

Toward Centering Access in Professional Design

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Abstract

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Human-Computer Interaction research has long been concerned with foregrounding user needs in the design of technology. Indeed, its professionalized application, often called design, aims to put this philosophy in practice. For example, when designing for people with disabilities, designers aim to gather user needs specific to this population and translate them into accessible designs. Accessibility is gaining increased attention in the field, one indication being that accessibility was one of the most popular keywords describing publications at the 2019 CHI Conference on Human-Computer Interaction. But this dissertation argues that despite increased momentum, perspectives from the people with disabilities accessible designs purportedly benefit are under-represented, and these absences may negatively impact people with disabilities and the field of professional design.

As such, this dissertation engages and intervenes professional design with perspectives by

people with disabilities. First, I draw out some ways the field may exclude disabled people. Specifically, I analyze cases of professional design where disabled people were observed and invited to assist on design projects. My analysis shows that disabled people and their contributions were often cast outside of design in favor of designer perspectives. By imposing differences, professional designers separated, rather than drew close, the first-person perspectives they sought.

In response, I developed two interventions with the aim to rework professional design from lived experiences of disabled people. The first intervention, called biographical prototypes, materializes stories of modification, repurposing, and invention people with disabilities have done in their daily life to make something work better for them. This intervention accumulated a collection of narratives and lessons that informed my second intervention, called interdependence. Interdependence is a lens for analyzing the work people with disabilities and others do to make something accessible. When I applied the frame to analyze field observations of disabled and nondisabled people working together, the interdependence lens revealed two important findings. First, access building was a continuous effort of mundane attunements in contrast to the way access is written in professional design as a fixed state. Second, access building can be ableist—prejudice against people with disabilities. That is, in attempt to open opportunities for someone with disabilities, interdependencies show how this work may foreclose actions which privilege the natural ways people with disabilities work.

From my interventions, I learned that professional design may benefit by letting go of access as if it were a fixed state to either achieve or not. As such, I offer recommendations for centering access or, how to consistently, collectively, and accountably attend to what people

with disabilities, and others, need to meaningfully contribute to and be adequately recognized by professional design.

Acknowledgements

This dissertation is a culmination of interdependencies with, sometimes more dependencies upon, people who have given generously to mentor me and set me up for success. The acknowledgements are a grossly incomplete recognition of the numerous people who deserve credit for helping me survive the Ph.D. experience. And they begin with a crucial point, my introduction into research. As such, I thank my undergraduate research mentor, Nora Noel, Professor of Psychology at the University of North Carolina Wilmington, for starting me on this path.

Importantly, the chairs of my dissertation committee, Daniela Rosner and David Ribes, scaffolded a rigorous but caring mentorship, upon which I regularly reflect to advise my own mentoring. I particularly appreciate David Ribes's instruction in science and technology studies and incredible teaching. These skills have proven extremely useful for my own research, curricula design, and facilitation of group learning.

Broadly, Daniela Rosner's research has contributed to solidifying feminist perspectives among those recognized by HCI scholars, and she generously widened her concerns to help me to amplify disability studies in a similar manner. Impacts of her work to recognize women's contributions to space travel are everywhere in this dissertation. They helped me to read differently, receive and apply disability activist critiques of design, ask more questions, and even reorient my research commitments. Her legacy is just beginning and will certainly be long lived, as her approaches that uncover histories and amplify recognition of under-told and erased

perspectives undertone almost all conversations I have with students.

Megan Finn, my Graduate School Representative, has always generously provided feedback useful for improving the structure and legibility of my presentations to the specific audiences I am asked to address.

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Academia is extremely inaccessible, and from my experience, people with disabilities, or those otherwise under-represented, are rewarded when we conform and act as if we have done everything alone. This seeds inaccurate crediting, thereby setting us up to perpetuate the same injustices that keep us marginalized. I cannot name the numerous people who helped me format documents, make presentations visually appealing, make my PDF versions of publications accessible, use inaccessible software, assemble tiny hardware components, analyze photo and video data with me, navigate conference spaces, and do many, many other tasks that are time consuming or outright impossible for a blind person to do. Everyone I have named thus far has taken up some of this access work for me, particularly my advisor Daniela Rosner, and this has been on top of their job responsibilities and there are few systems of credit where they can claim this work as part of their service to justify promotion and other recognitions. In fact, their extra labor often backfires, as when it becomes known that they are caring of others' humanity, more and more people ask for their service. A few people have had explicit responsibilities to assist me and they include Karan Gupta, Alex Haagaard, Jennifer Justice, Anna Schmitz, and Bonnie Tran. Finally, the office staff of the Human Centered Design and Engineering department at the University of Washington regularly help me with administrative tasks like booking meeting rooms and processing my financial-related documentation, including travel reimbursements and participant payments, activities which were also sometimes inaccessible to me.

My family including my mother Susan Bennett, father Brian Bennett, and siblings Donald Bennett, Karla Emery, and Greg Emery, have been unconditionally supportive of my decade-long career in the higher education system. In particular,

my mother, Susan, sewed some prototypes for me which came in useful in the biographical prototypes project. More importantly, through our conversations while I was in grad school, I learned that in the early 1990's, she copyedited Ph.D. students' dissertations as part of her typing business. Her reminders to me of this skillset were initially dismissed by me. No one prepares their dissertation for printing anymore. I am now less naïve; electronic documents have their own slew of presentation conventions against which academia loves to judge imperfection. And as I learned with Daniela Rosner, my mother's primers led me to expand my own education. By reading more and paying closer attention to my women mentors, I learned to recognize that many, many women, often unpaid, did, and still do, immense work to ensure that dissertations, and other manuscripts that scaffold academia are actually published and are actually readable. Now that I'm enlisting my own assistance to copyedit this dissertation, I know that this labor will never be adequately recognized and will continue to be exploited as long as it remains an invisible line item on the budget we do not procure to pay for this important work.

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intersectional, on-the-ground organizing frequently brought my dissertation research to Earth, and regularly replenished my hope in humanity when that ran low several, several times. Locally in Seattle, the Crip Women Supper Club, D Center at the University of Washington, and the University of Washington Disability Studies Graduate Students kept me fulfilled and gave me breaks from the isolation that being a disabled academic so often engenders.

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Finally, my research was conducted on unceded Indigenous land of the Coast Salish people, specifically the Duwamish tribe, and Indigenous people are still there and under-recognized. I continually benefit from colonization that displaces and erases Indigenous people and histories. In acknowledging this land, I call for all readers to more intentionally steward the land responsibly, build relationships with Indigenous people, and actively recognize and support their contributions and customs.

Table of Contents

Chapter 1: Questioning Stories of Design and Disability: When Personal Reflection Motivates Research Program	1
1.1 Introduction	1
1.2 Definitions	4
1.2.1 Professional Design	4
1.2.2 Disability	5
1.2.3 Disability Studies	8
1.2.4 Access	8
1.3 Research Questions	9
1.4 Dissertation at a Glance	10
1.4.1 Chapter 2: Perspectives, Critiques and Reworkings of Professional Design, Accessibility and Disability	10
1.4.2 Chapter 3: Disabled Person or Professional Designer? The Difference Empathizing Makes	12
1.4.3 Chapter 4: Reimagining Recognition and Disability in Professional Design	13
1.4.4 Chapter 5: Interdependence as a Guide to Recognize Access Work	14
1.4.5 Chapter 6: Toward Centering Access in Professional Design	15
Chapter 2. Perspectives, Critiques and Reworkings of Professional Design, Accessibility and Disability	16
2.1 Introduction	16
2.2 Design for Accessibility	18
2.2.1 Universal Design Strategies	20
2.2.2 Disability-Specific Design Strategies	25
2.2.2.1 User-Sensitive Inclusive Design/Design for Dynamic Diversity	26
2.2.2.2 Ability-Based Design	26
2.2.2.3 Design for Social Accessibility	28
2.2.2.4 Design for User Empowerment	29
2.2.3 Accessible Design Activities	30

2.2.3.1 Scaffolding	31
2.2.3.2 Tool and Technique Adaptations and Flexibility	33
2.2.3.3 Human Assistance	36
2.2.3.4 Reflection	37
2.2.3.5 Remaining Limitations	37
2.3 Professional Design Critiques from HCI and STS Scholarship	40
2.4 Adaptations by People with Disabilities	45
2.5 Recognizing Under-Told Perspectives in HCI	52
2.6 Methods	54
2.6.1 Chapter 3 Method: Essay	55
2.6.2 Chapter 4 Methods	58
2.6.2.1 Interview Method	58
2.6.2.2 Workshop Method	60
2.6.3 Chapter 5 Methods: Field Observation and Interaction Analysis	64
Chapter 3. Disabled Person or Professional Designer?: The Difference Empathizing Makes	67
3.1 Introduction	67
3.2 What is Empathy?	70
3.2.1 Empathy in Contemporary HCI	72
3.2.2 Empathizing a Person with Disabilities	73
3.2.3 Critiques: Where Empathy Goes Wrong	74
3.3 Dispatches from Industry: Stories of Simulation and Personas in Design	77
3.3.1 Simulation: The Case of the Voting Booth	77
3.3.2 Personas: The Case of Adapt-o-Pack	81
3.4 The Slipperiness of Empathy	85
3.4.1 Displacement 1: Denying the Authority of Disabled Experience	86
3.4.2 Displacement 2: Treating the Disabled "User" as a Spectacle	88
3.4.3 Displacement 3: Rendering Designers as Nondisabled and People with Disabilities as Nondesigners	89
3.5 Discussion	91

3.6 Conclusion	92
Chapter 4. Biographical Prototypes: Reimagining Recognition and Disability in Professional Design	94
4.1 Introduction	94
4.2 Empirical Research	95
4.2.1 Biographical Prototypes	97
4.2.2 Workshop Preparation	98
4.3 Lessons at the Workshops	101
4.3.1 Introductions and Set Up	101
4.3.2 Encountering Stories and Biographical Prototypes	102
4.3.3 Co-Creating Biographical Prototypes	103
4.3.4 Concluding Discussions	107
4.4 Workshop Reflections	108
4.4.1 Challenging Confined Stories: On Pressure to Tell Happy Stories	108
4.4.2 Disempowerment, Exhaustion, and Disinterest	111
4.5 Discussion and Conclusion	113
Chapter 5. Interdependence as a Guide to Recognize Access Work	116
5.1 Introduction	116
5.2 Independence and its Limits in Disability Activism	117
5.3 Interdependence	118
5.4 Empirical Research	121
5.5 Findings	121
5.5.1 Building Access Interdependently	122
5.5.2 Shifting Labors of Access	126
5.5.3 Uneven Access-Building	129
5.6 Discussion	134
5.6.1 Mundane Attunement	136
5.6.2 Non-Innocent Authorizations	137
5.7 Conclusion	138
Chapter 6. Toward Centering Access in Professional Design	140

6.1 Introduction	140
6.2 Centering Access	146
6.2.1 Centering Access Must be Equitable	149
6.2.2 Centering Access Must be an Ongoing and Collectively-Kept Commitment	151
6.2.3 Centering Access Will be Non-Innocent	152
6.3 Conclusion	154
References	156

Chapter 1. Questioning Stories of Design and Disability: When Personal Reflection Motivates Research Program

1.1 Introduction

“Our founder created the first OXO peeler for a pair of hands he loved more than his own. When his wife struggled with a traditional metal peeler, he knew there was a better way, and he created it” [OXO n.d.].

So says OXO’s website about Sam Farber, a founder of the popular kitchenware brand. It turned out that his wife, Betsey, had arthritis which impacted the use of her hands, making gripping the narrow handles on ample kitchenware difficult and painful. OXO has since released a slew of tools as part of their Good Grips line of products, which are widely recognized for being more comfortable to use (See Figure 1.1). OXO’s vegetable peeler was inducted into the Museum of Modern Art’s permanent Architecture and Design collection in 1994, and it was recently recognized for its lasting impact on the kitchenware industry and universal design. These are just some of the ways design pundits have celebrated the OXO kitchenware story as a paradigmatic case of disability and design gone right—illustrating how designing for someone with disabilities can result in products that appeal to everyone [Center for Excellence in Universal Design n.d., Holmes 2018, Museum of Modern Art 1994, Wilson 2018].

This story is powerful, and I did not escape its influence. In my seven years thus far occupying space as both a disabled person and an accessibility researcher of human-computer interaction (HCI), I have listened to this story, told this story, and taught this story. Indeed, lecturers promoting accessibility, or designs useable by people with disabilities, populate their slides with OXO’s exemplar. To me, the story was so powerful

because, in my experience, behind closed doors, away from the lectures, accessibility pundits, including myself, lament how hard it is to get people who have power in high technology firms to enforce that basic accessibility standards are met before products are released. They may be well established, but those standards still too rarely materialize at product launch. But OXO provided an ‘otherwise.’ The company demonstrated that accessibility may not merely be the checklist of requirements for use by a minority of users [United States Access Board 2002, World Wide Web Consortium 2008]; it might comprise widely praised ergonomic designs intended for use by everyone.



Figure 1.1: A set of kitchen tools made by OXO, showcasing the large grips of each tool.

But stories like OXO’s are not unique. Narratives of disabled people’s impact on design are gaining recognition. Whether dictating a text message, preparing dinner or brushing our teeth before bed, many of us regularly benefit from designs influenced by people with disabilities. In fact, several commonplace products employed to complete such activities

were originally invented to be specialized devices to provide some sort of access for people with disabilities [Hendren 2013, Pullin 2009, Ladner 2015]. Decades before voice-controlled computers, smart speakers and appliances adorned shelves and kitchen counters, people with motor disabilities controlled computers with speech, and the first electric toothbrushes were pharmaceuticals meant to assist people with tremors to independently maintain dental hygiene. And in the field of HCI where interpreting and responding to user needs has long been priority, these stories exemplify not only the application of the discipline, they also evidence that people with disabilities can influence entire industries .

Returning to OXO's story, almost 30 years after the company's founding, disabled design activist Liz Jackson wondered who Betsey Farber was. In OXO's version, she was referred to as a pair of hands, arthritic hands which inspired Sam Farber and his company's inventions. Retired from a career in architecture, Betsey Farber gave Jackson an interview and during their conversation, she reflected, "The general understanding was of the brilliance and kindness of Sam who made these tools for his poor crippled wife so she could function in the kitchen. I will probably go down in history as having arthritis rather than having the conceptual idea of making these comfortable for your hand" [Jackson 2018].

