philosophy. |
Disabilities—Social aspects. | Voice disorders. | Phenomenology. |
BISAC: SOCIAL SCIENCE / People with Disabilities | SOCIAL SCIENCE /
Media Studies
Classification: LCC HV1568 .S698 2021 (print) | LCC HV1568 (ebook) |
DDC 362.4—dc23
LC record available at https://lccn.loc.gov/2021013326
LC ebook record available at https://lccn.loc.gov/2021013327

Cover art: *Front:* Dork-o-phone in its faux-leather case,
with lanyard attached. *Back:* Dork-o-phone microphone
in windscreen, 3.5 millimeters mono plug. Photos by
Carrie Rentschler.

For Carrie

EULA BISS

"The Pain Scale"

The sensations of my own body may be the only subject on which I am qualified to claim expertise. Sad and terrible, then, how little I know.

MICHAEL BÉRUBÉ

"Autism Aesthetics"

There must be no performance criteria for being human.

CONTENTS

01 1 Degrees of Muteness
02 41 Meet the Dork-o-Phone
03 69 In Search of New Vocalities: An Imaginary Exhibition
04 117 Audile Scarification: On Normal Impairments
05 157 There Are Never Enough Spoons
>> 193 Impairment Theory: A User's Guide

209 *Credits*
217 *Notes*
249 *Bibliography*
281 *Index*

Content Note: This chapter contains graphic references to surgery, all sorts of weird stuff happening to my throat (including feelings of suffocation and strangulation), and phenomenology.

01

Degrees of Muteness

Begin again.

Then: “Breathe, Jonathan!”
“Breathe!”
“Can you breathe for me?”

I can see the lights of the surgical theater arrayed above me. The lights are out of focus; they have halos, like they are doubling out from themselves. I see the blurry outlines of bodies in surgical outfits around me. People are mostly standing still. There are machines making sounds. I hear Dr. Q's voice imploring me to breathe.

I cannot breathe.

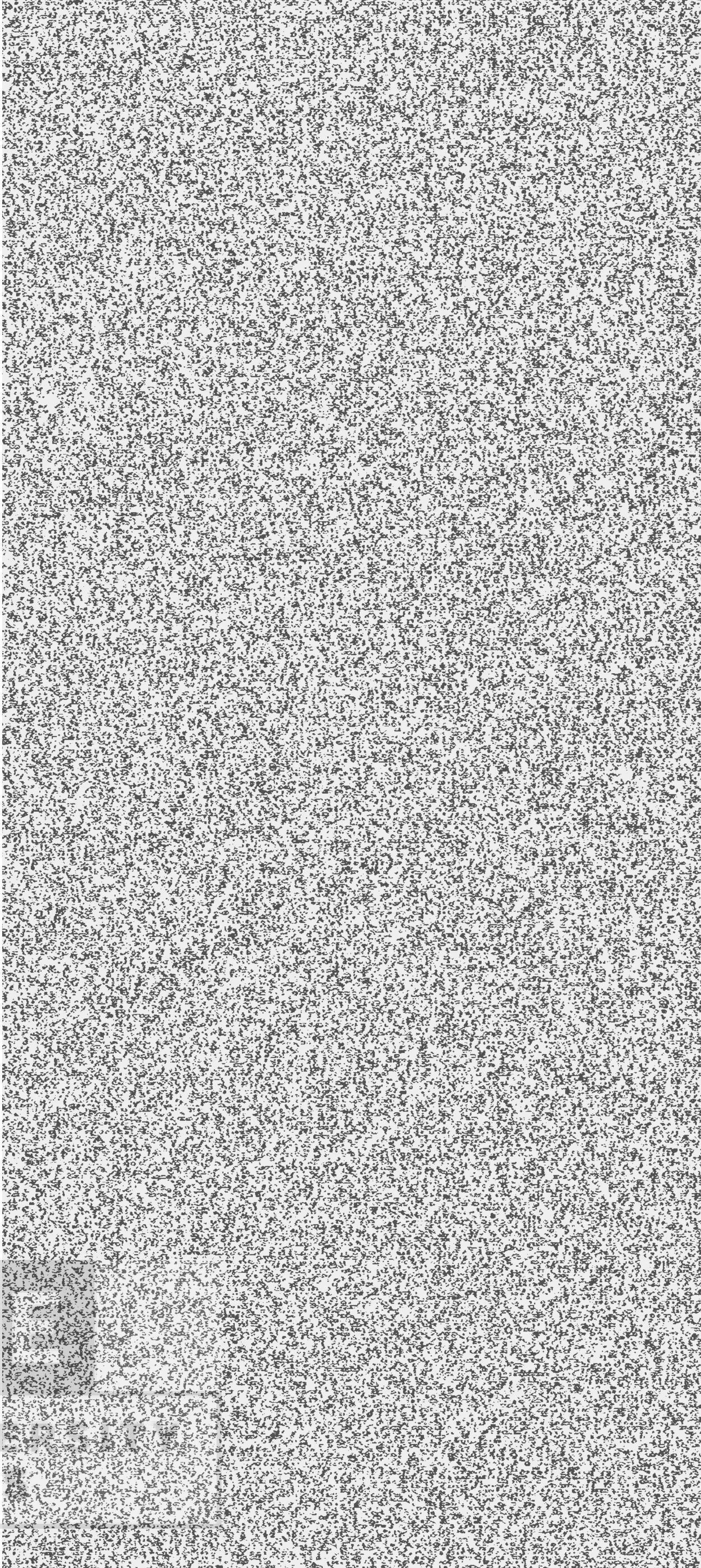
I can move the muscles in my diaphragm, but no air is coming in or out.

I think he walks around toward my head. "Breathe, Jonathan!"

There's a weird throttling sound that comes out of me. Or maybe it goes in.

Someone says to put me back under.

Everything fades.



I wake up, and it's sometime in June 2012. Or maybe even June 2011. Or 2013. I just know how it came to me, and that it was June, when the light leaks out from behind the bedroom shades early in the morning. Whenever it is, that memory of supervised, experimental asphyxiation explodes in all my senses, radiating through my body, as the early morning light peeks into the bedroom. I cannot stop it. I did not dream it. I know it happened to me, and yet for months or years, I had no recollection until I awoke in those early morning hours. The attempt to have me breathe on my own probably occurred during a completion thyroidectomy that happened on February 12, 2010. But I can't rule out the fifteenth either, which was the day I received my temporary tracheostomy. This is not one of those tales of patients waking up during surgery by accident.[1] My brief return to consciousness was intentional on the part of the surgeon and the anesthesiologist—there was really only one way to find out if I could breathe on my own. Breath is life.[2]

The experience and the memory begin from two different kinds of unconsciousness. As I have learned, surgical unconsciousness feels more like being dead than asleep. But the experiences of coming to consciousness share a certain morphology: one awakens both from anesthesia and from sleep, or one hopes to. What do I do with this memory, only available to me some time after the fact? It seems to enact two totally different temporalities, two different relationships to consciousness. Generations of thinkers have asked after the condition of possibility for experience. Is it consciousness, the body, culture, divinity, or something else?[3] This story starts instead with conditions of *im*possibility: What does it mean that I can never really know what happened and that, as a result, neither can you?

Did the awakening *happen* to me in the surgical theater in February 2010? Or did it happen *to me* some undetermined time later, when I consciously experienced it? Is it *happening to me* again as I am recalling it on the page? It happened, but when it happened depends on what it means to say that it happened. Am I talking about consciousness, consciousness of consciousness, or retrospection of consciousness? From what vantage point is it possible to account for this consciousness? Is it the materiality of my body and its sudden inability to access the air in an operating theater? Is it my experience of that fact? Which one?

This opening chapter is the story of an acquired impairment in my voice that followed from this series of surgeries—a paralyzed vocal cord—and its implications for my experience of vocalization. I cannot tell you when the story of my voice begins. But in this text, it has already begun in one of the least likely places, at least for me: phenomenology.

INTRODUCING IMPAIRMENT PHENOMENOLOGY

Phenomenology tells its practitioners to begin again. As Cressida Heyes explains, phenomenology is a philosophical method that "attempts to identify the essential structures of consciousness, starting from a first-personal perspective [with the goal] to shift our attention from what is experienced to how it is experienced, and what makes this experience possible."[4] Most phenomenologies of sound, and of voice, have been untenable for me in the past. In *The Audible Past*, my first book, I critiqued and provided an alternative to the problematic tendency to universalize and naturalize a certain kind of white, male, bourgeois, Christian experience of sound (and voice). But as Heyes points out, there are actually two completely different things called phenomenology (and a third, which simply uses the word *phenomenology* as a fancy term for the word *experience*). To greatly oversimplify: the tradition of phenomenology that just calls itself "phenomenology" refers back to the work of Edmund Husserl, who reflected on structures of consciousness and how objects in the world present themselves to consciousness. To achieve this, Husserl built his method around the suspension of judgment—*epoche*—and believed that through it, a subject like him could produce a transcendental account of consciousness and its possibilities. Martin Heidegger would later critique Husserl, arguing that existence was more fundamental than consciousness, and Maurice Merleau-Ponty problematized perception as something that mediates between consciousness and the world.[5] However, this tradition of phenomenology is still usually transcendent and universal in its aspirations. As Heyes explains, today a second, parallel line of phenomenology draws from feminist, queer, Black, Latinx, and disability traditions that began from the politicized analysis of experience outside university settings and only later directly engaged with phenomenology as a method or tradition. This work uses the methods of phenomenology to "critically reveal the naturalization and contingency of subjectivity"—which is quite different from the projects of Husserl or Heidegger.[6] A critique of naturalization is especially important for the phenomenologies of impairment, illness, and disability, which are defined by their contingency and situatedness but often treated as naturalized. As Havi Carel writes, for a phenomenology of illness to work, it must abandon its transcendental pretensions. Every body (and everybody) is situated historically, ecologically, and politically. I will call this bundle of "posttranscendental" approaches *political phenomenology*, to highlight their common thread and interest.[7]

I borrow the phrase *political phenomenology* from an early essay by Jody Berland.[8] She does not define the term but performs it as a method, combining her analysis of listening with talk of history, policy, and space. If political phenomenology sounds like other critical methods such as genealogy, historical materialism, or reflexive ethnography, that is because it shares some of the basic concerns about the origins and mechanisms through which experience becomes possible: how people come to act and intend, but mostly in conditions not of their own making. Like these other approaches, political phenomenology is fundamentally interested in power. Phenomenology provides some useful methods and traditions for interrogating experience of the self; it is not unique in this respect—ethnography and hermeneutics are other paths in. But since this book begins with consciousness of unconsciousness (or is it unconsciousness of consciousness?), and since I will be speaking to the way humanists narrate experience in our own writing, phenomenology is a good place to start because it is an approach that requires such narration in order to work.[9]

Diminished Faculties fleshes out a little corner of political phenomenology that I am going to call *impairment phenomenology.* Impairment phenomenology is different from other kinds of phenomenology in that it does not assume a subject in command of their own faculties. Most phenomenologists describe their experience to you as a reader, and you are asked to believe them. But I am an unreliable narrator. For instance, I "begin again" by telling the story of waking up in surgery. Except I don't have a solid foundation for a beginning. And to do phenomenology, do I need to be in control? Because I am clearly not in control. How am I supposed to tease out the foundations of my own experience when I don't even know what it is? My impairment phenomenology therefore cannot be self-sufficient. In writing this chapter and this book, I depend on other approaches, other scholarship, and other experiences. I frequently make recourse to work in disability studies, media studies, cultural studies, art history, science and technology studies, and anthropology in these pages. A successful impairment phenomenology should by definition produce an indisciplined text.

I am also drawn to political phenomenology because I no longer fully know my own voice. That's just weird for someone who has had a powerful voice in the past in both the physical and metaphoric meanings of the term: I could be loud and take up a lot of sonic space with my voice in a gendered and raced way, and things I said seemed to have efficacy in the world. Against every critical impulse in my body, my own voice was tied up in my own self-conception, even though I had repeatedly critiqued the idea in my prior writing. As my voice changed, so did my relationship to it. Please resist the impulse to read this as a tragic story of loss of an ability, or a tale of overcoming. Of course there was fear in going into surgery, in not being able to breathe, and in the prospect of never speaking again. But this is really a story about how to exist in a changed body and how to negotiate that change. It is not meant to be offered as a lament or a form of mourning. I experienced a change in orientation, and phenomenology is *all about* orientation.[10] The research on disability and self-acceptance is pretty clear: people who accept and incorporate their disabilities are as happy as (or happier than) anyone else. As Christina Crosby explains, "Whatever chance I have at a good life, in all senses of that phrase, depends on my openness to the undoing wrought by spinal cord injury, because there is no return to an earlier life."[11] This was my plan from the moment the possibility of a total loss of the ability to speak was explained to me by Dr. Q in a presurgery consult: whatever happened, I would experiment with it and make it work for me. But even in accepting a new vocal condition, I still had to learn to live with it, and analytically, living with and through it is the interesting part. My working hypothesis is that this experience is actually so common that it could be the founding basis of phenomenology. Living means changing, and often in fundamental ways. Many traditional phenomenologies treat time as continuous and contiguous: a person exists because of some historical continuity, an unbroken line in time. But that continuity has more to do with conventions of storytelling than with the experience it represents. Thus, many of the stories I relate in the first two chapters of *Diminished Faculties* can be read as experiments. Some worked, some did not.

As a method drawn from political phenomenology, impairment phenomenology amplifies four challenges for writing and thinking: (1) how to account for an experience of self that is unstable and ultimately not fully available; (2) how to account for selves, subjects, and experiences while presupposing the constant possibility of impairment, error, breakdown, and incommensurability; (3) how to represent that experience in writing and thought; and (4) and what to do with the implications of that experience. It aims to connect the personal and the political but always in relation to a terrain of "unknown unknowns," to borrow from Danielle Spencer (who borrowed from former U.S. defense secretary Donald Rumsfeld). It recognized "ignorance as the basis of knowledge."[12] Impairment phenomenology is what a disability simulation fails to be. Disability simulations aim to simulate the experience of disability for nondisabled people through such techniques as temporarily blindfolding sighted people and then asking them to complete a task. These simulations have been used as philosophical and teaching tools for a long time, and widely criticized by disability studies scholars. For example, in the 1968 article that coined the modern use of the word *soundscape*, Michael Southworth began from disability, using characterizations of blind, Deaf, and wheelchair-based experiences to build his theory of sonic space.[13] He took twenty people around the city: "People loved that, and they were blindfolded and I pushed them through on a wheelchair. . . . As a control, we had normal people who could see and hear. And then I had people who could see but not hear. Everyone had a tape recorder so they could talk into it so they could discuss what they were experiencing." He then used reports from the studies as the basis for his analysis of urban sonic space in Boston, a move that would come to influence subsequent uses of the term *soundscape*. Similarly, Don Ihde blindfolded himself in *Listening and Voice* in order to get a better sense of how sound works. Both Southworth and Ihde use a trope that Georgina Kleege criticizes as the "hypothetical blind man," which substitutes a stigmatizing account of blindness by the seeing for an account of blind people's experiences given by blind people themselves. The wheelchairs in Southworth's experiment probably have more to do with sighted people's absence of blind navigation skills than anything about mobility impairment. Blind people who are not mobility impaired can navigate urban space on foot, whereas sighted people pretending to be blind do not instantly acquire those skills by covering up their eyes.[14]

In my impairment phenomenology, the experiment does not involve taking on a condition temporarily (though impairments can be temporary); it involves the incorporation of impairment into the self, which is the opposite of what happens when someone puts on a blindfold they can take off. One of the ironic results of disability simulations is that they produce too much stability in accounts of experience—"this is how it really works"—because they have not spent enough time to acquire the variety of experiences that come from living with an impairment or disability. A political phenomenology of impairment should be more unstable, because it takes more time; and while it may traffic in hypotheses and fictions, those are generated from real conditions of impairment.

A PREVIEW OF DIMINISHED FACULTIES

Diminished Faculties is my attempt at an impairment phenomenology. It makes no deliberate gesture toward an integrative subject or a coherent narrative. Instead, I begin from a set of impairments: vocal impairments, hearing impairments, and fatigue; I will mention many others but those are my big three. (The original plan for this book included a chapter on visual impairments, but it didn't pan out.)[15] *Diminished Faculties* thus undertakes a maneuver I have been half-jokingly calling the "reverse Laura Marks." In her wonderful book *The Skin of the Film*, Marks constructs a theory of cinematic sensation and "living between cultural regimes of knowledge" by focusing on vision, taste, smell, and touch while briefly mentioning a host of other capacities.[16] *Diminished Faculties* constructs an impairment phenomenology (which also involves living between regimes of knowledge) by examining three faculties she deemphasized in that book: speech, hearing, and embodied apperception; it considers many others in passing, including seeing, moving, touching, remembering, sleeping, fighting, teaching, and tasting. By its very nature, such a project must be empirically incomplete and inadequate to the plurality of experience. But since that is the case for all theory by definition, I use these partial accounts to ask big questions about impairment, subjectivity, power, and experience.

In an academic book, it is probably impossible to produce a truly unstable or fragmented authorial voice to match the rendition of impaired experience. It would be especially difficult for me since I have already published a lot of other material under my own name and it is invested with all sorts of significations I do not control. Like my sonic voice, my authorial voice in *Diminished Faculties* will vary from time to time. Right now you are reading the "Jonathan Sterne talks didactically" voice; it will show up repeatedly. But other voices appear in other chapters (along with callbacks to voices that have already appeared on the playbill). Chapter 1—you are here—shuttles between narrating my experience of vocal transformation and interrogating it. The somewhat ponderous phenomenological style feels appropriate for representing the exploration that goes with acquired impairments—or at least it does to me. Chapter 2 introduces the dork-o-phone, a personal, portable speech amplifier, and revels in the traditions of crip humor, play with stigmatizing terms and self-deprecation (and a touch of artist or design research, or, as it's called in Quebec, research-creation), while engaging with ongoing conversations about voices, design, prosthesis, and disability. Chapter 3 stages alternative figurations of voice through an imaginary exhibition, and is written mostly in the second person in the form of a guide and a spatial narrative, moving you through the exhibition. Throughout, it challenges commonly assumed connections among voice, ability, intention, and agency. After these first three chapters, a more didactic scholarly tone takes over. Chapter 4 deals with a suite of normalized auditory impairments, often grouped under the misnomer "hearing loss," and is written somewhere near the intersection of Deaf studies and science and technology studies, with a bit of anthropology, music, and cultural studies thrown in. Coining the term *audile scarification*, it treats the transformation of hearing as something normal and desired in many cultural contexts, using that case to develop a more general theory of normal impairments. Chapter 5 is an account of fatigue. It offers a genealogy of its various permutations as a normal impairment and a kind of energy depletion in industry, science, medicine, disability politics. It then assembles an alternative approach to fatigue that begins from understanding fatigue as a presence rather than an absence. If it is tiring to read, please be assured that it was exhausting to write. The book ends—or begins again—with a user's guide to impairment theory, complete with sample applications and troubleshooting instructions. It comes at the end because so few people start using something by reading the manual, if they ever read it at all.[17]

A book-length impairment phenomenology also requires abandoning recourse to two overused pronouns in humanities writing: *we* and *our*. Impairment phenomenology gives the lie to the idea of an unimpaired phenomenology, that a *humanities we*—a common experience assumed to be shared between author and reader, usually framed in terms of affects and desires—could be the source of coherent descriptions of the world, felt relations to it, texts, aesthetic experiences, and political crises alike. The problem with the *humanities we* is that it is its own bizarre universalism and assumes a fixity of experience. If I use those pronouns, it will be in reference to a specific group of which I am a part, and which you may or may not be a part. There is no unified *we* here because the *me* is only available in multiples. As Édouard Glissant puts it, "It is possible to be one and multiple at the same time; . . . you can be yourself and the other; you can be the same and different." W. E. B. Du Bois, Paul Gilroy, and others have developed the idea of a "double consciousness" that speaks to the coexistence and disjuncture of a physical "fact" that is not actually a fixed fact—skin color—and its experience in consciousness. Consciousness of impairment is not consciousness of race, because their real manifestations do not follow matched paths, even if they often intersect. But the idea of a multiple consciousness is exceptionally generative, even as it can also be painful.[18]

To this end, descriptions of my experience are presented as texts to be interrogated rather than truths rendered in testimony. Like all authors, I will exercise some sleight of hand and will also slip in some experiential claims not in brackets. Most extended descriptions of my experience are already reflections at a distance: blog entries as I was trying to make sense of what was happening to me the first time around, or drawn from field notes and other disorganized but written reflections, or written versions of stories I've repeatedly told friends over the years (which is its own kind of textualization). In contrast, I tend to trust others whose experience I quote. Trusting others is not standard humanist hermeneutics (or social-psychological hermeneutics for that matter)—the goal is usually to uncover what is hidden in discourse. But as an exercise, I thought it useful to invert the standard scholarly approach of trusting one's self over trusting others.[19] This move is partly the product of the standpoint from which I'm producing this text—one need only ask which perspectives are generally treated as trustworthy in halls of academe to see where this goes. But, as someone who has benefited from that system, it seemed worth trying it the other way around. I have, of course, carefully curated the list of others I have chosen to trust (also not a bad thing to do in life). Everything in the narration of experience is a distortion. That is a well-established fact in literature, poetry, music, painting, and even some branches of psychology. What would it mean to treat it as a basis for phenomenology?

A Telegraphic History of This Chapter in Eight Parts

"*How ironic!* You write about sound, and something happened to your voice."[20]

(How come nobody says that to people in art history or film studies who wear glasses?)

"You should *definitely* write about your voice."

I had been writing about my voice constantly since 2009 on my blog, and in correspondence with friends and family. I had talked about it virtually nonstop in social settings.

"Your voice sounds good," say friends on the last day of a cattle call conference—the kind with thousands of academics crammed into a hotel conference center—when my vocal cords were shot and I was the most Lauren Bacall version of myself possible. Yes, it sounds good because *I've trashed it*.

To *write about my own voice*, to make a point about it, that was a different proposition. Do I really want to be on display like that? I am not a private person, and yet I always tell my students not to share their experience in class discussion if they don't want it debated. Or if they do and then decide that they don't, they can retract it. A published book is hard to retract. Also, I am really uncomfortable with the ways that writers in disability studies claim epistemic authority through claims to disability. Sure, I get that as a moment in history, but why can't it be more like feminism or queer theory, something where it's an epistemology informed by standpoint but where standpoint doesn't produce closure? What happens when two people claiming the epistemic authority of experience disagree?