This story was shocking to me. At the time of its publication in Spring 2018, I had spent several years reading, and attempting to practice feminism and disability studies. Amplifying voices of people who are systematically marginalized, especially people with disabilities, had long remained of paramount importance to me. In my role as an accessibility researcher of HCI, I had become well known at my institution for causing epistemic trouble. I challenged researchers to take seriously the messages of disabled

activists, writers and friends, long before inviting disabled people into their research as participants. I urged lecturers to incorporate readings from the field of disability studies into their curricula, regularly supported disabled students, and worked on committees to revise departmental policy to become more inclusive. But Betsey Farber and Liz Jackson taught me that I still asked too few questions. I did not assume that Betsey had done anything more than inspire OXO's designs, which I reach for daily in my own kitchen. I was researching how to increase the accessibility of professional design activities. But I hadn't yet taken seriously the adaptation work of people with disabilities as relevant for my research. I assumed this topic to be a relatively novel problem, with other HCI researchers working here and there on different areas within. But as I hope I demonstrate through this dissertation, being open to unlearning assumptions about what is happening (or not, in this case), and about who is well suited to rework design can be transformative.

1.2 Definitions

This dissertation engages several concepts which have been defined and contested by numerous scholars. Below, I will define and thus constrain four—professional design, disability, disability studies, and accessibility—to the ways I am thinking about them.

1.2.1 Professional Design

Beginning with professional design, I use this phrase to describe an expertise formalized through company-produced and academic institution-minted training, which leverages activities such as identifying and understanding users, brainstorming, prototyping, evaluating and teamwork to what science and technology studies scholar Lilly Irani argues allows, “corporate workers to tell stories about the lives of potential customers and imagine different futures for them” [Irani 2018]. People I call professional designers are those with

the word ‘designer’ in their job title, those who work with designers, and those who teach or are guided by design instruction. The institutions enfolded into professional design teach design, and/or employ or contract designers, And I constrain the objects of design to refer to the development of mass-produced technologies that the field of HCI informs.

I consider myself a professional designer. As such, I endeavor to use language such as ‘we’ and ‘us’ when articulating critiques and making recommendations to recognize my participation and acknowledge my complicity.

1.2.2 Disability

By ‘disability,’ I borrow from disabled activist Mia Mingus [2011] who delineates two types. The first is what she calls descriptively disabled. This refers to people whose bodyminds [Schalk 2018] either exist and interact with the environment, or are perceived to do so, in such a way that their full participation is systematically hindered or not recognized according to societal norms [Davis 1995, Kafer 2013, World Health Organization n.d.]. The second type, politically disabled, represents the enfolding of descriptive disability into one’s identity, using such experiences to makes sense of systems of power, and potentially to evidence desired change. Politically disabled people have also built a culture around disability identity [Kafer 2013, Mingus 2011].

Some word choices in my disability definitions were intentional. For example, there is a difference between ‘hindered’ and ‘not recognized;’ many definitions frame disability as self-evidently problematic. While people with disabilities may be ‘hindered,’ such experiences are not universal. For example, disability studies scholars including Alison Kafer note that disability is not universally negative. Some aspects of living with disabilities are, as I will show, positive, and everywhere in between, yet are seldom recognized as

legitimate experiences a disabled person can have. With this in mind, disability is not just defined by hindrances, but is also characterized when non-normative bodymind participation goes unrecognized.

Ultimately, I draw out both definitions to clarify that I write this dissertation as a politically disabled person and I foreground scholarship and activism by politically disabled people. But when I use the term ‘disability’ or ‘disabled,’ I refer to people who have that lived experience regardless of whether they make sense of disability politically or not.

As it is contested, I want to clarify how I write about disability. First, a note about the opposite; I refer to people who do not have disabilities as nondisabled. As disabled writer Sharon Waschler [2012] explained, centering ‘disabled’ to describe those who are not disabled challenges disability’s frequent relegation to the periphery where it is not leveraged to describe other things. Common substitutions including ‘able-bodied’ center abilities as superior, supporting deficit conceptions of disability as a lack of abilities.

Second, I use the word ‘disability’ to write about disabilities. As creator of the #JustSayTheWord campaign, disabled activist and performer Lawrence Carter-Long explained [King 2016] that when alternative language such as ‘differently abled’ or ‘diverse abilities’ substitute the word ‘disability,’ disability is erased. Instead, disabled activists argue it is a difference that matters, and its naming is important for transforming negative connotations to also reflect the pride and culture characteristic of disability communities [Kafer 2013].

Third, I use both identity-first (‘disabled people’) and person-first (‘people with disabilities’) language in my writing. However, my language choices are intentional. Some

people with disabilities prefer person-first language. This preference has roots in the 1970's disability rights movement when activists insisted that their humanity be recognized foremost. And some people with disabilities do prefer person-first language, so I use it sometimes. Now, identity-first language is preferred by many disabled activists, but many disabled people are encouraged (often by nondisabled people) to use person-first language instead. This has resulted in identity-first language becoming a political statement of claiming disability as part of one's identity. For example, autistic activist and lawyer Lydia X. Z. Brown [2011] argued in favor of identity-first language as follows:

'Autistic' is another marker of identity. It is not inherently good, nor is it inherently bad. There may be aspects or consequences of my identity as an Autistic that are advantageous, useful, beneficial, or pleasant, and there may be aspects or consequences of my identity as an Autistic that are disadvantageous [sic], useless, detrimental, or unpleasant. But I am Autistic...These are not qualities or conditions that I have. They are part of who I am. Being Autistic does not subtract from my value, worth, and dignity as a person. Being Autistic does not diminish the other aspects of my identity. ... Some Autistic people choose to engage more actively with Autistic culture and community, and others would prefer not to involve themselves in the larger community. ... It [identity-first language] simply shows the importance assigned by an individual to the various aspects of that individual's identity. But these factors remain equal as inherent parts of that individual's identity regardless of the individual's choice to tap more deeply into one or another of those aspects and not others.

In deference to individual preferences, when referring to individuals, I endeavored to use the words they used to talk about themselves. I asked them specifically how they talk about

their disabilities and other aspects of their identities. But when writing generally about disability, my usages of identity-first language are meant to honor activists who are reworking disability to refer to a legitimate, even desirable, life experience.

1.2.3 Disability Studies

Throughout this dissertation, I draw heavily on disability studies. This academic discipline studies the meaning, nature, and consequences of disability, and has been found to be a useful discipline from which HCI researchers can rework accessibility in professional design [Mankoff *et al.* 2010]. It importantly foregrounds first-person perspectives of disability by disabled people and challenges conceptions of disability that cast it as a primarily negative life experience that is best minimized, cured, and/or prevented [Society for Disability Studies n.d.]. I also reference disability activism. Disability studies is itself a form of activism that wedged its way into the academy from the 1970's disability rights movement. However, a disability studies perspective recognizes that first-person perspectives should foreground academic legitimacy. As such, in deference to the many voices who have been prevented from entering, oppressed by, and pushed out of the academy through violences of minimizing and erasure which have been named academic ableism [Dolmage 2017] and epistemic exploitation [Berenstain 2016, Ymous *et al.* 2020], I consider writing from disability activism as important to my work as that which is published as disability studies scholarship.

1.2.4 Access

By defining 'access,' I also point out two ways of thinking about it. First, HCI scholarship typically treats access as a physical state, a technological configuration with a certain degree of fixity which allows someone with disabilities to use a technology to the same

degree a nondisabled person could (e.g., a feature might be ‘accessible’ or ‘inaccessible’). This is evidenced by numerous sets of standards including the Web Content Accessibility Guidelines and Americans with Disabilities Act Accessibility Guidelines [United States Access Board 2002, World Wide Web Consortium 2008] which have done great work to encode access into technologies and workflows. This definition of access is also threaded through a series of principles and practices that HCI scholars have come up with to sensitize designers to design technologies which are accessible, some of which I will provide an overview of in Chapter 2. However, one of the key lessons of this dissertation will demonstrate some limitations of assuming fixity, particularly around how access is built by people with disabilities and their companions. But since reworking ‘access’ evolves throughout this dissertation, I often use the term according to this first definition.

The second definition of ‘access,’ which I will evidence particularly in Chapters Five and Six, is a process, an effortful and moving assembly of actions done to enable participation by descriptively disabled people. With this shift in ontological status, moving from noun to verb, I again draw from disability activism and disability studies scholarship [Access-Centered Movement n.d., Fritsch *et al.* 2016, Hamraie 2017, Schlesinger 2017, Titchkosky 2011].

1.3 Research Questions

Once I began to think with disabled design activists like Liz Jackson, I soon understood their passion for uncovering design work by people with disabilities like Betsey Farber. Researching accessibility without bringing close the contributions and practices of people with disabilities, I was, if tacitly, assuming that as a designer and researcher, my professional training made me an authority on access and disability. As such, I undertook this dissertation research as an attempt to rework notions of who defines and is credited

for doing access work and for influencing designs meant to benefit people with disabilities.

In this dissertation, I argue that professional design often casts people with disabilities narrowly as users of technology, yet their creative practices and lived experiences can inform the profession.

To make and respond to this argument, I asked two questions. They are:

- (1) How are people with disabilities cast in media which communicate the methods and experience reports of professional design?
- (2) How can lived experiences and creative practices of people with disabilities impact Professional Design regarding who can design, what counts as design, and how design should be done?

To explore these questions, this dissertation foregrounds lived experiences of people with disabilities to bring close their contributions to design and in turn, to inform design practices that recognize such contributions and aim to nuance disability as generative to professional design.

1.4 Dissertation at a Glance

1.4.1 Chapter 2: Perspectives, Critiques and Reworkings of Professional Design, Accessibility and Disability

In Chapter 2, I overview literatures important for establishing a theoretical underpinning for the research this dissertation intervenes in and takes up. The chapter opens with a brief overview of professional design and some of the ways its pundits are leveraging the

profession. In this brief description, I demonstrate that professional design promises to be relevant and applicable to effecting positive change in numerous cultural and geographic contexts, one being increasing quality of life of people with disabilities.

The theoretical underpinning begins with a summary of some principles and practices called design for accessibility. This umbrella comprises both conceptual descriptions and practical activities HCI scholars have published to sensitize professional designers to designing accessible technologies, as well as to make the work of professional design more accessible for disabled participants.

The second section provides an overview of critiques of professional design from HCI, science and technology studies (STS) and disability activism. These interventions contest some promises of professional design, namely the promise that the field has the expertise to relieve many social inequities through technology development and deployment. The analyses trace the circulation of power through multiple geographic contexts, drawing out some ways professional design bounds certain types of labor as innovative examples of the profession's potential, and others outside its auspices. These scholars provide an important foundation for the argumentative essay presented in Chapter 3 on how the boundaries of professional design similarly cast disability outside.

The third section reviews some disability studies and STS research to reveal the constant worldbuilding disabled people actually do. Named *crip technoscience* by disability studies scholars Aimi Hamraie and Kelly Fritsch [2019], the section traces some examples of disabled people modifying, repurposing, and inventing objects to get by in their everyday. These adaptations have intellectually expanded the ways technology and bodyminds are understood, described, and represented. They trouble definitions of assistive technology as primarily functional, to introduce types of use (and nonuse) which express disability pride

and culture, and resist ableism enacted through for example, the capitalistic commoditization of medical equipment.

The fourth and final section of the theoretical underpinning returns to HCI, and specifically feminist interventions, which seek to bring close under-told stories and labors which have contributed to professional design. Taking up practices of design from craft to digital prototyping, these interventions question who is absent in professional design and uncover meaningful but sidelined contributions. Through historical traces and uncomfortable absences, designs aim to recognize and better represent the diversity of people who have scaffolded the field. These practices underpin the research I describe in Chapters 4 and 5.

Chapter 2 concludes with an overview of the methods I undertook to conduct the research presented in Chapters 3 through 5.

1.4.2 Chapter 3: Disabled Person or Professional Designer? The Difference Empathizing Makes

In Chapter 3, I address my first research question: how are people with disabilities cast in media which communicate the methods and experience reports of professional design?

To do this, I contribute an argumentative essay that takes up two publicly available cases of professional designers' attempts to understand users with disabilities. Often couched as empathizing, I demonstrate how acts of coming to know users with disabilities by designers can other them to the outside of professional design practice. Ironically, this distance is amplified by the very efforts to bring people with disabilities close. As I will outline in detail, empathy-building techniques premise on a presumed separation of

empathizer and empathized. As such, even intentional understanding undertaken without reworking the structures through which empathy-building is conducted can mean that designers maintain privileges to step in and out of disability experiences at will, and may maintain the power to interpret them into design contributions while people with disabilities' work is pejoratively named as inspirational. From these cases, I recommend that professional design more explicitly recognize the ways disabled people contribute to design.

1.4.3 Chapter 4: Reimagining Recognition and Disability in Professional Design

Chapter 4 details the first exploration of my second research question: how can lived experiences and creative practices of people with disabilities impact professional design regarding who can design, what counts as design, and how design should be done?

Specifically, I introduce an activity called biographical prototypes. The activity combines storytelling from disability justice activism with prototyping techniques to recognize design contributions by people with disabilities. As first executed in design workshops, the activity inverted prototyping practices from their common purpose, to elicit feedback for design solution refinement. Specifically, it instead positioned prototypes as physical manifestations of under-told stories for encounterers to listen to and recognize. In doing so, this activity accumulated stories of design by people with disabilities, and opened opportunities for listeners to materialize, recognize, and rework how disability is cast in professional design. One poignant lesson opened by biographical prototypes regarded our unconditional celebration of design contributions by people with disabilities. Specifically, while workshop attendees were awed by others' stories of design from their own lives, they also wanted to share the exhaustion and disinterest that went into their making. Indeed, the stories and objects that underpinned biographical prototypes often responded to

prejudice against people with disabilities, or structural ableism that necessitated personal adaptation. Instead, workshop attendees wanted their individual stories to be celebrated while also urging those working in design and technology professions, who may be empowered with resources and influence, to effect larger-scale change.