I read Ann Cvetkovich's *Depression*, Lochlann Jain's *Malignant,* Georgina Kleege's *Sight Unseen,* Lauren Berlant's *Cruel Optimism*, and think about it some more.

Shit! To do it right, *I am going to have to debate myself.* That's going to be awkward.

Does this mean I have to resettle my accounts with phenomenology?

> Sometime around 2012, I began a file on my hard drive with the name Degrees of Muteness. I knew it was about my voice. Ideas and notes got poured in. I watched as public figures like Adele and Joe Buck acquired paralyzed vocal cords. This was not going to be something I could practice by giving public talks. It just had to be written. How else would I gain enough distance from my own voice?[21]

TURNING THE TABLES ON PHENOMENOLOGY

As Sara Ahmed explains, the foundation of traditional phenomenology is a certain luxury (and apparently a love of question marks).[22] Reading the standard phenomenological texts, I am struck by an aesthetic of immense quietude, and a satisfaction of basic desires and needs. I do not mean actual silence or quiet but the conditions of peace and space for reflection that silence and quietude are meant to signify. Phenomenology's original conceit is that it can identify a universal horizon of experience from the fixed, coherent point of a contemplating subject. Philosophers contemplate tables and hammers; sighted writers bang around rooms with blindfolds and canes or imagine hypothetical blind people; hearing theorists are able to hear far enough to outline horizons.

Consider the table: phenomenologists talk a lot about tables. They contemplate them, sit at them, maybe read or write at them. My phenomenology starts on a table too, except I'm the object on the table being contemplated by everyone and everything else in the room. The traditional phenomenologists seem to be in command. They declare that they have agency, or at least that they can discern when they do and do not have agency. In writing *The Phenomenology of Perception*, Merleau-Ponty repeatedly uses the figure "I can" to describe bodily intention. But his use of "I cannot" is equally revealing because it demonstrates that he believes he has a position to apperceive the limits of his own perception. He is in enough control to delineate the line between "I can" and "I cannot."[23]

I cannot.

I have the material privileges of the philosophers, and better gear, but not the agential luxury that affords the quiet contemplation of a table, a room, or a blindfold, to build my account of perception. A political phenomenology of impairment is therefore phenomenology minus one, minus unity, minus wholeness, minus quietude, minus a stable beginning.[24] It is a phenomenology plus power, plus gear, plus policy—but only because those things were already there in the first place, just not recognized. It must be founded on ambiguities, contradictions, fragments, webs: a subject who is somewhere and someplace, unsure of itself; a subject that oscillates between self-assertion and self-abrogation, between agential audacity and claiming its radical dependency and situatedness. As Susan Wendell has explained, "It seems possible to pay more attention to impairment while supporting a social constructionist analysis of disability, especially if we focus our attention on the phenomenology of impairment, rather than accepting a medical approach to it. Knowing more about how people experience, live with, and think about their own impairments could contribute to an appreciation of disability as a valuable difference from the medical norms of body and mind."[25] At the same time, impairment should not only be thought of as a limit. As Simi Linton writes, "The explication of impairment should in no way be confined to experience that has a negative valence. A phenomenological approach to the study of impairment will yield [a] rich array of descriptions of experience."[26] To be a phenomenology, and not just a recounting of experience, it must also reveal the conditions of possibility—and impossibility—for the experiences it describes. To do so means, as so many authors have argued in recent years, moving beyond the split between a medical and a social model of disability to a conception of biology as having historical dimensions, and history as having biological dimensions. It is possible to contest the compulsory medicalization of people with disabilities, without dismissing the reality of bodily and subjective differences that have physical, physiological, somatic, or perceptual aspects and implications. But how to address experience as it emerges from this dense web of causality?

If phenomenology often begins from an agential subject, the standard rhetorical road in disability studies is also to claim an agential voice against a death-fearing world, one that treats disability as an unwelcome reminder of an imperfect present, an imperfect future, and the certainty of finitude. The agential subject of disability theory emanates from the hard-won affirmative demands for space and recognition made by disability rights movements around the world. Alison Kafer tells the story of another person in her rehabilitation facility who recommended that she consider suicide as an alternative to life in a wheelchair after an accident; she also tells of the teacher who told her she needed to "heal" rather than to study disability academically. Michael Bérubé retells the story of a nurse's commentary on his and Janet Lyon's reaction to their son being born with Down syndrome: "Parents seem to be intellectualizing." Margaret Price asks, "If you are crazy, can you still be of sound mind?" M. Remi Yergeau begins *Authoring Autism* by relating a story about her childhood shit-smearing exploits to mock the ways in which autistic subjects are rendered as unreliable narrators of their own experience. Tobin Siebers writes that disability is the "master trope of human disqualification."[27] All these accounts offer glimpses of an impairment phenomenology. They all question the scene in which people around people with disabilities are revealed as unreliable phenomenologists. As well they should. But there is another radical reading of these foundational scenes. Yes, disability studies and disability activism need their agential subjects. But philosophy's agential subject has yet to reckon with what Siebers calls *the ideology of ability*—the unstated preference for ability over disability—and the necessity of dependency, and therefore has also never really understood the meaning of independence or transcendence despite its lofty claims.[28]

An engagement with the vast literature on disability puts a different spin on an imaginary humanist subject, describing its own perceptions and experience, as I am doing here. In response to her parents' narrative of her own childhood, Yergeau plays with the idea that she is an unreliable narrator of her own experience.[29] But in doing so, she also turns around the critique. The ideology of ability masks the prevalence of disability-like difference throughout the human variety. If people with disabilities are cast as unreliable narrators because of their disabilities, because they do not conform to imagined universals, then stories like Yergeau's show how the most universalist phenomenologists are the most unreliable ones. Every simple description of "I see," "I hear," "I say," "I can," and "I feel" requires its own questioning from a standpoint of a critique of the ideology of ability. How does phenomenology work when its subject begins from impairment rather than from an imagination of itself as agential and whole?

The ground for phenomenology—and perhaps for all descriptions of experience—is more like sand than a floor. If there's a table in the room, it's going to sink and rock a little. Existentialists have long argued that Western philosophers have not fully reckoned with the question of finitude; and when they do, they have often done so in ableist terms. But as Amanda Lagerkvist has shown, even finitude has its own historical conditions.[30] Disability theory advances this way of thinking while correcting its ableist error: many writers have claimed that fear of, and revulsion at, disability is precisely rooted in a subject's refusal to confront its own finitude.

Two concepts from Iris Marion Young's feminist phenomenology are especially relevant here: *ambiguous transcendence*, the inability to fully "transcend" as an embodied woman; and *discontinuous unity*, or the experience of one's body as divided between subject and object.[31] She uses an account of women's embodied experience in order to at once critique the effects of patriarchy and undermine the phenomenological imperative toward transcendence. While contemporary readers might challenge a unitary category of women, Young has identified a condition well known to many minoritized subjects. Experience like this ought to be the foundation rather than the exception for giving an account of experience. This is the founding contradiction of phenomenology: an agential, self-knowing subject that wants to claim enough mastery of its faculties to describe the world around it, even as no subject ever has full access to that world. As with Young's account of gendered embodiment, accounts of impairment also subvert transcendence and render bodies as objects to themselves. Crosby describes her own experience of her big toe after a spinal injury:

> My spinal cord was not severed, so I still have sensation all over my body, and can feel the pressure when someone touches me. When I was first injured, in intensive care at Hartford Hospital, he took hold of my big toe, told me not to look, and instructed me to tell him whether he was bending it up or down. So I did. I reported exactly what I felt. The problem was, I was wrong much of the time. It seemed so odd to me then, and continues to seem so today that I could be so misinformed by a part of my body I'd taken for granted always. My big toe! How could it be telling me the wrong information? Dr. Seetherama was testing my proprioception, and I failed the test. If the "felt sense" of my body is unreliable, how am I to think about the "bodily ego" that psychoanalysis theorizes is necessary to all of us, an image of the body that emerges internally through the differentiation of bodily parts and zones, and externally through relations with others. What becomes of my "self"? This question has haunted me from my earliest efforts to somehow grasp what had happened to me. How can I not be fundamentally different, estranged from myself?[32]

Crosby's story depicts a body divided against itself as subject and object. Crosby's account reflects what Siebers calls a "complex embodiment."[33] She is at once confronting the physical fact of not being able to read the "felt sense" of her body, and the institutional and political condition of disability. Alongside Young—in her account of why cis women (generally) take up less space than cis men as they move through the world—Crosby offers an impaired theory of motility.[34]

AGAIN: BEGIN AGAIN

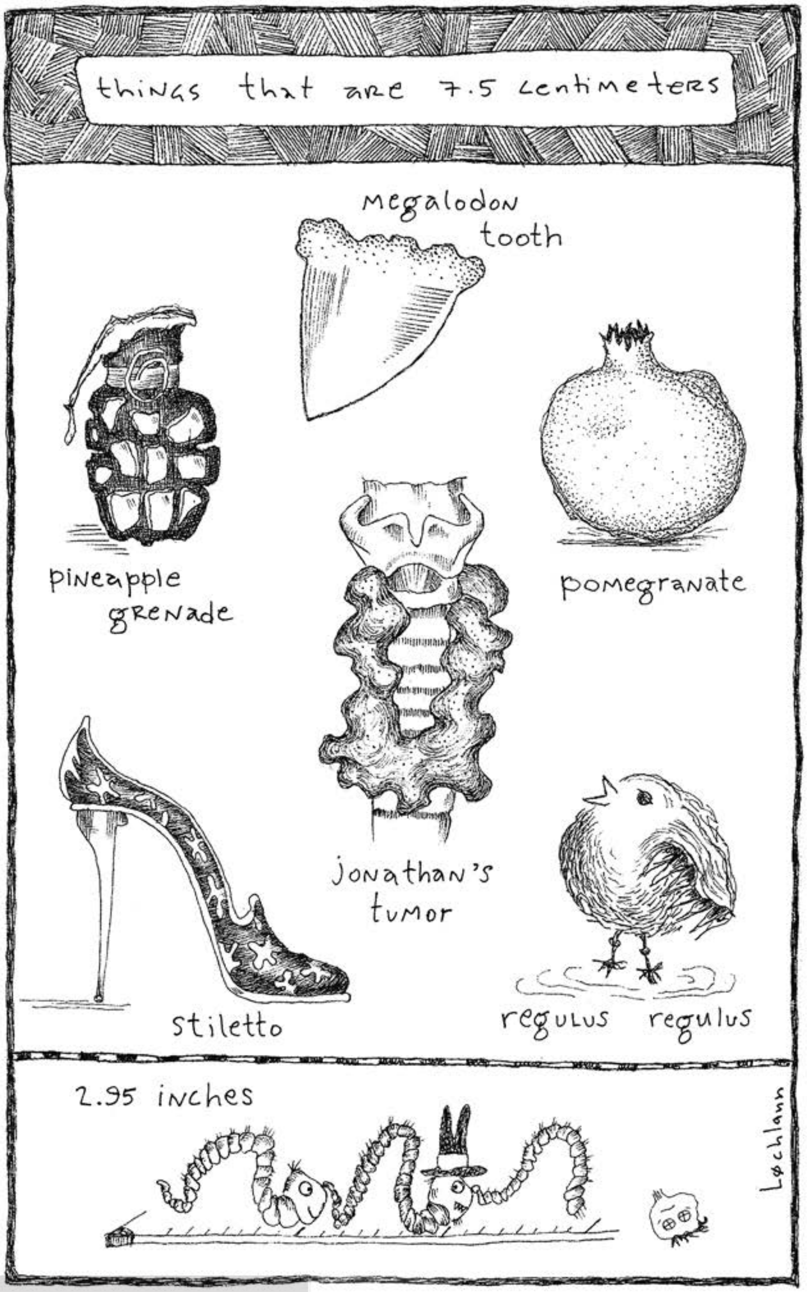
It is November 2009. I am at a different hospital, in the recovery room. Consciousness rises following an irregular orbit, as it dizzily wanders around the twin poles of lucidity and haze. I can hear; then I can see light, then the edges of bodies again as people and my surroundings fade into view. Dr. Q addresses me by speaking my name. He tells me that they could not find my right recurrent laryngeal nerve. They had to stop my thyroidectomy halfway. I would have a paralyzed vocal cord on my right side.

By the time I had that first surgery, the cancer had been in me for years. It first forced me to notice it while delivering a talk at the University of California, San Diego, in the spring of 2009. One minute, I was standing up, delivering a talk on my *MP3* project to an interdisciplinary audience, in a full seminar room. All of a sudden, it was not a normal talk: I was out of breath and the room was spinning, like I was going to faint. I grabbed the podium, kept talking, and powered through. I thought maybe it was just a stuffy, hot room with too many people and not enough oxygen, so I went on to dinner. But back in the hotel that night, I couldn't shake the dizziness or the shortness of breath. I wound up in La Jolla's very fancy hospital, where they did a series of tests. A computed tomography (CT) scan showed a large goiter on my right side, compressing my trachea. They found nothing else. I was cleared to return home and told to see my doctor, or rather doctors. Months of referrals, tests, more referrals, and more tests ensued, but they yielded more questions than answers. My heart was fine; I was diagnosed with asthma. Finally in the early fall, I had a biopsy. I remember it clearly, because as the needle went in, Dr. Q asked me to explain Noam Chomsky to him. I failed, but it was good for a laugh. The test came back positive for papillary thyroid cancer, and that is how I wound up in a recovery room in November 2009.

That light-headedness I felt in San Diego was probably caused by the tumor wrapping itself around my trachea. In the months leading up to the diagnosis, I couldn't quite figure out the bundle of symptoms—light-headedness, sudden dizziness, shortness of breath, weird feelings in my throat. The cancer diagnosis was actually a relief because it offered an explanation for my otherwise unexplainable symptoms: I was being slowly-but-not-so-gently strangled. That is why every time air pressure changed, it had felt like a gerbil was slowly rotating inside my neck.

It is not a surprise that the surgery wasn't easy. As a fat person, I am hard to operate on in the best of circumstances, and the cancer had been in me for a long time, growing undetected as I went around living my life.[35] By the time Dr. Q first encountered it in person, the tumor on my right side had calcified into some kind of hard, jagged form with sharp edges—sharp enough to cut his glove—and was about seven and a half centimeters in size (figure 1.1). It had taken up a large portion of the right lobe of my thyroid gland and wrapped itself around my trachea. The "average" papillary thyroid cancer tumor is about one centimeter in diameter and soft. I wish I had a picture. Dr. Q had to carefully scrape it off, in thin layers, so as not to puncture my windpipe. Then, after removing the tumor, they couldn't find my right recurrent laryngeal nerve. Normally when a nerve like that is cut, the surgeon at least sees the ends flapping around. But there was nothing. Between the scraping and the searching, the surgery stretched on for hours. Eventually, with no sign there ever was a recurrent laryngeal nerve there (other than that I had clearly needed one to talk and swallow for all those years), they closed me up.

Right after Dr. Q gave me the news, I remember trying to talk and my voice betraying me. "Hearing oneself speak is not the inwardness of an inside that is closed in upon itself; it is the irreducible openness in the inside," says Jacques Derrida. Sure enough, my insides had a new kind of openness, and I could feel myself not quite speaking. I don't think that's what Derrida meant, but it illustrates the problem.[36] The interior voice is at least as much imagined as a reflection of external phenomena, and if you have a voice and have heard a recording of yourself speaking, you probably know that the auditory perspective between your ears is like nowhere else. Now, imagine that that perspective is not available as a stable foundation for self-regard but changes from day to day and hour to hour. Imagine you are attuned to sound and have grown up in a culture that hears voices as indices. A shifting interior voice is an index of something very different from a stable interior voice. The vocal cords are essential for talking, swallowing, and breathing. They open and close the aperture of the throat, directing air, liquid, and solid to the right destinations, serving as a kind of gatekeeper of the body. The recurrent laryngeal nerves carry signals to the muscles of the



1.1 *Things That Are 7.5 Centimeters*, original illustration by Lochlann Jain.

vocal cords, which shuttle between voluntary and involuntary action. Or sometimes both. One of the strange things about paralysis is trying—and failing—to do something voluntarily that one had previously done involuntarily. It is strange to lose control over something over which I never had conscious control in the first place. Crosby's misplaced toe, my misplaced voice: a body aware of its own faculties but aware of them in a wrong way.

Within a day or two of my first surgery, I was home and recovering. Now there was going to be a lot of talk about what to do next, while I learned how to live with an ever-changing voice. A loss of both recurrent laryngeal nerves would, I was told, mean a total loss of control over my vocal cords, and I would have to have a tracheostomy in order to be able to breathe. Trach or no trach, my voice was already altered, though, just not *visibly* so. In a blog entry from December 12, I describe my voice as sounding "somewhere between Tom Waits and Marge Simpson" and improving somewhat from there. But I could not talk on the phone, and for a while I had to swallow while turning my head to the right to make sure food and liquid did not get into my lungs. The ensuing months led to a lot of people worrying about my voice.

> JANUARY 5, 2010
>
> At least once a day when I'm out or get a phone call, someone asks what is wrong with my voice. So I tell them that I've got a paralyzed vocal cord from thyroid cancer. I don't know who said that coming out is a constant, ongoing process, but again I feel that there is some kind of parallel between what disability studies scholars sometimes call normalism [2019 edit; ableism is actually the preferred term] (you can guess what that means) and heterosexism. In both cases, you're assumed to belong to a dominant category until suddenly, you do not. And when you do not, you must explain yourself.

Voices are always indices: caused by interiors exerting effects on themselves and in concert with their environments, they are heard as signs. For those asking, my voice was a sign of an uncertain future, or perhaps an uncertain future that had already arrived. Here was an audible difference immediately converted into a disability—the word *wrong* in the question "What's wrong with your voice?" declares as much. As Kafer explains, the dream of a future without disability is a dream of a future without the ills of the present, a fantasy world where the value of people with disabilities is disavowed, and where disability is reduced from a political category—that can be contested, that has a history—to a simple physical or biological fact.[37] My vocal disability did contain a fact that my voice worked differently than it had, and that it was no longer in harmony with a world constructed for a certain kind of voice, whether that world featured strangers listening to me or automated phone menus.

In their critique of text-to-speech technologies, Graham Pullin and Andrew Cook write about tone of voice being fundamental for meaning: "A lack of variation in tone of voice can never be neutral. A lack of expressiveness can itself send out a false message that the person is emotionally impaired as well as speech-impaired, or perhaps socially unsophisticated."[38] By expressiveness here, they are referring to controlled variation, where unexpected timbres can also signify a subject out of control or otherwise impaired to an uninitiated auditor. Ideas of expressiveness have probably manifested in all the arts, but in designing assistive technologies for speaking, expressiveness is directly related to ideas of an interior, intending subject that manifests itself through the speaking voice. Think of all the moving parts in that scenario: a subject whose body cannot match its will; but also auditors struggling to align themselves with whatever techniques the speaker is using. Everyone is trying; nobody is quite succeeding.

Disability Studies 101: Saturday Night Practicum

JANUARY 11, 2010

This is a post about some issues I encountered at someone else's birthday party, which makes it inherently pathetic and self-centered. But then, this *is* a blog, so I get to be pathetic and self-centered once in a while, right? I apologize up front. For the record, it *was* a fun party and any non-fun issues are strictly my own and not the responsibility of my hosts or friends. I was totally glad I went.

So, on to the story.

As I have mentioned here, my voice has not been the same since the surgery. Assuming that there isn't further damage in the next surgery—if there is a next surgery (or from the cancer itself)—I will get back about 70–80% of what I have. I've been going to an excellent speech therapist (it's like singing lessons) and every few weeks there is some improvement.

But for all that, I am functionally disabled in the meantime. I used to have much more vocal power than other people. Now I have considerably less, and what is projected is harder to hear. That said, I am not the kind of person who wants to sit at home and be depressed about a disability or being in the middle of treatment. If I feel good on a given day, I should do something. There's a Quebec saying that is something to the effect of "you have to live your life." And so I am trying to figure out how to do that.

Since the surgery, I hadn't been out to anything more than a dinner party, and even dining out has been kind of fraught because even moderate restaurant noise makes it difficult for my voice to be heard. It is easily masked. Carrie and I dined recently at Bombay Mahal and while she could hardly hear anything I said, I had an entertaining time watching her try to eat the "extra spicy" dosa she'd ordered, so that sort of made up for it. (The waiter said, "Have you had our food before?" She answered, "Yes, but I still want it extra hot.")

Anyway, Saturday night was a party celebrating two of my friends turning 40 so I thought it would be a good time to give this whole outside world thing another try. Sooner or later I have to, so if not now, when? The party was held at a bar, starting at 8:30 and then migrating upstairs two hours later for dancing. I figured I can at least dance if I can't talk, right? And I was clever—or so I thought. This whole being disabled thing means I've got to experiment and figure out something that works for me in the big bad normalist [ableist] world. So I took some index cards and a Sharpie, and came up with a series of stock phrases that I could flash at people, such as:

"Hi, how's it going?"

"My voice is messed up so I made these cards."

"Cancer sucks. I feel fine. Thanks for asking."

"I don't know yet. I'll know more Monday or Tuesday."

"Tell me how YOU'RE doing."

"Yes, please. Water."

"Great party!"

"Happy 40th birthday!"

"Tell me more."

"That's awesome/I agree/I'm happy for you." (select whichever one is appropriate)

"That sucks/I disagree/That's too bad." (select whichever one is appropriate)

"If you could hear me, I would have a clever 1-liner right now."

and so on. I brought my Sharpie and some more blank cards to improvise on the spot.

My hope was that with a little prompting, other people would talk and I would listen, aided by the cards. But two things happened.

First, people were self-conscious about asking me stuff. So I tried to talk. Today I was incredibly hoarse as a result. I should know better. They were trying to be nice. And I *do* like to talk, so the temptation is great.

Second, it turns out I wasn't the only disabled person at the table. In more than a few cases, each time a card came out, friends had to reach for their reading glasses in order to be able to see them. Foiled! Some disabilities, like farsightedness, are "normal" but I obviously didn't even consider them, since they are not my own. Others, like my voice, are "abnormal" and therefore marked. Though marked disabilities are equally unconsidered by those unaffected—I always hated phone menus that require you to speak; now they do not even recognize my voice as a voice.

As the disability studies motto goes, "Someday, you will join us." That is what is so difficult in thinking about anything like systematic accommodation. Bodies fall apart or are "absent" in different ways, and accommodations may themselves introduce new issues into play.

I still plan to get some kind of portable voice amplifier (or, more likely, buying whatever is out there as a template for something more advanced that I help design). But first we have to have some decisions about my course of treatment. I don't want to drop a few hundred bucks on something I won't be able to use.