1.4.4 Chapter 5: Interdependence as a Guide to Recognize Access Work

The second exploration of my second research question is detailed in Chapter 5 and aimed at widening recognition of contributions by people with disabilities. Taking lessons from biographical prototypes, I wanted to recognize contributions by people with disabilities without enforcing them into design language and practices or alluding that accessibility is solvable by disabled creativity alone. As such, the second intervention takes up interdependence from disability justice activism—an understanding that relationships are mutually reliant—to analyze field observations of disabled and nondisabled people assisting one another to complete tasks and do so accessibly, what we call building access. As such, a basis of interdependence, with its assumption of mutuality, helps us give credence to often-erased work done by people with disabilities in everyday interactions. The chapter reveals access work to be mundane and ongoing, and to both open up and foreclose disabled ways of sensing in the world, what I call non-innocent authorizations. In other words, an interdependence frame, by focusing on how people relate with one another while explicitly keeping notice of contributions of people with disabilities, not only brought close important creative practices which could be useful for professional design but also drew attention to the ways access-building can be ableist, in moments when dominant forms of labor, like seeing, open up worlds for someone instead of with someone. Interdependence reveals that crediting and indeed access work itself will not be made perfect by naming contributions. Rather, attending to the access of labor and to the

laborers themselves will require ongoing accountability. These lessons informed my recasting of access according to the second definition I shared above, as an ongoing process, and my exploration of what that might mean as applied in professional design contexts (Chapter 6).

1.4.5 Chapter 6: Toward Centering Access in Professional Design

In conclusion (Chapter 6), I bring together the insights from Chapters 3 through 5. I discuss how they evidence that people with disabilities are capable of, and continuously doing work that could be read as design. I show how their design work expands what we might think of as design and the ways it should be done. Regarding the latter (how design should be done), I draw specifically on the ways disabled interlocutors work to build access. Noting this work as ongoing, collective, and non-innocent, I provide a preliminary outline of some ways professional design can center access from its current periphery in the field in hopes of scaffolding more consistent and explicit recognition and inclusion of people with disabilities in professional design.

Chapter 2. Perspectives, Critiques and Reworkings of Professional Design, Accessibility and Disability

2.1 Introduction

As a reminder, in this dissertation, professional design refers to people who have the word ‘designer’ in their job title, those who work alongside designers, and those teaching and learning design. Professional design institutions hire designers, and the objects of professional design include the types of technology that HCI informs.

“Embracing human-centered design means believing that all problems, even the seemingly intractable ones like poverty, gender equality, and clean water, are solvable” [IDEO.org 2015, p. 12].

Professional design promises designers they have skills to address many challenges. Pundits argue its commitments to building deep empathy with users and creatively and iteratively solving problems give the field traction to uniquely address real-world challenges [IDEO.org 2015]. As the quote above suggests, professional design promises more than profit; it promises that design can help build a better world [Anaissie *et al.* n.d.]. One example of professional design put to use for social good is IDEO.org which applies its version, called human-centered design, toward improving the lives of those living in poverty. Similarly, professional design instruction facilitates student engagement with marginalized populations and urgent challenges to build skills in what IDEO calls “social innovation,” a design program they believe to be applicable across many industries and geographies [IDEO.org n.d. A]. Whether leveraged to empower refugees to rate the support they receive (or don’t receive) from humanitarian aid organizations, or to teach financial literacy to Latinx families [IDEO.org n.d. B and C], professional design’s potential is

argued to be a catalyst of justice.

In professional design, people with disabilities are no exception among those deemed marginalized and well suited for design intervention. Professional designers recognize that people with disabilities are systematically disadvantaged, often by design itself [Holmes 2018, Microsoft 2016 B]. As such, over the last few decades, a subfield that I call design for accessibility has circulated a variety of principles and practices aimed at sensitizing designers to needs of people with disabilities, to promote the design of technologies which are accessible to them. In this way, professional designers seek to widen the promise of the field's potential to include promoting justice for people with disabilities through greater access to technology.

In this theoretical underpinning of my dissertation, I will first provide an overview of some principles and practices professional designers have published in attempt to extend professional design's promise to people with disabilities. That is, I will demonstrate how this subfield, which I call design for accessibility, has positioned professional design as a tool for increasing access to technology and, more broadly, information and societal participation.

Next, I will delve into two critiques of professional design by disability activists, HCI scholars, and science and technology studies (STS) researchers. These perspectives caution that efforts like design for accessibility may address some inequities while ultimately still positioning systematically disadvantaged people narrowly in relation to professional design. In other words, while seeking to better include people with disabilities, the elite, corporate values of professional design may narrowly classify them and the types of work that count as professional design. My overview of these critiques specifically underpins Chapter 3, where I dive deeply into a professional design activity to explore how it casts

people with disabilities.

Next, I will turn to critical disability studies and STS scholarship, which offer rich accounts of, and language for, characterizing creative work done by people with disabilities in their daily lives. Called *crip technoscience*, I will share some examples from HCI and disability studies of alterations people with disabilities have made to get by in their everyday lives. This literature argues that within professional design, and even possibly design for accessibility, we may be missing important perspectives from people with disabilities that point to ongoing and meaningful contributions they make to professional design.

These literatures suggest that leveraging professional design for the purposes of increasing access may be more complex than increasing representation of users with disabilities and adapting design activities. Indeed, recent work by scholars of HCI, STS and critical disability studies argues that professional design itself may need reworking, and that the lived experiences and practices of people with disabilities may be a fruitful place to begin. As such, I conclude this theoretical underpinning with work from HCI, media studies and disability activism that is retelling stories of design while centering the voices of, and contributions by, people with disabilities.

Finally, the chapter concludes with an overview of the methods I undertook to complete the original research offered in this dissertation. Spanning argument through essay, to workshops, to observation, my mixed methods approach offers a multiplicity of vantage points through which I bring together disabled people and professional design.

2.2 Design for Accessibility

Recognizing that professional design often leads to technology development that excludes

people with disabilities, scholars and practitioners have published principles and practices aimed at keeping the disabled user in mind, which I collectively call design for accessibility. These guides vary in their terminology and how much structure they offer, but they unite in their aims to meet unique needs of users with disabilities and promote accessible design outcomes.

The interventions of design for accessibility take two forms. The first subset of design strategies consists of guiding principles meant to orient designers to people with disabilities and priorities they should maintain through their process to end with an accessible design. This subset is further divided into design strategies that aim to enfold accessibility into mainstream design, often called universal design, and strategies that aim for more individualized design solutions to address the unique needs of people with disabilities. The second subset of literature is still aimed at arriving at an accessible design outcome, but I overview them distinctly for the details they provide regarding how professional design activities can be adapted to be more accessible for people with disabilities. In describing these adaptations, I acknowledge that some of this research does promote the disabled person as designer, which particularly complements the work I set out in this dissertation.

In this synthesis, I will show that design for accessibility strategies and activities have made important strides toward promoting accessibility. But they still often demonstrate one or both of the following shortcomings. First, many remain focused on ensuring designed outcomes are accessible, rather than also attending to the accessibility of the tools, techniques and cultures of design. Second, many intend the strategies and practices of design for accessibility to function as disability awareness tools for designers, or activities for participants to provide feedback. As consequence, much design for

accessibility research may, if tacitly, send the message that designers may not have disabilities.

2.2.1 Universal Design Strategies

The first design strategies evolved in parallel but have the same aim, to encourage designs that are useable by the widest variety of people. Commonly known in the United States as universal design, parallel movements in mainland Europe and the United Kingdom offered similar philosophies called design for all and inclusive design, respectively [Persson *et al.* 2015]. Proponents argue that universally designed technology is superior because it allows nondisabled and disabled people to use the same technology. For example, specialized technologies built explicitly for use by disabled people are often more expensive [World Health Organization 2018] and less aesthetically pleasing according to disabled users [Shinohara and Wobbrock 2011] than mainstream technologies. Universally designed technologies also provide opportunities for nondisabled and disabled people to work together, promoting societal integration [Persson *et al.* 2015].

Universal design strategies were published originally for architects by a working group comprising a mixture of US-based disabled and nondisabled people, and architects and other stakeholders. Universal design offers seven principles to guide design useable by the widest variety of users. They include:

1. equitable use, which means explicit design aimed at being useable by people who are systematically marginalized,
2. flexibility to be used in a variety of ways, such as scissors useable by left and right-handed people,

3. simple and intuitive design that does not require prior knowledge to use,
4. perceptible to users who obtain information through a variety of senses,
5. ability to recover from error without consequence to the user,
6. low physical effort, and
7. approachable in a variety of ways such as with a keyboard, mouse, or space for a wheelchair user to pull up [Story 2001].

Named in Western Europe, design for all complements universal design by outlining some tiered priorities designers should take on to ensure usability for the widest variety possible, with the aim of placing the lowest burden on people with disabilities. First, designers should create a technology that most people can use without adapting it. Second, it suggests designers create adaptable user interfaces. Finally, for increased access, designers should ensure their technologies are accessible by the assistive technologies a user may leverage in tandem with the original design [Stephanidis 2013].

Traced back to the UK, inclusive design again complements the previous two approaches, but specifically notes that inclusion is always evolving as we discover greater human variation and each person's unique needs. As such, inclusive design should continue to evolve. Inclusive design also emphasizes designs should integrate use by people with and without disabilities. [Clarkson *et al.* 2013, Persson *et al.* 2015].

Accessibility scholars have introduced and expanded a universal design approach in HCI. For example, they suggested that universal design does not actually mean one solution but instead challenges researchers to devise multiple mainstream solutions to account for

different contexts and a wider variety of users. Additionally, they recommended that rationales accompany each mainstream design solution to clarify the situations and user characteristics for which each is best suited [Stephanidis *et al.* 1998]. Abascal and Nicolle [2005] expanded this call to argue that addressing social, privacy and other ethics concerns fall under the auspices of taking up a universal design approach in HCI. For example, while technologies that monitor the whereabouts of people with dementia may meet universal accessibility guidelines, they argued that the ethics of monitoring and tracking people who may not be able to consent must also be considered during the design process [Abascal and Nicolle 2005].

Some companies such as Microsoft [Microsoft 2016 A and B] and institutions like Cambridge University [Inclusive Design Group n.d.] have packaged their design guides to be useable by professional designers (as opposed to the aforementioned academic articles). They augmented principles like those found in universal design, design for all, and inclusive design with specific activities for learning more about people with disabilities, and for navigating the design process while keeping the disabled user in mind. I overview these activities in this section since they are not explicitly meant to be accessible. Rather, like the other design for accessibility strategies reviewed here, their main purpose is to sensitize designers toward designing an accessible outcome.

Two features that set these toolkits apart are that they offer an orientation to disability and that they scaffold activities which aim to help a designer to better understand experiences people with disabilities may have. First, to introduce designers to disability, Microsoft links readers to their disability sensitivity training, and video profiles narrated by disabled people [Microsoft 2016 B].

Second, the Microsoft Inclusive Design Toolkit suggests designers iterate on their design

by imagining they have a situational impairment. Situational impairments refer to situations that decrease or prohibit an ability that is usually available to the designer. For example, someone may have use of one arm while carrying bags although they typically have two arms available for use. By consulting the Temporary/Situational Limit card in the toolkit's activity cards, a designer can imagine how they might have a related experience to someone with disabilities, even if temporarily (See Figure 2.1) [Microsoft 2016 A].

Cambridge University, another institution that circulates inclusive design materials, sells products to enhance empathy-building. Among their offerings are disability simulators intended to support designers in imagining what it is like to have disabilities (See Figure 2.2). Among these products are glasses that simulate the types of vision people with various vision disabilities have, and gloves that occlude tactile sensations. Designers may attempt to complete tasks with these simulators, to learn what it may be like to have the simulated disability and consequently, what design solutions might be accessible [Inclusive Design Group n.d.]. As with the principles described above, toolkits like those from Microsoft and Cambridge University outline priorities and phases, but this material is complemented with hands-on activities.

Uniquely, these toolkits provide another reason why incorporating accessibility into mainstream designs is beneficial. Whereas universal design advocates pointed out the ways their philosophy can foster integration of people with disabilities, Microsoft believes accessibility improves user experiences for nondisabled users as well. They, along with others [IDEO.org 2015], consider disability to be an extreme but rich case that exists on a spectrum of broader human variation, and which can elicit insights that can be scaled into solutions for everyone. For example, Microsoft Inclusive Design's mantra, "Design for one,

scale to many,” [Microsoft 2016 B, p. 34] emphasizes how accessibility need not just benefit people with disabilities. Rather, it provides a business case for coming up with innovative designs that will benefit all users.



Figure 2.1: Microsoft Inclusive Design Toolkit. This card describes four types of temporary or situational limits: can't see, can't speak, can't hear, and can't touch.

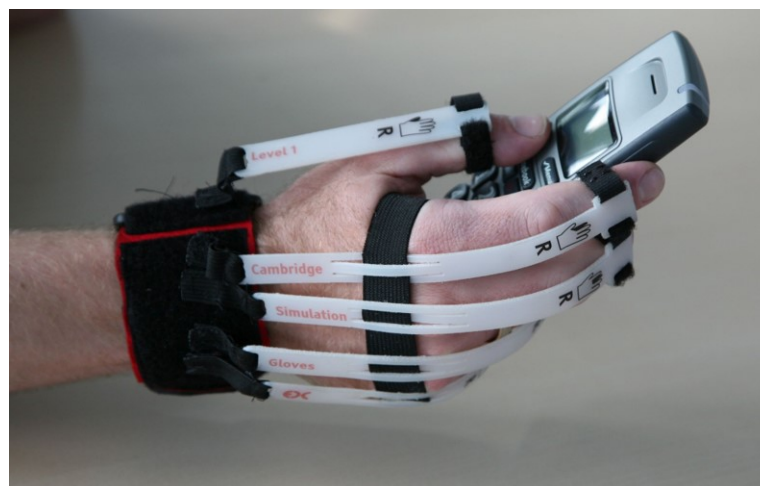


Figure 2.2: University of Cambridge, Inclusive Design Toolkit Simulation Gloves. The shape of the gloves restricts the abilities of otherwise able-bodied hands, representing the abilities of someone with hand-mobility disabilities.

In summary, universal design strategies aim to foreground needs of people with disabilities while ultimately integrating accessible design solutions into technology that is also useable by nondisabled people.

A shortcoming of approaches that seek to unite accessibility for people with disabilities with philosophies aimed at ensuring designs work for the widest variety of users is that disability may be obfuscated. For example, even though the seven principles of universal design were written by a contingent of disabled and nondisabled stakeholders, and even though they grew out of the disability rights movement, the word ‘disability’ is not written in the principles themselves. A designer could consult these principles without thinking of disability [Hamraie 2017]. Taking the sixth principle of universal design as an example, a designer may think of decreasing physical effort according to the amount of physical effort that social norms dictate a person should be able to expend, rather than taking into account the types of physical effort people with disabilities can make, or alternatives to physical effort altogether. Some researchers instead propose strategies that explicitly account for unique needs of people with disabilities, which are reviewed next.