I am happy to report that I can still dance. If by dancing we mean "semi-rhythmic movements on a dance floor." I was never very good at the whole "particular-body-part-in-a-particular-place-at-particular-time" thing.

Postscript: I learned that film critic Roger Ebert is a thyroid cancer survivor, though he's had a particularly rough go of it. He's written a few things about it, but they're pretty sobering, since he no longer eats or speaks with his own voice.[39]

One common trope of acquiring a disability is that you wake up in a different body. But the process of negotiating that body is more like a process of awakening than one that happens in a particular instant. This entry is a textbook case of the ideology of ability in action. My friends and I fetishize and exclude disabilities and impairments from discourse even though they are right in front of us (or inside us); we treat disability as private and individualized matter. My entry mobilizes the idea that loss of ability translates into loss of sociability; the idea that to focus on disability is self-centered; and that "nondisabled people have the right to choose when to be able-bodied. Disabled people must try to be as able-bodied as possible all the time."[40] I even end the blog entry with a tale of impairment that I don't want to have. Though it remains funny to me, I would write the story differently today. But to do so would be less useful for my argument. An anecdote in a blog entry shows that there is no pure, ideal, or perfect position from which to negotiate disability and impairment. One must always start somewhere in the imperfect world.

DEFINING IMPAIRMENT

What counts as disability, or impairment, or normal? Glasses have a history as a marked prosthetic, socially diminishing the wearer.[41] This is why, for instance, the British National Health service issued pink glasses for women in the early 1960s: they were supposed to be "skin" colored and not call attention to themselves (nor, apparently, to the racial presuppositions behind assuming that pink would blend into the color of "skin").[42] Today, at least in my social milieu, eyewear is a kind of fashion accessory, and I wear glasses that frequently draw compliments and comments—though reading glasses appear to inspire ambivalence for others (and I know people in other social milieus who still feel some stigma around any kind of glasses). The borderline status of mild visual impairment—and the historical and emotional weight it still carries for some people—illustrates how difficult it is to draw a line around impairment, especially against disability, and how the politics normally ascribed to disability seep out into the borderlands marked by ambiguous, or even mild, impairment.

I have been shuttling between these two words—*disability* and *impairment*—because they are difficult to parse, and because in the stories I am quoting, my own status is ambiguous to me (it is no longer). But what is the difference between impairment and disability, and what is the meaning of that difference? The easy first attempt at an answer would be that *impairment* is the physical reality of *disability*, which is a social construct. This answer treats impairment as a purely material substrate for disability, which is then considered as a hybrid discursive and material phenomenon. But other theories of the subject have already been around this block: sex and gender, skin color and race, and on and on.[43] The putatively material term—sex, skin—that is supposed to be a substrate of the other turns out not to be. Impairment and disability are no different: they are historical, contested categories that fall in on themselves, inextricably linked to bodily or intellectual differences, or experiences like pain and fatigue, but always more than that as well. Much work has been done to explore the political ramifications of disability as a variable, contested, and political mode of classification, as in Wendell's classic question: How far does one need to be able to walk to be considered able-bodied?[44] The answer varies contextually and environmentally. Communities that have grown up around autism or Deafness struggle with the label, often rejecting it. Visible bodily differences, for instance the absence of a nose, often bring social stigma that operates like disability even though they do not otherwise reduce a subject's abilities in most ways. Racial differences have at different times been coded as disabilities as well, but the rejection of disability as the basis for racial advancement itself has a complex and vexed political history. Conversely, legal pushback against corporate responsibility for environmentally caused illnesses, including cancer, results in new constructs like "fear of cancer" as legal placeholders for actually debilitating or deadly conditions.[45] Disability is a notably slippery category, central to identity construction and political organizing but difficult to pin down definitionally. In chapter 4, I have much more to say about the construction of norms, following the work of Georges Canguilhem, who argues that the norm comes after its infraction.[46] For now, it is enough to consider that norms are those things against which impairments and disabilities are defined.

In discussions where impairment is rendered as the substrate of a disability, it might be understood simply as the diminishment of a faculty, as in the UN's language from the 2006 "Convention on the Rights of Persons with Disabilities and Optional Protocol": "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."[47] But a faculty is defined as a kind of ability or agency—and therefore etymology gives us nothing but a recursive, self-referential loop. According to the entry in the *Oxford English Dictionary*, the term *faculty* has a long and varied history in the English language related to power, agency, and function: the power to do something or a virtue; an ability or branch of art and science (including the people who populate a university); conferred power, authority, or privilege.[48] A faculty is a fundamental capacity of a subject, whether that subject is a human subject or a body of knowledge. If impairment is simply a diminished faculty, then faculty sounds an awful lot like "ability" and impairment sounds an awful lot like "disability," down to the use of "ability" in the definition. The ability to affect the world is conflated with virtue or goodness; it is connected with prestige, and then elevated into the abstraction of systematized knowledge. Impairment is no more brute fact of the body than disability, which is to say that it both is and is not.[49]

The recent history of impairment is considerably more enlightening than its etymology. As Mara Mills has shown, early twentieth-century U.S. medicine and engineering took up the English-language term *impairment* as a preferred term to *defect.* As Mills demonstrates, impairment was tied both to a rehabilitation model of disability—could a person work?—and to the possibility of repair, of a person or a system. *Impair* may be an individualizing term, since it focuses on the machinic capacities of an individual—impaired movement, speech, hearing, cognition—but it is also subindividual, focusing on particular faculties in relation to particular tasks rather than the whole being. The concept of impairment doesn't even have to refer to a person. Mills shows that "transmission impairments" were formalized in communication engineering around the same time as medical impairments, as engineering problems in communication systems, not all of which were ever meant to be overcome. Interestingly, while the ideology of ability would cast impairment as something to be either overlooked or overcome, the engineering discourse highlighted by Mills assumes the inevitability of transmission impairments, some of which might be repaired, but not all. Perfect communication might have been an imagined ideal for engineers or philosophers, but actual engineering practice assumes every system will have some kind of impairment, if for no other reason than that perfection is simply too expensive.[50]

A theory of impairment built around a pragmatic, economistic, or existential acceptance of limits is a very different frame from the recent history of the concept in disability theory. As many writers in the field have noted, the social model of disability was important for overcoming the idea of disability as a defect inherent in an individual, but it had a difficult time dealing with pain, fatigue, and chronic illness, where subjects are in some sense divided against themselves, where a subject's lived experience of the body prevents them from embracing a constructivist account of its disability story, or simply where access to care requires strategic medicalization. The irony of the social model of disability is thus that in its critique of disability as something in need of repair or overcoming, *impairment* came to work semantically more like *defect*, even if disability activists and theorists would never use that term, and even if ultimately the politics of disability aimed for a utopic horizon where the human variety would not be spread out on a grid of abilities and disabilities.[51]

In life, impairment works in a shady place between function and nonfunction. Nowhere is this clearer than in the theory and practice of communication: a mobile phone or a videoconference connection is glitchy; a spam filter lets through some spam, or filters out correspondence the recipient desires; radio waves come with static and noise; an online video never stops buffering; books and photos age and change color; the meaning you take from these written words never perfectly lines up with my authorial intent; what you heard or read on my lips is not what I said.[52] Sometimes those distortions are even fundamental to how things mean: electrified and recorded music is full of harmonic distortions—textbook transmission impairments—that come to signify the depths of meaning and that countless digital devices have sought to re-create or simulate. When digital video came along, filmmakers sought ways to reproduce the noise on the screen that accompanied analog film stock. Digital synthesizers sometimes include a parameter with a name like "slop" to reproduce the tuning variances of analog oscillators.[53] In speech, accents signify all sort of things about the subjects who speak with them (and every speaker has an accent to someone else).[54] Impairment may be a blockage, a failure, a defect, but it is also a supplement, rich with texture and potential meaning. If impairment is at the center of communication, then it is already at the center of experience.

Nothing works exactly like it is supposed to—machines, media, models, conversations—and least of all, people. If almost everyone and everything has some degree of impairment (though not in the same way), then impairment is a quality of experience. Impairment is always already there. Drawing a sharp line between *impaired* and *not impaired* would then obscure the ways in which one impairment or another conditions almost every human action, reaction, and relation.[55] But of course these lines are drawn and lived—the lines *must* be drawn or the term has no meaning at all. A phenomenology of impairment is also a phenomenology of policy.

Institutions define impairment and disability all the time—who requires accommodation and who does not; who is judged "able to work" and who is not; what even qualifies as work; who needs extra time on a test; whose impairments even matter and under what conditions; what differences must be accounted for in the design of a building, website, or broadcast system; how and by whom: "The very fact that so much energy is funneled into defining disability and impairment suggests the fundamental instability of the terms."[56] Policy wades into practical philosophy—it has to operationalize a classificatory schema even if it claims to bracket ontological debates—and policy segments impairment and disability so that they can be commensurated with money one way or another.

There is a long history of attempts to quantify and make sense of disability and impairment in some aggregate form for the purposes of policy making. As Sarah Rose writes of disability policy in the early twentieth-century United States, what might be considered a disability in one context might be considered within the realm of normal in another: "Early twentieth-century Pittsburgh steel mills were so dangerous, for example, that missing a finger was considered normal and did not prevent laborers from finding employment."[57] Part of the drive to quantify disability came from policy makers' varied motivations: they at once sought to create a common basis to comprehend the sheer variety of things that come under the sign of impairment or disability, and to deal with the ways they intersected with race, class, gender, age—and, in the United States, occupation.[58] In fact, it could be said that disability was part of the drive of modern states to quantify: from Lambert Adolphe Jacques Quetelet's scientific racism and ableism, to emerging bureaucracies' use of statistical aggregation of their self-constitutions, to nineteenth-century public health discourse as a medium for state anxieties about and interventions in its populations.[59] Today, this legacy lives on in institutions like the Educational Testing Service, which began as a "Census of Abilities" and still produces tests that sort out American children ostensibly according to ability, despite their tests' cultural biases being well documented. Quantification of disability has become an issue in global attempts at policy making as well. Measures like the Global Burden of Disease (GBD) and Disability-Adjusted Life-Year (DALY) are used in health policy, both as a tool for allocating World Health Organization (WHO) funds and by epidemiologists analyzing WHO policy.[60]

The idea of a pristine subject—body or mind—that is then impaired or disabled is of course a raced, classed, historical, and geographic construct as well. Before its twentieth-century bureaucratic existence in liberal democratic states, disability was part and parcel of the disqualification of women, racialized or Indigenous people, and people who did not conform to gender or sexual norms. But the nondisabled, able-bodied, nonimpaired, or otherwise "whole" subject against which these differences were compared was also always a fantasy. As an alternative to disability and its liberal institutional history, Julie Livingston has posed the concept of *debility*, which "illuminates how fundamental social, moral, and biological dynamics are grounded in experience as people struggle to marshal care and rework meanings and lives within and around bodies that are somehow impaired or different. The relationships between bodies and persons, history and meaning-making are highlighted and transformed in the context of debility."[61] Based on her fieldwork in Botswana, Livingston's use of *debility* includes both impairment and disability, but does not exhaust either. It foregrounds the networks of familial and community care as well as fraught relationships with medical institutions and practices, and it is inextricably tied to what she calls the "moral imagination": "stark reminders of the physical dangers of moral uncertainty and reaffirming the long-recognized fact that the human body does not exist as somehow separate or abstracted from the complex lives of persons."[62] In other words, for the Tswana people with whom Livingston worked, *debility* was inseparable from the experiences and constructions of subjects in time and space: the history of colonialism and postcolonialism in Botswana; increased independence for young women following political independence for the country; the rise of industrial capitalism, which affected both work opportunities and the practice of biomedicine; and of course the experience of work and embodiment itself.

One major difference between debility and the conception of impairment advanced by Mills, and as I describe it in my experience, is that the body-machine analogy—between human impairments and system impairments—is distinctive to a Western, bourgeois context, as explained by Livingston: "Despite the fact that some Batswana have begun to invoke mechanistic imagery when describing the human body, they by no means liken impaired bodies to broken machines, nor do they envision a world in which technological fixes will obviate the need for grappling with difference through benign sentiment and healthy social relationships."[63] In the Tswana context, the concept of communication impairments wouldn't work at all as a foundation for thinking about impairment and disability. For Livingston, *impairment* as well as *debility* facilitate thinking across disability, illness, and aging: "Reduced mobility and physical strength, as well as blindness and a range of other infirmities, have long marked understandings of senescence. These were not regarded as disability: indeed, they were 'normal' and in some cases even expected impairments."[64] I will take up the idea of "normal and expected" impairments, specifically of hearing and fatigue, in chapters 4 and 5.

But even my *unexpected* vocal impairment raises this issue of classification between impairment, illness, and disability, especially the uneasy relationship between disability and chronic illness: "Recognition of impairment is crucial to the inclusion of people with chronic illnesses in disability politics. Chronic illness frequently involves pain, fatigue, dizziness, nausea, weakness, depression, and/or other impairments that are hard to ignore."[65] Strictly speaking, my vocal cord paralysis is the result of cancer. Because modern medicine has developed ways to deal with papillary thyroid cancer, I exist in an ambiguous space. The word *cancer* is a conversation stopper. But even with the metastases in my lungs (technically stage IV as of this writing, though that is being actively debated in the medical literature), I experience myself as chronically ill, not in imminent danger, because of my access to the Canadian medical system, private insurance, and the various privileges that follow me into the hospital.[66] Diane Price Herndl writes that "most people in the disability community do not want to be considered ill, and most people who are ill don't want to be considered disabled"; this mutual resistance is partially about the intersecting politics of stigma and classification, and the differential institutional histories of *impaired*, *ill*, and *disabled*.[67]

The problem of chronic illness as (or and) disability is also about the different work of metaphors—especially in its punctual (nonchronic) form, a concept of illness as "globally incapacitating" would be more acceptable to activists than a concept of a disability being globally incapacitating.[68] I move between these terms in my daily life: reassuring friends that I am chronically ill when telling them about new cancer treatments (as I just did for you, dear reader, in the previous paragraph), claiming the right to disability accommodation for my vocal cord impairment when teaching or giving talks, and passing for nondisabled (but fat) in many public spaces (because it would be too much work to come out in each and every situation).[69] Chronic illness fits neither category: it is illness that will not kill me, but from which I will not recover.[70] The semantic ambiguity among impairment, disability, and illness remains a constitutive feature of all three categories. They move through the same space and bump into one another, sometimes overlapping, sometimes repelling. All three are conditioned by a divergence from medical or social norms. All three are conditioned by an ideology of ability and a preference for ability and health. Indeed, phenomenologists of illness have even defined it in terms of "a loss of wholeness," a condition of "bodily doubt."[71] These preferences may be political and ideological, but they are also orientational: they are felt, lived, and negotiated.

The *loss-of-wholeness* thesis runs right up against another category problem: impairments that are acquired versus those that are not. The loss-of-wholeness thesis is not even really adequate to my experience of impairment as more of a change in orientation than a loss per se—it's not just about blockages and where I don't go, but where I now want to go and what I want to do. The experience of impairment and its relationship to self and to orientation can be very different depending on whether a person knew themselves differently before. I can tell you a whole lot about my life before acquiring a vocal impairment. My partner, Carrie (who will repeatedly appear in this book as a character), was diagnosed with type 1 diabetes at twenty months of age and has never known anything else. We experience our impairments differently in that she did not experience its acquisition—or, rather, her body certainly did, but the subject Carrie did not. I experienced a moment of acquisition.

Impairment is only a loss or lack if it is experienced that way. As Geyla Frank writes in her cultural biography of Diane DeVries, a woman born without arms and legs: "The clinical term *congenital amputee* has been applied to Diane. But to call up an image of Diane in the company of people who have had an arm or leg cut off leaves something to be desired. Her arms and legs can only be postulated. They exist in a state of potential as much as a state of loss."[72] In other ways, my experience is the same as Carrie's or Diane's: our bodies don't work like bodies are supposed to work, and none of us fit the cultural script for the unified, continuous, whole subject. But our relations to something like phenomenological integration or wholeness may be different: I am more likely to experience my impairment as a challenge to integration; had I been born with a paralyzed vocal cord, maybe it would be different. But this is not just a question of experience: some impairments are minoritized, some are dismissed, some are disbelieved, others are attributed when they are not present. Impairment phenomenology is political phenomenology because impairment is a term that always has multiple references that exist in relation to one another. Something cannot be impaired unless something else is not impaired. The meaning of that difference may be something left to an individual to resolve, but more often, like all meanings, it is situationally variable and a place for contestation.

For some disability writers and activists, and for some culturally Deaf people who may entirely reject the labels of impairment and disability, an experience of wholeness and personal integration is essential to claiming identity. On an operative level, a sense of personal integration is also essential to all sorts of everyday actions. In this text, I am trying to thread the needle of holding on to that possibility, while producing a theoretical account that does not demand of impaired subjects that they position themselves in respect to (or aspire to being) an idealized, whole, integrated, self-consistent person. It's a very different thing if you come to it on your own than if others are making the demand that you do it. Make yourself a whole person if you want to; just don't demand that others do it to themselves.

SPEECH REQUIRES CLOSURE

Even though I keep insisting that the story of my voice is a story about orientation, that doesn't mean the fear of loss never appears. In December 2009 and January 2010, we were at a crossroads in my treatment. I'd lost the use of one vocal cord. I didn't want to lose another. As Tom Shakespeare has written, "Those of us born with our disabilities are used to our form of life, and we rarely bother worrying about it—we cannot imagine any other way of being. But ask any disabled person how they would feel about losing further abilities, and most would be less sanguine, I think."[73] At first, we thought I could perhaps go straight into radioactive iodine therapy, which works by starving the body of iodine, then adding radioactive iodine, which the thyroid cancer cells soak up. If this treatment sounds medieval, that's because it is: the only known cause of thyroid cancer is exposure to radioactivity. The poison is the cure! Enter the pharmakon! Or don't: the problem with that option turned out to be that a dose high enough to kill the tumor would also kill me. A second surgery was scheduled for February 12. The goal was to save the nerve, but not at the cost of leaving cancer in my body. To do that, the doctors would attach my nerve to a device that electrified it, sort of like the old buzzer-and-tweezers game Operation. If they got too close to the nerve, an alarm would sound. In addition to Dr. Q, my neck surgeon, a thoracic surgeon came on board. But my nerve could still go: if it was wrapped in cancer, then it could not be saved.[74]

We all knew a possible outcome of the surgery was losing the nerve, or that it could go into spasm temporarily. It was the latter experience with which this chapter began. Unable to breathe on my own, I was intubated, put into the recovery room for the weekend (the ICU was full), and kept in a state of sedation so I did not instinctively pull the tube out. Since I was still unable to breathe on the following Monday, they installed a temporary tracheostomy, and by Tuesday I was in my own hospital room.[75] By the following Sunday, I could not speak for myself, but I could write (the following post has been edited for usefulness).

> FEBRUARY 21, 2010
>
> Didn't Foucault say something about hospitals and jails?
>
> Anyway, I have been gradually coming back to personhood over the past few days. 2 days in pants. 24 hours narcotic free now, though the trade-off is, well, pain. My neck feels like it has been rearranged. Because of course it has. There's a new hole in my head. It's hard to describe the "new tracheostomy feeling" but I can offer an exercise that probably works for any major body modification. Imagine a range of things that you would find it disturbing for others to do to your neck. Now imagine that you've become comfortable with half of them. Congrats, you have accepted your new trache.
>
> I still can't talk at all. In my head, it's all logorrhea.[76]

To say that I could only communicate by writing is to assume that everybody could read. By this time in the story, your protagonist should theoretically have known better. If writing to speak didn't even work on my overeducated social scene, why would it work on hospital staff who might have very different histories with and relationships to writing, and who occupied very different class positions? In a way, it's miraculous—and a testament to the commitment of most of the nurses and orderlies—that in a large part it worked and I was able to communicate with the people around me (better, in fact, than at that fortieth birthday party). It also probably helped that Carrie went on a campaign of bribery, bringing in baked goods from the Portuguese bakery around the corner from our apartment a couple of times a week. But one orderly in particular who seemed not to like me at all may well have formed that attitude *because* I kept writing stuff to him. It's entirely possible he couldn't read whatever I was writing him, which added frustration to our interactions for both of us. Years later, I have taken his side in our conflict: I was stoned out of my mind on Dilaudid for the first few days of interactions with him—and everyone else in the ostomy ward. Who the hell knows what I wrote and what it meant?[77]

Two days later, I would have my trach tube replaced with a smaller one, which meant that I could talk and swallow. When the possibility of a trach was first presented to me, it was explained as a total loss of voice. But as I learned firsthand, having a trach can mean many things, from no speech at all, to speech that is altered in one of many ways. Trach voices are highly variable from person to person, depending on the condition of their throats and chests. Some are hoarse sounding, some are whispers, some produce robotic, metallic, or inharmonic timbres because of the particular prosthesis they use. As with accents, the visible and audible differences may well combine in the hearer: just as a sighted auditor might see brown skin and "hear" accented English where there is none, a trach voice might collapse into the sight of a trach on a body for an auditor.[78]

Every person who has spent time as an inpatient probably has their story of hospital dehydration, but what I remember most profoundly from the smaller trach was not the recovery of speech but the discovery that I could swallow little bits of water.[79] Sometime around 2 a.m. the night before I was to be tested to see if I could swallow well enough to eat or drink, I learned that I could swallow, and I proceeded to fill a tiny cup with water over and over again, sipping and sipping until I was too exhausted to continue. It also allowed enough air through my throat for speech. I had spoken a "1 2 3 4" under sedation on February 12 or 15, but on the twenty-third, I was able to cover the hole in my trach and talk. That was *also* a euphoric feeling, and I talked myself hoarse in short order. About what, I do not recall; logorrhea demanded its satisfaction. With the smaller tube, I had one of those hoarse trach voices. It sounded like "me" in my head, but after a lot of yelling in a smoky bar.

Another two days later, I was "taped" for twenty-four hours to see if I could handle a closed trach. The challenge turned out not to be breathing in or talking but exhaling, which simply had to do with the bulk of the tube. The next day, my trach was removed, and the hole was imperfectly sealed. I wrote, "It feels good to be back 'in' my nose and mouth."[80] I have lost the memory of that particular feeling, but today I would read it as a reflection on breath more than anything else. That is the dynamic I have been playing throughout this chapter: every time I give an account of experience, I also give an account of how it is not fully available to me.