2.2.2 Disability-Specific Design Strategies

The following sample of strategies briefly exemplifies a body of research that more specifically attends to ensuring access for people with disabilities. While proponents of accessibility believe the best case scenario is for mainstream technology to be accessible to the widest variety of people possible, some accessibility researchers note that people with disabilities do have unique needs that must be addressed intentionally, and argue that these strategies may avoid obfuscation of disability and help designers to ensure they are designing accessible technologies.

2.2.2.1 User-Sensitive Inclusive Design/Design for Dynamic Diversity

The first strategy, called user-sensitive inclusive design, advocates for human-centered design to take up a new paradigm, designing for dynamic diversity. This means that human-centered design should consider users to include people with and without disabilities, and should also account for individuals' shifting abilities over time and in different contexts. Proponents suggest mapping various abilities users may have along different dimensions, such as physical and cognitive abilities, to consider the spectrum of abilities their design should leverage [Newell and Gregor 2000, Newell *et al.* 2011]. Microsoft's Inclusive Design Toolkit recently released their persona spectrum which similarly encourages designers to develop user profiles with a variety of abilities and disabilities [Microsoft 2016 A]. In sum, user-sensitive inclusive design aims to account for human variation to close the gap between inaccessible off-the-shelf technologies and accessible but specialized technologies created primarily for use by people with disabilities and older adults [Newell and Gregor 2000, Newell *et al.* 2011].

2.2.2.2 Ability-Based Design

The next strategy, called ability-based design, endeavors to center people's abilities, rather than disabilities. To accessibility researchers Wobbrock *et al.* [2011], centering disability may distract some technology developers from creating accessible technologies, by keeping their focus on what someone cannot do rather than on what they can do. By centering ability and placing the onus of adaptation on systems rather than users, Wobbrock *et al.* [2011] believe ability-based design can account for more human variation, inclusive of people who do and do not have disabilities. Focusing on what a user can do provides avenues for technologies to adapt to the user's input and output options in ways that work best given their abilities.

Seven principles guide ability-based design:

1. designers should focus on abilities rather than disabilities,
2. designers should produce systems that adapt to users rather than expecting users to adapt to systems which are inoperable with the abilities they do have,
3. devices should be self or user-adaptable to provide tailored experiences depending on a user's abilities,
4. systems must be transparent when they adapt and give the user options to override any adaptations,
5. systems should monitor user performance and adapt accordingly (for example, if performance is poor given a configuration's predicted use patterns),
6. systems should sense context and adapt, as context may impact use just as abilities will, and
7. when possible, systems should be low cost.

Ability-based design inverts the ideals of universal design, which has been critiqued for reducing the complexity and variety of needs of all people, including those with disabilities, and for potentially misleading designers to design for 'everyone.' Ability-based design proponents believe this homogenization of users is reductionist and may not truly promote access for everyone. They seek instead to universally apply "design for one" [Wobbrock *et al.* 2011, p. 28] to produce designs that can adapt to individuals' unique user experiences while leveraging individual abilities.

2.2.2.3 Design for Social Accessibility

Design for social accessibility is deeply informed by empirical research with people with sensory disabilities. In their early work, Shinohara and Wobbrock [2011] noted that social factors seemed to be ignored during the design of assistive technologies, and that this bothered disabled technology users. Accounts of their interviews featured stories of disabled interlocutors being embarrassed about, or altogether abandoning, assistive technologies that sometimes worked well from a functional perspective, but which did not match their aesthetic or drew negative attention toward them. For example, some assistive devices like braille notetakers for blind users and hearing aids for hard of hearing users were larger than the sleek mobile devices their nondisabled friends used, and boasted unattractive visual designs, sometimes attracting unwanted attention. From this study, Shinohara and colleagues began to refine design for social accessibility, which attends to the design of technologies that should both be socially acceptable and functionally useable by both disabled and nondisabled people [Shinohara *et al.* 2016, 2018 A, 2018 B].

Design for social accessibility has three tenets:

1. that designers work with users with and without disabilities during the design process,
2. that designers make design decisions that explicitly address both important social factors and functional needs by all users, and
3. that designers engage in awareness-raising and reflection activities to attune themselves to social factors particularly salient for users with disabilities.

Recognizing that social and functional needs may conflict, design for social accessibility

offers a framework to guide designers. In this framework, social factors occupy one axis whereas functional needs occupy a perpendicular axis. At the negative-most corner, a design would be neither socially acceptable nor functionally accessible. In contrast, a design evaluated to fit in the diagonal corner would be both functionally accessible and socially acceptable. Designers can map feedback about design features on this plane to create a spatial representation of social and functional trade-offs they may have to make, depending on how a feature is designed. A set of methods cards [Shinohara *et al.* 2018 B] encourages designers to reflect on their personal experiences and apply that awareness to the design. For example, one card asks designers to recount whether they have observed a person with disabilities, whether they assisted or thought to assist the person and whether, looking back, they believe that person actually needed assistance. From this reflection, designers are encouraged to be aware of their assumptions and emotional responses, and to ideate on how to minimize the possibility that their design-in-progress could engender inaccurate and negative stereotypes about disabled people by both users and passersby.

2.2.2.4 Design for User Empowerment

Accessibility researcher Richard Ladner's [2015] design for user empowerment is a unique design strategy. Instead of proposing principles for creating accessible design outcomes, he argued that increased employment of people with disabilities in design fields will increase the accessibility of designs. Design for user empowerment stipulates that people with disabilities should be provided educational opportunities to cultivate technical skills and self-determination to solve problems, including those caused by access barriers that they encounter. Notably, some HCI researchers including Shaun Kane and colleagues [2014] also emphasized that involving people with disabilities as lab assistants (either students getting course credit or payment) is essential for designing accessibly.

Although not comprehensive, my review of user-sensitive inclusive design, ability-based design, and design for social accessibility exemplifies some strategies developed to help designers prioritize accessibility during the design process. Design for user empowerment uniquely posits that accessible design will benefit from increased employment of people with disabilities as technology designers. These approaches, and the universal design strategies, all emphasize accounting for users with disabilities. However, they often lack specific activities and techniques for working directly with people with disabilities to do design activities. Fortunately, some HCI researchers have shared their activity adaptations, detailed in the next section.

2.2.3 Accessible Design Activities

Though the professional design strategies reviewed above lay out multiple principles to facilitate the design of accessible technologies, their primary focus is to sensitize designers to the unique needs of people with disabilities. They attend less to questions about how to elicit feedback from users with disabilities. Since professional design encourages direct engagement with users, a review of research that has aimed to make design activities more accessible can complement these less concrete strategies.

The activities described in this review are largely gathered from two bodies of literature. The first is concerned with projects that invite people with disabilities to conduct professional design activities with designers and researchers. The second body of literature is concerned with increasing the accessibility of activities often associated with the maker movement, or activities that allow a novice to create something for themselves. However, rather than present these two literatures separately, I have instead reviewed articles according to the types of professional design adaptations they exhibit.

I have synthesized these activity adaptations into five categories. They include:

1. activities which scaffold learning of design and making skills,
2. tool and technique adaptations,
3. embracing flexibility,
4. human assistance, and
5. reflection.

The next paragraphs share examples that exemplify these five types of adaptations to professional design activities.

2.2.3.1 Scaffolding

Some researchers [Buehler *et al.* 2014, Buehler *et al.* 2015, Giles *et al.* 2018, Hurst and Kane 2013, Jelen *et al.* 2019, Li *et al.* 2019, Siu *et al.* 2019] have scaffolded activities to make them easier for participants with disabilities who may not have prior experiences with designing or using materials that are common in design workshops, such as art supplies and electronics . For example, in a workshop on accessible wearables, Williams *et al.* [2015] discovered that despite the presence of several theoretically accessible tactile materials, some blind participants did not engage. Scaffolding often includes several phases where researchers first learn what materials and processes will be most accessible, what tasks may present challenges, how those challenges will be worked around, and how to provide accessible examples and guided opportunities to explore materials and processes.

To exemplify how scaffolding might occur, Giles *et al.* [2018] carefully detailed their steps to teach and assist novice blind makers to create a wall hanging out of textiles and electronics. Before hosting blind makers, they met with blind people in the community. They learned that certain techniques like fine stitching and programming might be difficult or time-consuming, and that crafting with multiple materials while preventing short circuits could be unwieldy to keep track of tactually. Subsequently, they offered participants adhesive to connect materials, layered and insulated conductive components so materials could overlap without interfering with a circuit's functionality, and buttons that when activated, could record and play back sounds multiple times so participants could iteratively create sounds for their pieces without having to encode playback instructions in a program. Researchers assisted participants when they asked for help with specific tasks, such as when fine stitching was more effective for connecting certain materials, rather than glue, which was easier to apply. Finally, they constrained the textiles project to a wall hanging, which allowed the researchers to create a delimited spectrum of examples for the participants to follow. The first sessions were dedicated to teaching general principles of electronics, fabrics, and circuit building; individual project construction became the focus of later workshops.

Another scaffolding strategy provides time, expectation, and materials for disabled makers to create their own instructional guides. This gives them flexibility to document their learning for later reference in the format (whether handwritten, typed text, pictures) that best suits them [Buehler *et al.* 2015]. Finally, as part of scaffolding, researchers have developed tools to assist novices with disabilities to design and make more accessibly. Although they were created for disabled makers, these tools could be taken up in professional design to circumvent inaccessible activities. For example, tools have been created to support nonvisual development of various media including tactile graphics from

equations written in Excel [Hurst and Kane 2013], spatial layouts of web designs [Li *et al.* 2019], and 3D models [Siu *et al.* 2019]. Jelen *et al.* [2019] have developed materials and instructions to ease circuit-building with craft supplies like wood and fabric with the aim of increasing access for older adults, and Buehler *et al.* [2014] created tools to assist novices to 3D-model custom prosthetics.

2.2.3.2 Tool and Technique Adaptations and Flexibility

The second and third types of adaptation found in HCI literature on designing and making with people with disabilities comprise tailoring activities and increasing the flexibility of design sessions, respectively. First, researchers have shared some strategies for adapting activities and embracing flexibility when working with autistic and otherwise neurodivergent participants [Frauenberger *et al.* 2016, 2017, 2019 A, 2019 B, Gaudion *et al.* 2015]. For example, Frauenberger *et al.* [2017] presented a case study of participatory designing with an autistic child, Mia. During the design process, the authors recognized her love for Mario characters and incorporated a Mario theme, along with the toys she brought to design sessions, into design activities and the designed object. Researchers also learned that Mia appreciated routines so they established beginning and ending activities at each session, which reflected their progress. However, during one session when Mia expressed interest in doing an activity different from what the schedule called for, the researchers were flexible to rearranging activities. As such, they found that a roleplay activity intended to evaluate a prototype instead helped spark ideas that the subsequent prototype incorporated. They and other researchers working with children with disabilities [Hofmann *et al.* 2016] noted that incorporating free play and offering several tools, like LEGO bricks, with which children and other participants can experiment, can help children with disabilities better direct flexible design sessions.

Several researchers have adapted and invented design activities to be nonvisually accessible as well as to raise awareness about nonvisual forms of exploration. Of paramount importance, as noted by Researchers [Metatla and Cullen 2018, Cullen and Metatla 2018] organization systems made finding supplies easier nonvisually. Next, Researchers have implemented a variety of strategies for ideating and prototyping in ways that were more nonvisually friendly. For example, researchers have augmented traditional ideation which tends to be represented in 2D and with hand drawings by creating tactile versions of mockups [Morrison *et al.* 2017] and allowing participants to annotate sticky notes and paper prototypes with audio recordings [Metatla *et al.* 2015]. Metatla and Cullen [2018] and Metatla *et al.* [2019] recommended bodystorming over brainstorming. Although it was popularized outside of accessibility contexts [Stanford d.school n.d.], bodystorming is conveniently accessible for both blind and sighted children, as the activity facilitates codesigners acting out their ideas using physical objects and roleplay. Additionally, Brewer *et al.* [2018] and Sahib *et al.* [2013] used conversation among blind participants and researchers as a tool for sparking design ideas and guiding prototype exploration, respectively.

When working with children specifically, Metatla and Cullen [2018], and Cullen and Metatla [2018] incorporated play and participants' personal objects to make design sessions relatable, accessible and engaging. For example, they brought tactile objects such as stuffed animals to design sessions, to provide concrete and tactile representations of characters they incorporated into 2D storyboards of designs. In addition to tangible objects serving as props, such as stuffed animal representations of storybook characters, physical objects were key to including visually impaired people in prototyping. For example, Metatla *et al.* [2019] and Thieme *et al.* [2017] used LEGO bricks and tangible programming pods, respectively, to build and overview programs. Participants could

assign differently shaped and colored objects to represent computer science concepts like variables and functions, and they could physically connect objects to build programs. Furthermore, participants could overview code by visually and tactually tracing the physical progression of objects. Finally, researchers [Metatla and Cullen 2018, Metatla *et al.* 2019] explored how to establish blind codesigners as equal partners with sighted codesigners. Noticing blind children were often left out of classroom activities, they organized one activity led by the blind students where they guided sighted codesigners to both tour areas of their school and interact with prototypes while blindfolded. Researchers found that this guided exploration helped sighted students to take nonvisual exploration more seriously as a new form of sensory engagement, and helped to establish the blind students as equal partners in codesign.

Researchers have adapted workshop activities to focus less on verbal communication, and to be easier for people who have difficulty remembering things. For example, Galliers *et al.* [2012] ran participatory design workshops with people with aphasia and the associated paper described their process of adapting several group activities that traditionally involve verbal communication. Similar to Frauenberger *et al.* [2017], they learned that routines were helpful to reintroduce everyone to each other and to the purpose of the project at each workshop's outset. In this and other research [Kane *et al.* 2012], activities and communication were multimodal, with an aim to not constrain engagement based on people's ability to speak. For example, participants could communicate with gestures, by creating art [Lazar *et al.* 2018], or by pointing to images depicting positive or negative emotions to share feedback. Additionally, researchers have learned that as many activities as possible should be interactive. For example, interacting directly with prototypes and storyboards or watching video tutorials increased engagement and recall by participants with difficulty remembering things, as opposed to post interviews and surveys absent of

props [Galliers *et al.* 2012, Kane *et al.* 2012, Buehler *et al.* 2015]. Finally, to minimize distractions, researchers sometimes conducted workshop activities one-on-one with participants, noting that open workshop areas often produced distractions that prevented participants from expressing themselves [Galliers *et al.* 2012].