The project of interpretation often relies on *ethos*, on the production of the interpretant as a vessel through which the reader can access the world. This is one of the most important, and one of the most difficult, insights that disability theory offers to hermeneutics more generally. But it is a description of consciousness that few scholars in the humanities — never mind philosophy, psychology, or cognitive science — would recognize as plausible if applied to any party other than the authorial voice in a scholarly text. Few serious scholars believe that a subject's discourse simply reflects a real condition or an unmediated experience — not ethnographers, not lawyers, not psychologists, not philologists, not literary critics, not historians. Yet academic texts and criticism perform all the time as if this were the case for them, even if for nobody else. Even writing in disability studies often relies on the power of testimony as a mode of access to reality. But to subject disability theory to disability theory's critique of experience is hard, and it's possible that my inaccessible-to-myself-self constructed in this chapter is more annoying than satisfying. So be it! This is the challenge: to include the testimony of disability while subjecting the very category of testimony to a critique. While there is a rich literature on the politics of testimony, it is still rare to critique the term from the standpoint of impairment or disability. This chapter has been one attempt; there should be more.

NOTES

ONE. DEGREES OF MUTENESS

1 See, e.g., Bischoff and Rundshagen, “Awareness under General Anesthesia.”

2 On July 29, 2019, I checked this story with Dr. Q. He looked at his notes and reconstructed the scenario with me. He was careful to say that his memory of the events was as subjective as mine (and he does more than three hundred surgeries per year). From his notes, he concluded that the events I describe did happen, and they probably happened on February 12. He also believes that the scenario ended with me being able to take a breath on my own before being put back under. But I am not so sure, and my partner, Carrie, also questions this because of the sequence of events. Since I was sedated and intubated for the weekend, and then given a temporary tracheostomy on February 15, it’s possible that I might *not* have been sufficiently able to breathe on my own and that that was confirmed on the fifteenth. In the end, none of us will know for sure what happened on what day.

3 In other writing, I have explored these conditions technologically, materially, culturally, and historically.

4 Heyes, *Anaesthetics of Existence*, 15.

5 Husserl, “‘Phenomenology’”; Heidegger, *Being and Time*; Merleau-Ponty, *Phenomenology of Perception*. If you are new to these authors and want a good introductory gloss on their positions, I recommend the relevant entries in Center for the Study of Language and Information, *Stanford Encyclopedia of Philosophy*.

6 Al-Saji, “Bodies and Sensings,” 16n9.

7 Carel, *Phenomenology of Illness*, 21. For more on phenomenology, see Peirce, *Philosophical Writings of Peirce*, 76; Merleau-Ponty, *Primacy of Perception*, 12–27; Ihde, *Listening and Voice: A Phenomenology of Sound*, 25–46; Ramsey, *Long Path to Nearness*, 13; Young, “Throwing like a Girl”; Ahmed, *Queer Phenomenology*, 5–12; Abrams, “Cartesian Dualism and Disabled Phenomenology.”

8 Berland, "Contradicting Media." There is also a literature in political science and political philosophy that calls itself political phenomenology but works more in the universalist tradition. I deliberately do not engage with that work.

9 For a more formal attempt to resolve the contradictions between genealogy and phenomenology, see Heyes, *Anaesthetics of Existence*, 27–51.

10 Ahmed, *Queer Phenomenology*, esp. 1–24. I discuss Ahmed in more detail later in this chapter.

11 Crosby, *Body Undone*, 20. This is a running line of argument in several canonical disability studies texts, such as Linton, *Claiming Disability*; Claire, *Exile and Pride*; Siebers, *Disability Theory*. But the intellectual and political history of the idea is difficult to trace because different terms are used, and different writers draw from feminist, Black, and queer traditions. See, e.g., Pliner, "Listening to the Learning Disabled," 52–90. A similar idea to what is found in the disability studies literature is also quite prevalent in writing that uses the medical model of disability. See, for instance, Brillhart, "Predictors of Self-Acceptance."

12 Spencer, *Metagnosis*, 7.

13 A note on nomenclature: currently, there is no consensus within Deaf studies regarding how to represent deafness typographically. Capital D–*Deaf* generally refers to people who use sign language and understand themselves as belonging to a deaf community. Lowercase d–*deaf* is generally used to refer to people who cannot hear but may not understand themselves as culturally Deaf. Even this category is difficult, since "cannot hear" is itself a cultural status: most biologically deaf people have some residual hearing. Some writers in Deaf studies have used *d/Deaf* to describe both categories, while others wish to use *deaf* as a more general, capacious category. I use *Deaf* to describe a self-conscious identity and *deaf* to describe a mixed biological and cultural phenomenon, which *may* also include the culturally Deaf.

14 Quotes are from an unpublished oral history of Southworth's work taken in summer 2013 in Berkeley by Sabine von Fischer. Many thanks to Sabine for sharing it with me. See also Southworth, "Sonic Environment of Cities"; Ihde, *Listening and Voice: Phenomenologies of Sound*, 57–71; Kleege, *More Than Meets the Eye*, 14–28; Fleet, "Accessibility, Augmented."

15 Happily, Danielle Spencer's *Metagnosis* appeared in early 2021, just soon enough that I could include this note. Its heavy focus on impaired visuality makes it an excellent companion to this book. Spencer is working in a slightly different frame—narrative medicine—but the approach is complementary.

16 Marks, *Skin of the Film*, 1.

17 It also began as a riddle. I had originally wanted *Diminished Faculties* to simply end with a cat vomiting on me as I passed out, which is how chapter 5 concludes. However, readers of the manuscript unanimously wanted a conclusion. This presented a problem: there are very few examples of "great" conclusions to scholarly books. A search through my bookshelf and queries on social media yielded little. The function of a conclusion is usually to restate a book's argument and to suggest some further implications—how it might be useful out in the world, beyond its pages. This led me

to the genre of the user manual, which didactically provides instructions for use, application, and problem solving. There are many great examples of creative user manuals. I decided to follow the genre conventions as rigorously as possible and to apply them to the scholarly approach developed as I wrote this book.

18 Diawara, "One World in Relation," 6; Du Bois, *Souls of Black Folk*, 3; Fanon, *Black Skin, White Masks*, 109–40; Gilroy, *Black Atlantic*, esp. 1–40, 111–45; Moten, *Black and Blur*.

19 The standard critique of "paranoid" reading is Sedgwick, *Touching Feeling*, 123–51. But my purpose here is not to advocate for reparative reading. Instead, it is to advocate for impaired reading. See also Poss, "Distortion Is Truth." Please note that this is not meant as a comment on the current "post-truth" and "fake news" discussions. For that, see Harsin, "Toxic White Masculinity."

20 As told on August 2, 2020. Throughout this text, there will be "as I write this sentence" notes referring to what's happening to me or to the world as I'm writing that sentence. But the sentences in the text were written out of order, so the exercise also reveals the mixed-up chronologies operating in *Diminished Faculties*: there is the time of the text, the time of my experience, the time as marked by date, and whatever temporality you enact in reading it. These temporalities do not line up, which nicely performs a version of the disjunctures that constitute impairment more broadly.

21 There was one experimental presentation, "Footnotes to a Manifesto for Diminished Voices," as part of the Hemispheric Institute's 9th Encuentro in 2014. During the "5 Minute Manifestos" project, I sat and played a video I made and then answered questions. The video is available at https://player.vimeo.com/video/108830830?app_id=122963 or https://hemisphericinstitute.org/en/enc14-5-minute-manifestos/item/2609-enc14-5min-sterne.html. In chapter 2, I discuss presenting my voice in the context of other kinds of public speech. Buck's vocal cord paralysis was the result of misapplied anesthesia during a hair plug replacement surgery (in 2011, when it happened, he lied and attributed it to a virus). See Casselberry, "Joe Buck Admits." Adele's vocal cord problems were just the latest in a long line of singers who have had similar issues. See Warner, "Why Do Stars?"

22 "Consider the history of 'what appears' and how it is shaped by histories of work. . . . Going back to the table, we would remember that the table was made by somebody, and that there is a history to its arrival. . . . Things come to matter by taking shape through and in the labor of others." Ahmed, *Queer Phenomenology*, 43–44.

23 Young, "Throwing like a Girl," 36; Ahmed, *Queer Phenomenology*, 197n15; Merleau-Ponty, *Phenomenology of Perception,* 93, 204, 220, 221, 247, 330, 390.

24 Later in this chapter, I discuss an alternative perspective on wholeness. The choice to avoid a language of wholeness or unity is also borrowed from another source, Gilles Deleuze and Félix Guattari's injunction to "write to the *n*th power, to the n-1 power" (*Thousand Plateaus*, 24).

25 Wendell, "Unhealthy Disabled," 23.

26 Linton, "Disability Studies," 530. Immediately following this, she cites the "corridors at a Society for Disability Studies conference" and "the back rooms of an indepen-

dent living center" as the two examples for impairment phenomenology. While both certainly could provide phenomenological discussions of impairment, as I discuss later, we may not want to tie the concept too closely to a status as a "real substrate" to disability as a social and constructed phenomenon, both because of critiques of disability as *only* a construct and because impairment is a leaky concept that exists both inside and outside disability. However, it's worth noting that calls for a phenomenology of impairment appear very quickly after the emergence of disability studies as a field, at least in the United States and the United Kingdom.

27 Kafer, *Feminist, Queer, Crip*, 1; Bérubé, *Life as We Know It*, 14; Price, *Mad at School*, 1 (see also her helpful discussion of rhetoric and credibility, 25–57); Yergeau, *Authoring Autism*, 16, 24, 31; Siebers, *Disability Aesthetics*, 37.

28 Siebers, *Disability Theory*, 10. I discuss the ideology of ability throughout this book.

29 "Under such a construction of symptomatology, the only arguably reliable story I've offered in this introduction comes from my presumably nonautistic mother, her competing narratives of my autistic selfhood. Her words about autistic identity and shit smearing carry far more weight than my own. In many respects, this is how I feel about the world of rhetoric—it is a steaming pile of competing, ableist theories about distant Others that extend up to my neck. How to lob rhetoric at the wall? How to smear it on my face? Where is my intentionality? Must one have intentions in order to be rhetorical? Theory of whose mind?" Yergeau, *Authoring Autism*, 31.

30 Lagerkvist, "Existential Media."

31 Young, "Throwing like a Girl," 35–38.

32 Crosby, "Articulating Disability and Debility," 4–5.

33 Siebers, *Disability Theory*, 24–25.

34 Crosby, "Articulating Disability and Debility," 2.

35 If I had to guess, it probably began sometime in the early 2000s, while I lived in Pittsburgh. At least two other people in my old department at the University of Pittsburgh had been diagnosed with thyroid cancer during the time I worked there, so it is possible I was one of them and simply didn't know it until much later.

36 Derrida, *Speech and Phenomena*, 86. I am aware of the inherent contradiction in the very question of Derrida's intent. But that joke has already been told enough already.

37 Kafer, *Feminist, Queer, Crip*, chapter 1.

38 Pullin and Cook, "Six Speaking Chairs," 40. Pullin and Cook continue: "Writing and speaking are fundamentally different ways of conveying language, and yet text-to-speech treats them as if they were equivalent."

39 Sterne, "Disability Studies 101."

40 Siebers, *Disability Theory*, 10.

41 There are certainly exceptions to this history, usually where intellectuals, reading, and learning were celebrated, but loss of eyesight has always been a fraught and contested category.