Designing with people with disabilities has taught researchers that each participant often has unique needs. Preconceived notions of what should be designed and how it should be represented during design sessions can interfere with creativity and participant agency. As such, conducting design sessions with a variety of tools and materials provides flexibility for facilitators to tailor activities and program schedules to individual preferences and strengths.

2.2.3.3 Human Assistance

Next, researchers have identified human assistance, the fourth professional design activity adaptation I overview, as a method for making design activities more accessible [Giles *et al.* 2018, Hofmann *et al.* 2016, 2019, Meissner *et al.* 2017, Parry-Hill *et al.* 2017]. For example, Meissner *et al.* [2017] invited disabled people to complete projects in a makerspace, and identified moments when participants assisted one another to circumvent inaccessible activities. Further, Parry-Hill *et al.* [2017] and Hofmann *et al.* [2016, 2019] have identified collaborators as being crucial for helping designers and people with disabilities to make affordable prosthetics that reflect available materials and adhere to safety best practices. In absence of many accessible design tools and techniques, and recognizing the potential for increased safety and creativity when people with different skills are invited as collaborators, these researchers argued that human assistance remains an important component of design for accessibility.

2.2.3.4 Reflection

Finally, researchers including Brulé and Spiel [2019] and Gaudion *et al.* [2015] are forthcoming that reflection is essential for designing with people with disabilities. Specifically, Gaudion *et al.* [2015] noted how reflecting on their perception that interlocutors were disengaged helped them to be open to their autistic interlocutor's activity preferences, rather than enforcing a narrower set of preplanned, structured design activities. Drawing on their careers largely spent doing participatory design with children with disabilities, HCI researchers Emeline Brulé and Katta Spiel [2019] posited that reflexivity must be a systematic activity of designers, as identity and contested facets of it, such as gender and disability, are continuously negotiated through design practices. Positioning identity and design as co-constructed not only places a particular emphasis on reflection as imperative for remaining accountable to how professional design may send messages about how people with disabilities can exist through design practice, it also points to an absent sector of accessibility, and professional design more broadly, insight into how design practice is co-constructed by people with disabilities themselves. According to Brulé and Spiel [2019] no one is ever simply present; everyone, including people with disabilities, shapes the design encounter and design itself. Engaging the impacts of their lived experiences on professional design may be a promising way to enrich the field's alignment with disability culture.

2.2.3.5 Remaining Limitations

Although they are thoughtfully curated, these activities have several intertwining limitations. First, though this review seems to point out many promising accessible design strategies, many of the researchers cited here acknowledge that there remain significant challenges for people with disabilities to participate. A few studies that have yet to be

mentioned here, and which have surveyed such challenges are Bennett *et al.* [2016 A and B], Hook *et al.* [2014], Hurst and Tobias [2011], Rajapakse *et al.* [2014].

Second, much of this research positions people with disabilities as users (with notable exceptions where the project was largely left open) [Hurst and Kane 2013, Jelen *et al.* 2019, Meissner *et al.* 2017, Li *et al.* 2019, Siu *et al.* 2019]. Although people with disabilities were invited to conduct professional design activities with designers and researchers, the purpose of these activities was to ideate and iterate specific accessible technologies. This limitation is two-fold. First, a literature review [Spiel *et al.* 2019] has pointed out the ways in which the structure of design projects often leaves little agency for people with disabilities to exert much power over the inception and direction of projects. Second, because these activities often gather feedback on the single project at hand, they often do not engage deeply with how people with disabilities are contributing to professional design more broadly. Important exceptions include Giles *et al.* [2018] and Buehler *et al.* [2015] who specifically recruited disabled participants to help them develop an accessible workshop program, as well as Kane *et al.* [2014] and Ladner's [2015] assertions that accessible design will be most possible when disabled people are better represented within the ranks of professional design. These limitations point to important areas for additional research that imagines participation extended beyond specific projects to the entire professional design process.

Third, drawing on the prior limitation, many of the accessible activities were superseded by more common ways of designing. Researchers have noted cultural and experience barriers that prevent people with disabilities from participating in design activities even when they are given accessible materials [Brewer 2018, Stangl *et al.* 2019, Williams *et al.* 2015]. For example, Brewer [2018] has noted that activities that are seemingly accessible for blind

participants, such as conversation, can quickly become inaccessible when the designs being talked about are not thoroughly passed to visually impaired participants, or when facilitators do not intervene to ensure that quieter participants can share their perspectives. Although some research has incorporated scaffolding [Buehler *et al.* 2014, Buehler *et al.* 2015, Giles *et al.* 2018, Hurst and Kane 2013, Jelen *et al.* 2019, Li *et al.* 2019, Siu *et al.* 2019], much of this infrastructure needs continued iteration to maximize the accessibility of instructions, tools and techniques.

Finally, HCI scholars have documented feelings of not belonging, and stigmas of interaction techniques like touch that keep people with disabilities hesitant to enter and engage in design spaces [Stangl *et al.* 2019]. For example, Metatla *et al.* [2015] noted that even when design materials were augmented with audio recordings, participants were drawn to interact visually with sticky notes by default. Additionally, Metatla *et al.* [2019] shared a paradox that although LEGO construction involves touch, the visual affordances of LEGO bricks allowed people who could interact with them visually quicker access to the bricks, and to changes in their assembly. This research teaches us that the presence of materials and careful attention to including people with disabilities cannot supplant the dominant culture of design [Avle *et al.* 2017, Irani 2018], which in this case prefers mass-produced methods and techniques of designing, like handwritten sticky notes [Irani *et al.* 2010 A] to accessible alternatives.

Despite their limitations, these adaptations deeply inform my research, and my research aims to build on them. However, the limitations are important in uncovering structural shortcomings of professional design, which may not be solvable by outfitting professional design sessions with people with disabilities and tailored design activities. For example, as Brulé and Spiel [2019] pointed out, people with disabilities shape design encounters, but

these contributions may not be adequately recognized. Fortunately, research in HCI and STS, along with disability activism, have investigated this paradox of a field that claims to embrace inclusion while failing to uphold those promises. I summarize these critiques in the next section.

2.3 Professional Design Critiques from HCI and STS Scholarship

Researchers of HCI and STS point out tendencies for the field of professional design to propagate its methods as universal, and caution about the field's power to enculturate people into these hegemonic methods with an altruistic guise. For example, in their paper offering postcolonial computing as an important lens for professional design to take up, Irani *et al.* [2010 B] asserted, "all design research and practice is culturally located and power laden, even if considered fairly general." Reflecting on several research programs to which they had contributed, the authors traced professional design's colonialist roots and ongoing practices, which, for example, supported the extraction of resources and exploitation of labor from systematically disadvantaged communities, and credited professional design for addressing poverty. Lilly Irani later named this uneven power distribution the "design savior" complex [2018], in which design is perceived to be the solution to widespread injustices. This is illustrated by the quote introduced at the beginning of this chapter, "Embracing human-centered design means believing that all problems, even the seemingly intractable ones like poverty, gender equality, and clean water, are solvable" [IDEO.org 2015, p. 12]. From this quote, we are reminded that irrespective of context, professional design may still promise to equip designers with the rhetoric and methods to distill design solutions and to argue them superior.

Indeed, as the previous section demonstrated, professional design shapes the world in more ways than transferring tools, techniques, and philosophies across national borders

[Avle *et al.* 2017, Irani *et al.* 2010 A and B], impacting people with disabilities among others. As disabled activists have shown through public demonstrations like the Capitol Crawl up the stairs leading to the United States Capitol Building, design decisions stipulate who can move through certain worlds and how easily they can do so [Hamraie 2017]. Though shocking, disabled activists struggling to ascend stairs represented just one of many and continuous encounters with architected barriers that hindered their freedom of movement. Given this reality, it might seem valorous for professional design to assume responsibility to conscientiously reshape the pervasive inaccessibility that is characteristic even of designs symbolizing purportedly democratic and equal opportunity institutions, like the United States government.

As I hinted throughout the section, however, the promise that professional design can create more accessible worlds, in response to the inaccessible ones it arguably influenced, may have consequences and limits. For example, while design for accessibility has paid substantial attention to ensuring design outcomes are accessible, less consideration has been given to how the internal workings of professional design may reproduce hierarchies that keep people with disabilities cast in primarily user roles. After all, who gets to determine what is right, or whether a design solution is appropriate? Those questions have not been explored deeply in most design for accessibility research. Consequently, this body of literature tends to uplift the professional designer leaders and facilitators of projects as the experts. Some critiques of professional design explore the uneven distributions of power in professional design fields and how this particularly affects people who are already systematically disadvantaged, a specific argument I unpack in Chapter 3. Where these critiques are not currently fleshed out well in HCI research from the perspective of people with disabilities, I turn back to the scholars introduced at the beginning of this section for lessons on consequences of transporting methods without challenging power distributions

in professional design.

Specifically, Lilly Irani and others argue that widening professional design's promise may actually promote the field rather than 'save' the diverse interlocutors it claims to [Irani and Silberman 2016, Irani 2018]. These critiques point out several shortcomings of professional design that sideline diverse perspectives, of which I will outline two.

First, the rhetoric and methods of professional design are often packaged to travel, indicating that they are universally applicable. This packaging legitimizes professional design as the right way to innovate, or to come up with a design solution. In turn, governments and non-governmental organizations alike, based in geographies exploited for resource extraction and hard labor, have taken up professional design in order to be taken seriously as creative innovators in global technology markets. Reflecting on ethnographies of the uptake of professional design in China, Ghana, Jamaica, and Silicon Valley, Avle *et al.* [2017] demonstrated some limitations of professional design's rhetoric and methods. For example, they traced the transformation of a public market called Huaqiangbei, in the Chinese city of Shenzhen, from before and through an uptick in the technical and entrepreneurial workforce. Where the market once drew hobbyist hardware enthusiasts for its informal, DIY and open-source offerings, upon turning to the methods and rhetoric of professional design, the priority shifted toward building partnerships with high technology firms to sponsor and ultimately mass-produce entrepreneurial projects. Consequently, patched-together computers powered with open-source hardware and software became taboo in favor of corporate-stamped devices. Research [Irani *et al.* 2010 B, Irani 2018, Avle *et al.* 2017] demonstrated that this prioritization rippled to affirm racialized means of production, among other inequities. By narrowing the design outcomes that count to those which rely on the labor of the Global South, non-Western economies

taking up professional design may re-cement their lower place in capitalistic production hierarchies, or relegate a new labor force to that status, in their attempts to rise above it. Ironically, interlocutors were not interested in reproducing professional design as it was done in the United States. For example, the Chinese government intended to challenge Western hegemony by sponsoring entrepreneurial ventures. But in this case, the rhetoric and methods of professional design that authorize Western high technology firms to stamp what they fund as ‘designers’ and ‘design solutions,’ respectively, could not be applied outside Silicon Valley without interlocutors in China, Ghana, and Jamaica adapting their practices to comply and ultimately uphold already dominant ideals of designing and design solution.

In summary, Avle *et al.* [2017, Irani et al. 2010 B, Irani 2018] teach us that the modes through which we attempt to accomplish our goals impact our outcomes. Relevant to my dissertation is that enrolment of people with disabilities into existing cultures and methods of professional design, which are already known to pose significant access barriers, may force people with disabilities to adapt within the constraints of the field rather than maintain power to urge designers to reimagine the field altogether.

The second critique of professional design that I will unpack concerns the design solutions that result from it. Looking at postcolonial analyses of professional design interventions, I learn how solutions may be alluring to the observer but unhelpful for the recipient. A researcher who interviewed Indian people living in a rural village learned that their design firm’s assumptions about the appropriate solution to clean that community’s water aligned with the product they could distribute, rather than the type of filtration system the community needed. In cases such as this, local communities are often sought as interlocutors in the design process, but the outcomes may instead fulfill the priorities of

professional design rather than those ostensibly in need [Irani *et al.* 2010 B].

Though less recognized academically, disabled scholars and activists have implored professional designers to stop crafting false narratives about disability in order to laud and justify the field's accessibility interventions. Such narratives, they argue, force disabled people to assume a narrow set of characteristics, such as being willing to serve as inspiration rather than empowered partner, to succeed in professional design. Keynoting the 2019 ASSETS Conference on Computers and Accessibility, anthropologist and disabled academic Karen Nakamura highlighted numerous well-intended but mismatched designs that at best elicit humor among disabled communities, and at worst do harm within them, such as by introducing safety risks when people don DIY prosthetics or when autonomous vehicles intervene in someone's path. Taking designs meant to enhance communication between signing and speaking individuals as an example, she pointed out how stories that would fit Irani's "design savior" narrative [2018] thread through the positioning of disabled people alongside technology. In these vignettes, designs that recognize limited vocabularies of American Sign Language signs are portrayed as innovative advancements in communication, whereas people who are fluent in the language and its associated culture are characterized as being at a loss without these devices [Nakamura 2019]. Disabled design activist Liz Jackson argued that as long as these mismatched inventions (which she calls "disability dongles" [Jackson 2019 A]) and tactics that portray disabled people inspirational recipients of design continue to be employed at scale, the benefit of professional design's solutions, and the methods by which they are achieved, will remain with those who are already among its ranks [Jackson 2019 B].

But these critiques also introduce conceptions of different, radical futures. Recognizing that professional design has opened up possibilities, these scholars believe that the

worldbuilding done within professional design can effect change that does not rely on ranking one way of designing over another. As such, they recommend that rather than aspiring to a type of professional design that authorizes and universalizes particular solutions and methods, local, culturally specific practices could serve as starting points for reworking the field. Outlining commitments of postcolonial computing, which complements the critical disability studies and feminist perspectives I take up here, Irani *et al.* [2010 B] and Avle *et al.* [2017] scope out possibilities when the structures of professional design are reworked with local knowledges: “Seeing the ways that design is culturally specific should allow us to broaden the conversation about what other practices can count as good design...This specificity is not a problem to be solved, but a reality that should be central to design practice” [Irani *et al.* 2010 B]. In the next section, I overview research from HCI and critical disability studies that documents what some of these “other practices” might be. Indeed, people with disabilities have been altering their worlds in response and resistance to inaccessibility, and continue to do so, and a key aim of this dissertation is to read such work as transformative for professional design.

2.4 Adaptations by People with Disabilities

Although this theoretical underpinning has thus far broadly reviewed principles and practices undertaken to sensitize designers to design for accessibility, it has also taught us that the local, situated practices often cast outside of professional design may offer the field a different type of access, one based on lived experiences and unconstrained by professional design’s universalizing methods [Avle *et al.* 2017]. As such, I turn to critical disability studies and HCI scholarship that documents creative alterations disabled people have made to get by.

To begin, disability-informed alteration, which may include activities of experimenting,

modifying, inventing and dismantling inaccessible infrastructures comprise what disability studies scholars Aimi Hamraie and Kelly Fritsch call *crip technoscience* [2019]. Crip technoscience politicizes alteration by people with disabilities as activist and resistant. This demarcation is made because the adjustments are intentional, material arguments for the legitimacy and generativity of disability-informed knowledge production. Importantly, the type of access crip technoscience engenders is not assimilationist so as to disappear disability, but explicitly brings it close in friction with ableism that often materializes through design's inaccessible methods, products, and rhetorics.

For example, disabled academic and writer Jillian Weise [2018] and disabled STS scholar Laura Forlano [2016] have documented how they rely on and simultaneously resist cultures where technical solutions are preferred (technical deterministic cultures with which professional design confers) through their use of prosthetics and diabetes monitoring equipment, respectively. Relying on these technologies for survival, they nonetheless resist the ways in which they involuntarily and non-transparently surveil their users. Weise depicted urgent concerns of disabled people, whom she calls 'common cyborgs' in critique of the argued mythical and mystical feminist and ostensibly nondisabled cyborg [Haraway 1991, Kafer 2013]. Relying on medical insurance to fund her prosthetic leg, Weise had to perform the prescribed amount of movement, not too little, which would define her as not ambulatory enough, but not too much, which could distress the equipment. In this case, her crip technoscience use patterns intervened in the feminist cyborg imaginary [Haraway 1991] as a material "common cyborg" way of interfacing with technology, just enough, to get by in her everyday.

Similarly, Forlano's crip technoscience [2016] concerned her experiments with interfacing diabetes monitoring equipment with her skin and clothing. Placements suggested by

manufacturers neglected local (feminine) contingencies including outfits, such as dresses, without obvious placement affordances like those offered by belt loops. Also not attended to with the product's design were the disparate demands of differing contexts. The minutiae of constantly checking her blood sugar at restaurants remained incompatible with close quarters, and the social expectations of cleanliness and the absence of medical equipment around food. Additionally, loud noises that shared potentially important changes in her biometrics could cast her as inconsiderate in quiet environments like movie theaters. Through making continual adjustments to the placement and settings of her equipment as she discovered new incompatibilities, Forlano then learned how she could disrupt universalizing discourses that ignored local contingencies to expand her resistance from how she intimately connected with her devices to how she affected marketing and distribution key to upholding the medical industrial complex which commoditizes healthcare supplies for profit. For example, Forlano disrupted the flow of disposable diabetes monitoring supplies by using them for longer a time than was recommended. In this way, embodied experimentation not only helped Forlano more comfortably connect with her devices, but inspired outward resistance of prescribed purchases based on her lived experiences.

Weise's and Forlano's lived experiences with disabilities, which necessitated reliance on and resistance of healthcare to survive, impacted their worldview and worldbuilding. They recognized new possibilities for living alongside technology while working within frictions with hegemonic systems, like professional design, which may enforce participation according to narrow, ableist conceptions of humanity and design.

But crip technoscientific practices are not new. For example historian of design Bess Williamson [2019] and disability studies scholar Aimi Hamraie [2017] have written rare

collections of crip technoscience by disabled people. These archival analyses uncover a myriad of ways disabled people have engaged in crip technoscience and circulated such knowledge to other disabled people. For example, after transferring home from inpatient rehabilitation care, Ida Brinkman and her husband adapted her breathing tube. The new design allowed Brinkman to reach around the apparatus with a dowel rod held by her teeth, which she used to type her life hacks in the form of articles for the *Toomeyville Junior Gazette*, a newsletter written and subscribed to by polio survivors [Williamson 2019, p. 70-72]. Another periodical, called *The Technical File*, circulated braille and cassette-recorded articles of nonvisual electronics tinkering instructions in the 1980's and 1990's (its recent digitization was led by blind accessibility researcher Joshua Miele) [Gerrey n.d.]. Indeed, disseminating curated content to subscribers represented one way knowledge was transferred among far flung disabled people to build community and inspire further experimentation. But as Williamson [2019] and Hamraie [2017] rightly point out, the easily uncoverable and academically minted histories primarily concern lifehacks from white suburban families, and adaptations tended to augment homes, automobiles, and medical and workplace technologies dispensed through government-sponsored rehabilitation programs, eligibility for which often necessitated veteran or employed status.

As such, storytelling has recently become increasingly important for people with disabilities and especially those who are also queer, trans, Black and Indigenous people of color, to nuance and pluralize the disabled experience. Some of the recent stories series and anthologies include those written and/or edited by Keah Brown [2019], Lydia X. Z. Brown *et al.* [2017], Belo Cipriana [2018], Disability Visibility Project [n.d.], Haben Girma [2019], Leroy Moore [2017], Leah Lakshmi Piepzna-Samarasinha [2018], Rooted in Rights [n.d.], Alice Wong [2018]. While these are not solely focused on sharing crip technoscience

but life experiences more generally, a wealth of memoirs and anthologies (like some of their periodical predecessors) are insisting that their local experiences and adaptations should be recognized forms of worldbuilding, if they are seldom accounted in rehabilitation medicine and mass-produced assistive technologies.

Education scholars Daniel Solorzano and Tara Yosso [2002] call this type of storytelling counter-storytelling. Dominant stories, they argue, are often damage-centered, presenting minoritized lives as deficits in need of saving, similar to Irani's "design savior" [Irani 2018]. Counter-stories, in contrast, resist deficit storytelling, and are narrated by marginalized people, representing their own life experiences. Counter-storytelling, a framing I borrow in Chapter 4, offers first person, nuanced portrayals of disability that pluralize it from negative stereotypes, and celebrate the creativity and resilience the disabled experience agitates from the margins.

In addition to storytelling, disabled people are intervening in design with crip technoscience and disability culture, to reimagine both the purposes and techniques of design as well as disabled futures. Sara Hendren calls these design explorations 'investigating normal'. Through art exhibits and her students' course projects, she argues that the design of technologies meant for use by disabled people can be functional and provocative. Much of her work concerns the ramp, a seemingly banal symbol of access. But through its assumed unremarkability, Hendren designs ramps to take up prominent space, both physically and aesthetically, drawing questions about why disability, like the frequent placement of ramps, is relegated to the periphery of normal and even further from art [Hendren 2017]. Both Hendren and designer Graham Pullin show how reimagining specialized technologies from silos, like the evolution of eyeglasses from assistive device to popular fashion accessory, can bring about societal transformation [Hendren 2013, Pullin

2009].

Similarly, Alison Kafer [2019] argued that design can exude joy and create intimacies for disabled people and passersby, while questioning and troubling ‘normal’ bodyminds. To make these arguments, she showcased Sandie Yi’s art which reimagines prosthetic adornments for disabled amputees. For example, gloves constructed for a wearer with two fingers provide warmth and aesthetic appeal while outwardly challenging normalcy; they are embellished with extra fingers of different shapes and sizes. In contrast, Yi’s braces focus not on bending disabled bodies into normal submission but are made to be comfortable specifically for the wearer. One set of braces feature embroidered clumps on their inside which are meant to directly connect with skin. As braces are often fashioned for the individual, so too are the inward-facing adornments of Yi’s; designed specifically to fit within small and unique spaces of the wearer’s body, the sensory pleasure they may invoke upon rubbing alongside actually depends on wearers occupying bodies that cannot be fitted into mass-produced accessories. (Yi’s art, along with that of other disabled artists featured their crip technoscience at the Recoding CripTech exhibit [Chang and Felt 2019]).

Several disabled artists and activists use design more overtly in resistance. As written in the Introduction, Liz Jackson is retelling design stories from under-told perspectives like Betsey Farber’s [2018]. Her curation of disabled creatives on The Disabled List [The Disabled List n.d.] consults and critiques professional design, with one outlet being Critical Axis, which evaluates products and media marketed about disabled people according to how their portrayals (mis)represent disabled people [Critical Axis n.d.]. Additionally, HCI and disability studies researcher Rua Williams offers provocative design recommendations that turn the design of surveillance technologies, often oriented to monitor individuals’ behavior, onto institutions to enforce accountability [Williams and Gilbert 2019].

Another example of design as resistant advocacy comes from disabled artist Shannon Finnegan, who invented the Anti-Stairs Club Lounge, a space and pop-up protest that challenges perceptions of stairs as the most functional and artful way to change elevation [Finnegan 2017, 2019]. The project began when Finnegan was invited to exhibit in the Maxon Mills space in Wassaic, New York. But because Finnegan does not use stairs herself, if she accepted the invitation, she would not be able to visit her own art. In response to this conundrum, she developed Anti-Stairs Club Lounge, which occupied an unused room on the ground floor of the facility. To gain entry, patrons had to sign a commitment that they would not ascend any stairs, thereby agreeing to visit only her exhibit. The Anti-Stairs Club Lounge has since turned into a resistance movement, protesting blatant usages of stairs with no accessible companion pathway. Recently, Anti-Stairs Club Lounge activists protested outside The Vessel, a public art structure that celebrates New York City views with ample staircases leading to opulent observation points. Yet the hidden elevator skips past most of these vantages, making it an inferior mode of transport that misaligns The Vessel's intentional coupling of increasing elevation with ever-widening New York cityscapes.

Importantly, movements like Anti-Stairs Club Lounge, and the crip technoscience inventions mentioned previously, blur function and aesthetic, activism and utility. What may begin as an object invented in resistance may morph into on-the-ground organizing. What may begin as an irritation with uncomfortable braces may reimagine stereotypes that dissociate pleasure from disability. Crip technoscience is not constrained by a narrow set of practices or predetermined design outcomes. Rather, the lived experiences of people with disabilities, and their desires to worldbuild on their own terms, characterize it as a frictional but flexible approach to designing.

Although they are gaining traction, crip technoscientific practices and appropriations of techniques characteristic of professional design by people with disabilities remain under-recognized. But HCI and media studies scholars are exploring how recognition can serve as a starting point for bringing these perspectives and alternative modes of designing into the field. The next section will briefly overview how recognition is remaking design in HCI.

2.5 Recognizing Under-Told Perspectives in HCI

Feminist HCI and media studies scholarship has explored recognition as a pathway toward bringing under-told perspectives into design and computing fields. For example, feminist HCI scholar Daniela Rosner posited that by, “remaking the stories that get told with the stories we neglect to tell,” under-told perspectives may be heard rather than appropriated or erased [Rosner 2018, p. 119].

Recognition not only encompasses the ways in which we might affect activities directly, but introduces and holds onto traces, which may include bodyminds, practices, histories, and cultures that occupy or are left out of design spaces [Rosner *et al.* 2013]. This work points to a possible avenue for reworking professional design to undertake a new type of access by recognizing contributions by disabled people and positioning their lived experiences as a starting point.

For example, Tiffany Chan, Mara Mills and Jentery Sayers [Chan 2016, Chan *et al.* 2018] recognized Mary Jamison, a blind inventor of the optophone, an early audio reading technology that converted print into sound. Her contributions to the device’s development and redesign have rarely permeated common depictions of her as a user of the technology. To tell Jamison’s story, they reconstructed an optophone and highlighted her specific contributions to inform its design and promote the product through public

demonstrations. In this project, Sayers foregrounded Jamison's contributions by creating a prototype and using it to amplify the immense work she did to master, teach and design the technology [Sayers 2015]. This and other Prototyping Past projects [Goertz 2016, Morgan 2016, Sayers 2018] challenge the stories that get told in HCI and wider media reporting, and specifically draw attention to largely silenced women and disabled contributors [Chan 2016, Chan *et al.* 2018, Jungnickel 2018, Rosner 2018, Rosner *et al.* 2018].

Some accessibility research takes account of the ways people with disabilities get by in their everyday lives, and some of this work concerns adaptations. For example, Profita *et al.* [2016] conducted a trace ethnography of an online community of deaf and hard of hearing people trading hearing aid hacks and decorations. Community members treated their assistive technologies as canvases for tinkering and embellishment to personalize their devices and draw attention to them. Other work explored how blind and sighted people co-construct access in order to work, live at home, and craft [Branham and Kane 2015 A and B, Das 2020, Hawthorn and Ashbrook 2017]. However, whereas crip technoscience celebrates disabled forms of adaptation in and of themselves, this work tends to motivate directions for future professional designs. My research will aim to combine the two, such that crip technoscience is celebrated as well as situated as a tool of futuring, one that may inform new intervention points not just by current conceptions of professional design, but as starting points for reworking professional design itself.

These accounts begin to push back on dominant forms of design that cast the disabled person as a user. In particular, I take up the work of Jentery Sayers [2015] and colleagues, Daniela Rosner [2018], along with crip technoscience [Hamraie and Fritsch 2019] and the storytelling going on in disability activism as starting points to change the common "design

savior” [2018] narrative of professional design, in regard to the status of people with disabilities in the field.

2.6 Methods

In this section, I overview the methods I undertook to conduct the research presented in this dissertation. Most importantly, in line with feminist HCI perspectives [Bardzell and Bardzell 2011, Suchman 2007] I foregrounded first person perspectives of people with disabilities, including my own and those of other disabled researchers and activists with whom I collaborate and regularly join in community. As they are systematically under-represented in professional design, in the words of Anna Tsing [2015], this act helped me to “narrate against the grain” of prolific accounts (such as those by professional designers).

Second, I aimed to remain reflexive and partial, in line with feminist HCI commitments, to acknowledge how I was very much part of the making of my research and not an outside observer. This commitment for example, led me to reflect on the ways my choice of research activities and analytical lenses brought forth some things while disappearing others. Specifically, reflexivity helped me take seriously participant criticism in Chapter 4.