42 Pullin, *Design Meets Disability*, 16–23.

43 Fanon, *Black Skin, White Masks*, 84; Rubin, "Traffic in Women"; J. Butler, *Bodies That Matter*; Du Bois, *Souls of Black Folk*; Gilroy, *Black Atlantic*.

44 Wendell, "Toward a Feminist Theory," 109–10.

45 Kafer, *Feminist, Queer, Crip*, 11–13; Wendell, "Toward a Feminist Theory"; Goffman, *Stigma*; Dolmage, *Disabled upon Arrival*; Chen, *Animacies*, esp. 157–222; Murphy, *Sick Building Syndrome*; Jain, *Malignant*.

46 Canguilhem, *Normal and the Pathological*.

47 "Convention on the Rights of Persons with Disabilities and Optional Protocol," opened for signature March 30, 2007, United Nations Treaty Series, Article 1, https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf. Interestingly, this updates the UN definitions cited in Wendell's classic 1989 article, where impairment was a loss of ability compared with a norm, disability was a lack of ability compared with a norm, and *handicap* was a disadvantage (including stigma). In that model, disability was the substrate of handicap and impairment was the temporal experience of disability; in the 2007 definition, impairment is the substrate of disability. Wendell, "Toward a Feminist Theory," 107.

48 In French, the term *impair* refers to an odd number as well as to a faux pas, which would provide another interesting reading, at least in a bilingual setting.

49 Mills, *Hearing Loss and the History of Information Theory*.

50 Noll, *Introduction to Telephones and Telephone Systems*, 89, quoted in Mills, *Hearing Loss and the History of Information Theory*, quoting: "Hence, the human factors of transmission impairments are an important consideration in the performance specifications for transmission system."

51 Mills, *Hearing Loss and the History of Information Theory*.

52 Chang, *Deconstructing Communication*; Peters, *Speaking into the Air*; Hainge, "Of Glitch and Men"; C. Kelly, *Cracked Media*; Alexander, "Rage against the Machine."

53 Mowitt, "Sound of Music"; Poss, "Distortion Is Truth"; Hilderbrand, *Inherent Vice*; Pinch and Trocco, *Analog Days*.

54 For a much deeper cultural approach to accents, see Rangan et al., *Thinking with an Accent*.

55 This is my amendment to Kafer's proposition 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." Kafer, *Feminist, Queer, Crip*, 8.

56 Kafer, *Feminist, Queer, Crip*, 11.

57 Rose, *No Right to Be Idle*, 7.

58 Rose, *No Right to Be Idle*, 7.

59 Danziger, *Constructing the Subject*, 68–87; Quetelet, *Treatise on Man*; Schulten, *Mapping the Nation*; Bouk, "History and Political Economy," 89; Dolmage, *Disabled upon Arrival*.

60 The DALY was designed to combine data about morbidity and premature mortality, essentially converting all disability and impairment into a numerical "effect" on life expectancy. The idea was to create a universal statistic that allowed for comparative decision-making on a global scale, a measure by which organizations like the WHO could decide to target funds. Given that it is an astounding work of quantification and averaging, it has come under criticism from a variety of quarters. An ironic result

of this critique is the growing trend among epidemiological researchers to retreat to a *different* universal measure that has many of the same problems, just in a different register. Kristin Voigt and Nicholas King have argued that epidemiologists have been too quick to assume that proper or optimal funding would "align" with the GBD and that a higher relative "burden of disease" would bring more funding to a country. Just as DALY converts quality of life (itself a highly contestable term) into quantity, the GBD fails to account for *severity, communicability*, or a variety of other factors. Further, as Voigt and King argue, "misalignment" of WHO and GBD factors may also be a result of decision-making processes, which raise their own questions of legitimacy (those decisions that are made by a representative, deliberative body versus those that are made by wealthy donors). Bouk, "History and Political Economy," 96; Voigt and King, "Out of Alignment?"; Voigt and King, "Disability Weights."

61 Livingston, *Debility and the Moral Imagination*, 234. Jasbir Puar has proposed *debility* as an alternative to *disability*, which she locates as a particular condition within a field of debilities. Inasmuch as she is drawing on Livingston's coinage, she is right to parochialize the concept and experience of disability as geographic, raced, and classed. Puar is, of course, *also* correct that Anglophone disability studies is still shaped by a presumptive whiteness, a hypothesis that can be confirmed by a short look at any disability studies bibliography (and this study is unavoidably shaped by its whiteness—I can parochialize my experience at every turn, but it is still my story, even if it seems I live in a world where Jews have suddenly become *less white*). But Puar's critique of the whiteness of disability studies slides too easily into an imagined privilege for the concept of disability where there is none—a fantasy of friction-free disablement for white people. For instance, she writes, "The biopolitical management of disability entails that the visibility and social acceptability of disability rely on and engender the obfuscation and in fact deeper proliferation of debility" (*Right to Maim*, xv–xvi). While this statement is certainly the case in many instances where disability takes on a bureaucratically recognized existence, it is *also* the case that in many places—even within the most privileged spaces of the West—disability is neither visible nor socially accepted. Puar illuminates the moral and epistemic costs of the violence of states against their subjects in the cases of the Black Lives Matter movement and the struggle for Palestinian liberation; she describes the ways in which certain subjects and bodies are rendered as discountable, destructible, and disposable; but her critique of states' institutional approaches to disability cannot in any simple way be extended to the experience or politics of disability for people, *tout court.* As Liat Ben-Moshe explains in *Decarcerating Disability*, "The biopolitics of debilitation can't explain or account for what becomes of/to people on the level of activism or ontology once they are disabled/debilitated" (30). This may very well be a hard limit—or perhaps an impairment—constitutive of biopolitical analysis more generally.

62 Livingston, *Debility and the Moral Imagination*, 235–36.

63 Livingston, "Insights," 118.

64 Livingston, "Insights," 120.

65 Wendell, "Unhealthy Disabled," 23.

66 When I first wrote that sentence, I had been on a new course of treatment for expanding lung metastases for only a few weeks. Metastatic thyroid cancer in the lungs used to be fatal because it cannot be effectively treated with surgery, external beam radiation, radioactive iodine, or traditional chemotherapy. The drug lenvatinib is a new kind of targeted therapy—whereas chemo attacks cell division, tyrosine kinase inhibitors like lenvatinib attack proteins and reproduction of blood vessels in tumors. Like all cancer drugs, it can lead to a host of iatrogenic conditions, including high blood pressure, stomach ailments, hand and foot disease, all the way up to strokes. (Fragments of this story continue to appear throughout the text—the chemical fatigue I describe in chapter 5 comes months after the entry given here.)

67 Herndl, "Disease versus Disability," 593.

68 Amundson, "Disability, Handicap, and the Environment," 113.

69 There is also a parallel story to be told here around the intersecting and conflicted histories of fat studies and disability studies, though the contradictions are more on the surface: both address bodies that move through a world not designed to accommodate them; both share political and intellectual roots in civil rights movements and the academic response to those movements. But there are plenty of occasions in which fat and disability theorists would rather not be associated with one another: or, rather, where each group mobilizes (or in some cases internalizes) stigmas against the other in the service of their own cause.

70 See also Wendell, "Unhealthy Disabled," 30.

71 Carel, *Phenomenology of Illness*, 36, 38; Toombs, *Meaning of Illness*, 20.

72 Frank, *Venus on Wheels*, 124.

73 Shakespeare, comment on Bérubé's blog entry.

74 If the cancer went too low in my neck, they would have had to do a maneuver with the unfortunate name of "the sternal split."

75 Quebec hospital rooms have one, two, or four beds in them. I chose a private room and had to pay out of pocket for it. My private insurance through McGill University would have covered a semiprivate room with two beds for free. Including some meals, taxi rides for Carrie and my mom, and a few other frills, I estimated that the total out-of-pocket cost for my hospitalization came to approximately $1,500—totally absorbable for someone on a cushy full-time professor salary but prohibitive for someone who is poor, especially given that they would not have had access to my private insurance. Even under socialized medicine, class can still play a role.

76 Sterne, "Cancer Crawl Feb 20th."

77 It turns out I am one of the 5 percent of people who hallucinate while on Dilaudid. I now have a much better aesthetic appreciation for bad heroin art. Also, while I have rethought my interactions with that orderly, I have not revised my opinion of nurse M, who did not wash his hands, and who spread some kind of nasty gastro virus through the entire ward, to which I and everyone else succumbed (including him). Nurse M can still fuck off.

78 Stoever, *Sonic Color Line*; Eidsheim, *Race of Sound*; Stanyek, "If There's a Place in Your Voice."

79 See, e.g., Crosby's discussion of hospital thirst. Crosby, *Body Undone*, 25.

80 Sterne, "Cancer Crawl Feb 26th."

TWO. MEET THE DORK-O-PHONE

An earlier version of this chapter appeared as "Ballad of the Dork-o-Phone: Toward a Crip Vocal Technoscience," *Journal of Interdisciplinary Voice Studies* 4, no. 2 (2019): 179–89.

1 Hosokawa, "Walkman Effect"; Bull, *Sounding Out the City*.

2 McKay, "Speaking Up"; Emily Thompson, *Soundscape of Modernity*; Radovac, "Muting Dissent"; Tkaczyk, "Shot Is Fired Unheard"; Sterne, "Space within Space"; Michaud, "No One in the Spotlight"; Eidsheim, *Race of Sound*.

3 Maldonado, "Taking Eyeglasses Seriously"; Seagrave, *Vision Aids in America*; Mills, "Hearing Aids"; Mills, *On the Phone*.

4 "SoundBuddy Portable Speaker Kit."

5 Pullin, *Design Meets Disability*, 67–69, 93. On curb cuts, see Hamraie, *Building Access*; and on closed captioning, see Downey, *Closed Captioning*.

6 "Spokeman Personal Voice Amplifier."

7 See Hendren, *What Can a Body Do?*, 25–28. Although she doesn't mention Marshall McLuhan, her point that "a body is almost never not extended" (26) also suggests a crip critique of his ableist tropes of extension and amputation. See also Ott, *Artificial Parts, Practical Lives*, especially 21–24.

8 Much of the description in this chapter carries a heavy debt to Kleege, *Sight Unseen*.

9 Obligatory COVID-era footnote: this is not the same thing as wearing a medical mask. However, there is also a disability politics to masks for people with facial differences. See Buckley, "Covering a Facial Difference during COVID-19."

10 Labelle, *Lexicon of the Mouth*, 3. To be fair, Labelle is both ambivalent about this construct and at least in principle willing to critique some of its ableism and universalism. On the last two pages of his book, he claims a desire to extend and complicate "what a voice can be and how narrative may actually be performed—especially for those who might not have a voice, but who may certainly have a mouth," and he extends this sentiment in his brief discussions of muteness, aphasia, and stuttering, calling Christian discrimination against the deaf "problematic" and prejudices against vocal impairments "discriminations" (186–87). These ideas are not, however, worked out or developed in the rest of his book, which takes a more psychoanalytic and universalist approach to the problem of voice and mouth, as when he argues that "to lose voice is to lose agency" (143).

11 Haraway, "Situated Knowledges," 581.

12 Sounds and voices can also be perceived—and have real effects for the percipient—without a material analog, at least on this plane. See, e.g., Moreno, "Antenatal Aurality"; Hagood, *Hush*, 42. As the recent debate between Marie Thompson, Annie Goh, and Christoph Cox (as well as a recent article by Brian Kane) has demonstrated, a