Additionally, though they are combined in Chapter 5, my work on interdependence actually spanned two papers. The first presented interdependence as a frame for assistive technology research and design and upon reflection, read very utopian without acknowledging the frictions characteristic of crip technoscience and disability justice activism. The second paper aimed to reveal these frictions alongside any benefit interdependencies may offer. As such, my commitments to feminist traditions are threaded, imperfectly, through of my research activities.

In what follows, I will overview the specific methods I undertook to conduct the original research presented in Chapters 3 through 5.

2.6.1 Chapter 3 Method: Essay

My first aim, guided by my first research question, was to examine how people with disabilities are cast in professional design communications. While the literature review points to possible inequities, such as design activities that may not be accessible for people with certain disabilities, research has yet to deeply gauge the impact of casting people with disabilities as users. To investigate this, I scoped the project based on my ongoing experiences as an accessibility researcher, disabled person and activist. The triangulation and overlapping of these identities was important in the decision-making around which cases to unpack in Chapter 3. Throughout my career specifically as an accessibility researcher, I encountered little dispute over the inaccessibility of professional design activities or underrepresentation of disabled people working in the field. But little did my nondisabled colleagues know (from what I could gather), that making these activities accessible, often in response to inaccessible defaults, hardly changed my perceived power and ability to participate. Based on my own lived experiences as a disabled researcher, I suspected the work of accessibility must, then, be more complex than good intentions and material alterations.

However, a much more controversial (and publicly discussed) topic has concerned the ways professional designers are taught to initiate the design process, understanding users, when the users are disabled. Having spent decades as a disabled person and activist, I was well aware of the long-standing research and activism that argues simulation of bodily impairment is at best an inaccurate portrayal of someone else's lived experience and at worst, cultural appropriation. Yet as I gained more experience giving guest lectures to

undergraduate and masters professional design students, and working in industry myself, I learned that disability simulation is often used to introduce professional designers to disability when design and development teams are tasked with either working with users with disabilities, or responsible for making a product accessible. In fact, companies, universities, and disability service providers even boast labs comprising a plethora of assistive technologies and simulation tools, such as glasses that simulate different types of vision impairments and gloves that occlude touch sensations (See Figures 2.1 and 2.2). It seemed that the wealth of disability activism and research spanning disability studies, rehabilitation medicine, bioethics, and education that cautions and critiques the use of disability simulation as a tool to learn about people with disabilities had not yet permeated human-centered design enough to warrant changes in the ways disability simulations were conducted. There seemed to be a disconnect where the acts of learning what it was like to be a user could go unquestioned with the justification that engaging users adheres to professional design's commitments to prioritize user needs.

So, like any good researcher, I explored the novel problem, what I would now call a major friction, where good human intent rubbed against disability activism and scholarship. I thought my work could be more impactful if I explored the friction rather than accumulating evidence for something about which my colleagues wouldn't argue—the practical inaccessibility of certain tasks popular in professional design. As such, Chapter 3 comprises an essay on which I collaborated with Daniela Rosner. We took up the essay [Bardzell 2010] as a method to explore how human connection is established between professional designers and people with disabilities in two publicly available accounts of building empathy. Empathizing is the term the large design consultancy, IDEO, and influential professional design school, Stanford University's d.school, have assigned to encapsulate activities of understanding users [Doorley *et al.* 2018, IDEO.org 2015].

Positioning them as cases, we reflectively engaged in a critical, interpretive analysis of the text traces we gathered with other literatures on empathy. We scoped our reading to foreground perspectives different from those in the cases, to keep with our commitment to narrate against the grain and foreground the under-told.

The retelling of the two empathy-building experiences occurs in two forms. The first comprises an overview of each of the design projects as told by the IDEO design teams themselves and, when available, corroborated with materials by disability advocacy organizations and municipal records. Apart from bolstering the stories told in the original blog posts published by IDEO with other records when available, this retelling rehearsed the events without questioning them.

Next, I retold the events according to three forms of displacement that were synthesized from the empathy-building accounts when read with feminist, disability studies, and African American literature on empathy. In line with literary and archival analytic techniques as employed by the guiding scholars, I interpreted specific language from the accounts with the histories and politics that have kept disabled people systematically disadvantaged. This meant, for example, that if a disabled interlocutor was portrayed as inspirational, I did not just interpret that as a positive impact as the authors of the blog posts articulated. Rather, I also read their inspirational impact alongside histories of people with disabilities and other systematically disadvantaged groups, such as the fact the people with disabilities used to be explicitly put on display for the entertainment of nondisabled people, the pervasively high unemployment rates of disabled people, and low representation of people with disabilities in professional design fields specifically. As such, the second retelling pulls out specific cautions around empathy-building while ultimately addressing my first research question of how people with disabilities are cast in

professional design communications and experience reports.

2.6.2 Chapter 4 Methods

With this chapter, I begin to address my second research question: how can lived experiences and creative practices of people with disabilities impact professional design regarding who gets to design, what counts as design, and how design can be done?

To complete this project, I gathered a team of two other researchers (Burren Peil and Daniela Rosner) and five workshop volunteers (Augustina Liu, Alannah Oleson, Anne Spencer Ross, Anna Schmitz, and Annuska Zolyomi). Together we undertook a variety of methods outlined in three phases. In the first phase, I conducted preliminary one-on-one interviews with disabled people to collect stories of crip technoscience. Second, I took up interpretivist reflection and critical reading (similar to the process through which Chapter 3 was written) to orient myself intellectually for how I would turn the interview transcripts into examples for upcoming workshops. Third, I conducted workshops during which people with disabilities collaboratively made biographical prototypes to illuminate their own experiences inventing, modifying and repurposing in their everyday lives.

2.6.2.1 Interview Method

I conducted formative work including collecting stories by people with disabilities and developing a first round of biographical prototypes to serve as examples. Specifically, I conducted one-on-one semi-structured interviews [Charmaz 2014] with four people with distinct disabilities (here, termed ‘narrators’ to differentiate them from our workshop participants) during four months of 2018. From the interviews I produced audio recordings and full transcripts.

To learn how disability fit holistically into their life experiences, interview questions inquired not into disability diagnoses, but into the objects and environments that narrators had made, adapted or repurposed to work for them or make activities accessible. I also asked for stories of unsuccessful attempts and ongoing challenges. I conducted the interviews in narrators' own spaces where they often had access to the objects they spoke about, at which point they could also demonstrate their use. I chose to not use the word design during the interviews, with the hope that the narrators would tell any story related to material alteration or development (and not feel limited by the elite cultural status of the design professional, as demonstrated by prior work [O'Leary *et al.* 2018]).

Complementing the interviews, I curated a selection of stories derived from our review of related literature and popular media articles. I chose two stories from our review (including Betsey Farber's and one by disabled dancer Lisa Bufano who incorporates prostheses into routines [Shea 2013]) for their depictions of people's recent pasts from multiple perspectives, allowing us to contextualize for participants our motivation for taking up counter-storytelling practices. For example, interview sessions surfaced many rich first-person accounts but media articles offered a window to contextualize how different versions of stories of design by people with disabilities may circulate differently. For example, OXO has published a story almost absent of Betsey's contributions to their product development, whereas a disabled designer interviewed her directly to publish Betsey's version [Jackson 2018, OXO n.d.].

Together, interview transcripts and stories from popular media were used to create example biographical prototypes to introduce workshop participants to the types of stories we would ask them to prototype and share.

2.6.2.2 Workshop Method

In the third phase of this inquiry, I developed and facilitated three workshops with a total of 27 people with disabilities for the sharing and creation of biographical prototypes. I held the workshops at the downtown public library in Seattle, Washington, as it is a public place centrally located near public transportation, and the building includes standard accessibility features as outlined by the Americans with Disabilities Act. I also recognized the public library as a place that is enterable by wider groups of people than the university-educated, nondisabled employees who typically occupied our labs at the University of Washington.

My methods drew from participatory design workshops as well as feminist approaches to situated inquiry [Clarke 2003, Suchman 2007]. Feminist traditions emphasize the contingent and embodied nature of knowledge productions, and traditions of participatory design foreground alliances across expertise. Informed by a feminist commitment to reflexivity, I considered myself a participant in, rather than merely an observer of the design asymmetries to which we sought to draw attention.

To prepare for the workshops, my team created 14 sample biographical prototypes made of store-bought and found artifacts. Examples of these biographical prototypes are detailed in Chapter 4.

Contrasting with prototypes meant to solicit feedback, I intended the above artifacts to materialize a pathway toward listening to stories by people with disabilities. As such, to accompany and contextualize the artifacts, we created small cards displaying excerpts from our interview transcripts (in both print-form and braille) in preparation for workshop participants with a range of disabilities to read and engage with the prototypes.

The workshops were foremost grounded in my commitments to facilitate accessibly, an evolving practice of mine that I have learned from disability justice role models [Piepznar-Samarasinha 2018, Sins Invalid 2016]. This commitment began with sharing preliminary information in the recruitment flyer that the building was wheelchair accessible and located close to public transit stops. Second, participants could write in their access needs when filling out the screener survey. From their responses, I communicated with each participant about their access needs, reiterating what they requested according to how I interpreted it and what I would do. In this correspondence I gave an overview of the workshop program so they could revise their requested access needs if necessary. I shared that we would gather for four hours with snacks and breaks, that we would share slides, have some facilitator-led presentations, some large group discussions, and some small group discussions. I described that participants would be asked to examine objects, work with a small group to make their own object with 2D and 3D craft supplies, share their object and story, and discuss questions at the end.

This initiated email threads where the participant and I worked together to build a common understanding of their access needs and how I would respond to them. This dialogue often resulted in me rethinking, and sometimes disclosing to participants, my own access needs. For example, during one exchange, a participant requested to know what types of chairs were available to sit in. I emailed my correspondent at the public library who sent me photos of the different types of chairs available. I forwarded these photos to the participant and felt it was necessary to disclose that I am blind and cannot see the photos. I then explained to the participant that if they had requests based on what they saw in the photos, I would need to receive those requests with descriptions of the chairs rather than in the form of nonspecific references to imagery. During these communications, I often felt uncomfortable and at a loss; I had no models of other

researchers disclosing their disabilities to participants. Was it acceptable to ask someone in a participant role to do something for me that wasn't in a study protocol? This and other preparations that were adapted or evolved because of mine and other facilitators' disabilities and healthcare needs helped me to more seriously consider raising participation as inseparable from access, as Richard Ladner has done with his design for user empowerment strategy [2015], as I realized that most of my training rested on assumptions that fulfilling participants' access needs could be done by researchers, and that researchers would not share their needs with anyone. I return to this in Chapter 6.

From the various access requests I received, I curated a list of access commitments and respectful communication considerations to share with workshop participants at the very beginning. This established that access was everyone's responsibility to which we must commit and constantly work toward, as well as recognizing and repairing mistakes. Additionally, after we read the access commitments I brought, participants could share any access commitments they wished attendees to make that had not been included in my original commitments.

Access commitments and communication considerations that I brought to the workshops included: remaining scent-free, having one person speaking at a time, offering ample time for participants to express themselves, directly conversing with people and not interpreters, using people's correct pronouns, announcing one's name before speaking, and returning items to their place to maintain organization. Attendees were asked to reflect on whether they are generally outgoing or quiet. If the former, they were encouraged to step back and allow others to speak and if the latter, they were encouraged to step up and share. Details about the workshop program scaffold the findings section in Chapter 4.

I recruited participants by posting printed flyers in public and disability-centered spaces at the University of Washington. I also circulated email notices to local listservs run by people with disabilities. I selected workshop participants to reflect a diversity of disabilities, gender identities, and people from groups that are otherwise underrepresented within professional design practice. Both Narrators from the first phase of this research and workshop participants either chose a pseudonym or permitted me to choose a name popular among people with the same gender identity and ethnicity. Participants received an electronic informed consent form before the study and were given a hard copy to review in print or braille before signing at the workshop. They consented to participate altogether, and could then consent or withdraw from being recorded in different ways (notes, audio, photo, video). Narrators and participants received a gift card for their time.

Drawing on inductive techniques [Charmaz 2014, Clarke 2003], I analyzed our data thematically based on how they shed light on the role storytelling plays within prototyping, professional design, and disability. Three questions organized the analysis:

- (1) How do participants engage with biographical prototypes?
- (2) What types of biographical prototypes emerge from our participants' personal stories?
- (3) How do biographical prototypes lend themselves to discussions of design, disability, and storytelling within and beyond the workshop?

To develop to these questions, I iteratively wrote and refined reflective memos derived from my interview transcripts, field notes, biographical prototypes, and audio and visual recordings. The research team then identified important themes that occurred across the

three workshops through subsequent rounds of collective analysis. Chapter 4 reflects themes that were prominent in our synthetic analysis.

2.6.3 Chapter 5 Methods: Field Observation and Interaction Analysis

Taking lessons from biographical prototypes, Chapter 5 offers another response to my second research question, how can lived experiences and creative practices of people with disabilities impact professional design in regard to who counts as a designer, what counts as design, and how design can be done? I intellectually grounded this exploration in interdependence from disability justice activism (which I overview in Chapter 5), and I applied it to analyze some empirical data I collected as part of an internship at Microsoft Research Cambridge, mentored by Alex Taylor.

The work reported in this chapter formed part of a larger research project hosted by Microsoft Research Cambridge exploring potential roles of AI in assistive technologies for the blind and vision impaired. In partnership with researchers Alex Taylor, Anja Thieme and Cecily Morrison, I collected the empirical data, and later, colleagues Daniela Rosner, Stacy Branham and Erin Brady partnered with us to synthesize the data to exemplify how interdependencies can be seen in action.

The empirical data that informs Chapter 5 take the form of detailed transcripts of fragments from video we recorded. The video was captured while colleague Alex Taylor and I accompanied pairs of people who had consented to be filmed and also in some cases to wear small cameras during routine, everyday outings. From contacts gathered during the ongoing project, we reached out to vision impaired people in the Cambridge, United Kingdom community. We explained that we were specifically recruiting pairs of people with experiences guiding one another. Three pairs were recruited in total; two consisted of

one person with a vision impairment and a fully sighted person employed via a government scheme to assist them with work-related tasks. Both of these pairs had pre-existing relationships as good friends. The third pair consisted of a couple, each with different classifications of visual impairment. Each pair was accompanied by researchers for about three hours. For their time, participants were given gift cards to an online store.

To analyze the video fragments and produce the transcripts, we drew on a form of interaction analysis regularly used in workplace studies [Luff *et al.* 2000] and computer supported cooperative work research [Heath *et al.* 2010, Heath 2011]. This analytical perspective places an emphasis on the highly situated material and interactional resources people employ to accomplish activities.

For the purposes of our research, we opted for this orientation to help sensitize ourselves to the work of access. In small groups of two to four researchers we discussed the observations, alongside reviewing fieldnotes, video excerpts, and transcripts. This helped us prioritize the deeper analysis of what we thought were moments where access work seemed particularly important. We were especially drawn to what we observed to be the ways the pairs actively collaborated through a combination of conversational talk and bodily gestures, and where specific questions arose around: how people with different degrees of sight use talk and fine-grained movements to coordinate with each other, how pairs make their actions mutually intelligible to unproblematically (or sometimes problematically) get on with an activity, and where troubles arise in these interpersonal interactions.

Equally critical to the research, however, was the question of what might be missed through this orientation to analysis. Drawing heavily on our combined and complimentary interests in critical disability studies, feminist STS, and social justice activism, and

accounting for our own varied experiences having disabilities, having close relationships with people with disabilities, and staying open to learning from disability experiences unfamiliar to us, a particular methodological commitment was made to how our analysis might both sensitize us to others' labors, but also, through absences and elisions, invite alternative readings.

From the field observations and interaction analysis, in Chapter 5 I describe three excerpts from the data, which widen modes of recognition from the constraints of the design studio or its language, to acknowledge people with disabilities as always contributing to building access. Specifically, their work complicated fixed notions of access common in professional design. Together, the research presented in Chapters 3 through 5 point to future directions (written in Chapter 6) for reworking professional design from the lived experiences of the interlocutors with disabilities I engaged during this research.

Chapter 3. Disabled Person or Professional Designer?: The Difference Empathizing Makes

3.1 Introduction

This chapter is based on [Bennett and Rosner 2019].

In the previous chapter, I showed that designers and researchers have come up with a variety of strategies to better understand and involve users with disabilities in professional design. The goal of these efforts is to increase the accessibility of design outcomes. Often left unquestioned is how professional design communicates and facilitates the roles of people with disabilities. However, these questions are important to explore as the ways people with disabilities are cast implicate what people believe is possible. For example, in Chapter 2, I noted how an interpretation of work that focuses on disabled end users could include that disabled people are not expected to be professional designers. If people with disabilities are assumed to be users in professional design, their participation is limited.

To expand on the glimpses of people with disabilities' involvement in professional design that I introduced in Chapter 2, I now ask: How are people with disabilities cast in media that communicates the methods and experience reports of professional design? To approach this question, I chose to critically analyze two publicly circulated cases of empathy-building done by designers at a global design firm, IDEO, known for promoting and teaching a popular methodology of professional design called human-centered design [IDEO.org n.d. A, IDEO.org 2015]. I narrowed the scope of this chapter to study empathy-building up close because empathy-building is often cast as an initial and essential phase toward good design, and because it often involves attempts to understand people's life experiences. As such, reports of empathy-building to better understand what it might be

like to have disabilities offers windows into where and how people with disabilities are expected to be involved in human-centered design, and what designers find important to learn and communicate out about disability.

Indeed, empathy-building is considered to be even more important when designers encounter systematically disadvantaged people more generally, including people of color, people with disabilities, and those living in low-resource environments. Some inclusive design advocates including Cambridge University [Inclusive Design Group n.d.], Creative Reaction Lab [2018], Microsoft [2016 A and B] and Stanford [Anaissie *et al.* n.d.] have published specialized human-centered design toolkits that challenge designers to recognize their differences, often framed as privilege, and in turn they offer unique empathy-building tailored toward noticing and understanding marginalized experiences. For example, one unique activity professional designers engage in to empathize people with disabilities is the temporary simulation of bodily impairments [Alzheimer's Association 2017, Brownlee 2015, Hailpern *et al.* 2011, Hoss and Roopani n.d., Inclusive Design Group n.d., Manser 2016, Suri *et al.* 2005]. According to proponents of empathy-building, transferring experiences of nondesigners to designers through methods such as disability simulation may shape more inclusive futures.

But I will offer a different perspective through the two cases I analyze in this chapter. I will show how empathy, as performed by designers in order to know their users, may actually distance designers from the very lives and experiences they hope to bring near. For example, designers who use disability simulation techniques such as blindfolds to empathize with blind users may not need to consider the user with disabilities; instead, they may focus on their own experience wearing a blindfold. To make this argument, I draw from public accounts of professional designers empathizing disabled interlocutors to

describe how designers (as the empathizers) position their work to address the experiences of people with disabilities (as the empathized). Reading this work through recent critiques, I illustrate how designers may privilege their interpretation of the disabled experience over firsthand encounters, a position that further contributes to the prioritizing of nondisabled experiences over those had by people with disabilities [Kafer 2013, Moser 2006].

To make the argument that empathizing can separate design and disability, I thread three strands of scholarship through the cases of empathizing people with disabilities that I present below.

First, the analysis draws from a growing body of literature questioning idealized promises of professional design, that the field is suitable to address many difficult, global-scale problems [Avle *et al.* 2017, Irani *et al.* 2010 B, Irani 2018]. My critique takes up and complements this literature (that I overviewed in depth in Chapter 2), which has yet to systematically examine how people with disabilities are incorporated into human-centered design's promises to improve systematic marginalization.

Second, disability studies offers useful critiques of disability simulation, a popular empathy-building activity taken up in professional design (described above). Disability studies scholars such as Alison Kafer [2013], Michelle Nario-Redmond *et al.* [2017], Arielle Silverman *et al.* [2015], and Rebecca Garden [2007] trouble the practical simulation of bodily impairments as disability awareness tools. Instead, they call for more direct interactions with disabled people, without aiming to replicate their experiences. I expand these critiques by applying them to the use of disability simulation as a tool for professional designers to empathize disabled users.

Third, I draw on recent feminist scholarship that frames empathy as formed within and

through people’s connections with others—placing empathy in historical context and implicating it in the uneven distributors of power that cement dominant forms of storytelling (like the “design savior” complex [Irani 2018]) [Ahmed 2013, Hartman 1997, Pedwell 2014]. As Saidiya Hartman, a scholar of African American literature and history, wrote of documentation around the Transatlantic slave trade, “it becomes clear that empathy is double-edged, for in making the other’s suffering one’s own, this suffering is occluded by the other’s obliteration” [Hartman 1997 , p. 20]. I take up this literature to guide the retelling of the empathy-building cases I present, which uniquely foreground the perspectives of people with disabilities and question empathy’s self-evident goodness.

In what follows, I first put empathy in historical context. I briefly trace the roots of empathy work in HCI and human-centered design, reviewing in particular the literature around disability and empathy. Attending to the aforementioned disability studies and feminist scholars, I then analyze public accounts of empathy around disability shared by IDEO, a celebrated global design firm. This explication of some pitfalls of empathizing people with disabilities in human-centered design then sets up a provocation to rework professional design so people with disabilities might instead be brought close and recognized for their contributions.

3.2 What is Empathy?

Empathy, from the Greek term *empathia*, meaning *em-* or ‘in’ and *-pathos* or ‘feeling’, describes the ability to understand and share the feelings of another. Whether championing affective skills or challenging greed, to borrow from cultural studies scholar Carolyn Pedwell, “empathy is everywhere and is viewed, by definition, as positive” [Pedwell 2014, p. 13].

To understand this positive valence, I turn to empathy's roots, a genealogy tied up with earlier vocabulary. Bioethics scholar Rebecca Garden [2007], for example, reported how across the 19th century, the terms 'sympathy' and 'sensibility' described the ability to innately partake in another's suffering and to act toward its relief (within limits). For Enlightenment philosophers David Hume and Adam Smith, she pointed out, sympathy and sensibility came naturally to certain bodies (those of members of the educated, upper classes), and not to others. In the late 1800's, this concern for sensory capacity resurfaced with empathy's introduction into the German language. According to historian Susan Leigh Foster, the aesthetic theorist Robert Vischer devised the German term *Einführung* (empathy, or 'feeling-in') to explore the process of observing arts such as sculpture [Pedwell 2014, p. 191]. Following this usage, the early 20th-century translation of *Einführung* into English referred to the sharing of sensory experiences with other people and objects [Lanzoni 2003]. The term became particularly salient within traditions of modern dance wherein it described audience members' physiological and affective immersion alongside performing dancers. This "inner mimicry," as popular dance critic John Martin called it, represented a subconscious transformation from mere spectator to participant in the dance, unseen by others but very much felt within the bodymind [Reason and Reynolds 2010].

Its meaning contrasts with empathy's usage within contemporaneous European psychiatry wherein the concept of empathy signaled a solution to over sympathizing. Early 20th century psychiatrists such as Ludwig Binswanger began to position empathy as a technique of empiricism, using therapeutic interviewing to ostensibly maintain an empirical distance from clients while still understanding a client's thoughts and feelings [Lanzoni 2003, Pedwell 2014]. Across the later decades of the 20th century, this seemingly contradictory mix of concepts—on the one hand, creating an affective, subconscious connection and, on

the other hand, developing a removed scientific understanding—formed the activities that have come to characterize empathy in professional design today.

3.2.1 Empathy in Contemporary HCI

While they are less studied, the roots of empathy in HCI date back as far as 1974, when architecture professors Don Koberg and Jim Bagnall articulated the “analyze” stage in their widely circulated volume *The Universal Traveler* [1978]. Over the next few decades, empathy came to stand for that initial and essential exercise toward “good design,” often elevated as the very “foundation” of the human-centered design process [IDEO.org 2015, p. 4]. “Find (or create if necessary) ways to immerse yourself in specific environments to understand firsthand who you’re designing for,” Stanford’s popular guide for human-centered designing suggests [Doorley *et al.*, p. 5]. In another celebrated tool called the “empathy map,” designers synthesize intended users’ behaviors, feelings, and thoughts (see Gray [2017]). This and similar empathizing exercises can serve as justification for subsequent design decisions.

Empathy has also been examined in broader HCI scholarship. Specifically, several scholars have developed the concept with methods and ethics-oriented contributions [Brandt and Grunnet 2003, Dong *et al.* 2017, Mattelmaki and Battarbee 2002, Wright and McCarthy 2008]. In a widely cited paper, Wright and McCarthy [2008] identified empathy as an emerging trend within HCI studies aimed at more deeply understanding user experiences. Surveying empathy-building activities employed in HCI research, they reviewed a variety of techniques leveraged toward these ends: from observations and interviews, to narrative resources comprising diaries and art pieces, to roleplaying with simulations and personas. Across this set, they argued for regular ethical evaluation of empathy-building. For them, empathy marks a commitment to forming relationships and accountabilities (not just

understandings). Empathy, in these contexts, occupies a moral stance where it becomes associated with design to uphold social values. In line with Wright and McCarthy's call for the regular evaluation of empathy, I offer perspective on the impacts of empathy-building on nondesigners with disabilities.

3.2.2 Empathizing a Person with Disabilities

Research and commentary in professional design guides frame empathy-building as even more important when users have disabilities [Alzheimer's Association 2017, Brownlee 2015, Hailpern *et al.* 2011, Hoss and Roopani n.d., Inclusive Design Group n.d., Manser 2016, Suri *et al.* 2005]. By assuming that the life experience of disabled people is unfamiliar to designers, such guides suggest that empathy-building offers a way for designers to step into the user's shoes. From this perspective, elevating empathy constitutes a crucial step towards shifting a designer's thinking outside themselves, in hopes they will design for target users with disabilities.

Empathy-building activities largely overlap with user research methods. A unique empathy-building activity that sensitizes people to difference (racial, gendered, ability) is modeling or simulation. During disability simulation exercises, people who presumably do not have disabilities acquire a temporary bodily impairment with tools that may be low-tech, like blindfolds and gloves (See Figure 2.2), or high-tech, like virtual reality to occlude vision and tactile sensations, and then complete a daily task with these unfamiliar bodily constraints (for a range of work on how simulation has been applied more broadly, see Farmer *et al.* [2014], Lee *et al.* [2014], Maister *et al.* [2013], Peck *et al.* [2013]).

Proponents argue that immersion provides an unparalleled opportunity for designers to bring themselves closer to the experiences of people with disabilities by smoothing out

assumed differences with users [Alzheimer's Association 2017, Brownlee 2015, Hailpern *et al.* 2011, Hoss and Roopani n.d., Inclusive Design Group n.d., Manser 2016, Suri *et al.* 2015]. For example, researchers have created personas with disabilities [Schulz and Fuglerud 2012] and Microsoft's Inclusive Design Activity Cards [2016 A] suggest designers imagine times when they have situational impairments, to bring disabling experiences closer to themselves (See Figure 2.1). According to Microsoft's Inclusive Design Toolkit [2016 A and B], even if impairments are temporary (such as having just one hand free while carrying bags), if a designer can imagine how they, too, are impacted by inaccessible design, the brief connection it spawns between designer and user with disabilities can make the designers see disability differently (e.g., make accessibility guidelines seem more relevant).

3.2.3 Critiques: Where Empathy Goes Wrong

A range of recent scholarship has pointed to the ways empathy, and design thinking packages more generally, work as a means of convincing designers that they have superior training and ethical tools to quickly assess and innovate on problems in domains they are unfamiliar with (e.g., Bloom [2014], Meill [2015], Payne [2016], Stewart [2016], Vinsel [2018]), in line with Lilly Irani's identified "design savior" complex [Irani 2018]. In a widely circulated critique, media historian Lee Vinsel [2018] likens the empathy phase to a consult with would-be customers wherein designers distill what users want and capitalize on those insights. Other critics locate problems with how empathy directs designers to individual, sensationalized problems when societal transformation is necessary [Bloom 2014, Meill 2015, Payne 2016]. Across these critiques, commentators grapple with how to minimize harm while still reaping the benefits of human connection that inform design.

Decades of scholarship in rehabilitation medicine and social psychology [French 1992,

Kiger 1992, Nario-Redmond *et al.* 2017, Silverman *et al.* 2015], education [Burgstahler and Doe 2014], disability studies [Kafer 2013, Ladau 2014], and popular design blogs [Abreu 2018] caution about certain types of empathy-building around disability. Scholars argue that using disability simulations to empathize people with disabilities reproduces negative stereotypes and fails to highlight infrastructural and social challenges. For example, a designer navigating a food buffet while steering a wheelchair for the first time may foreground a beginner wheelchair operator's experience but does little to reveal nuances of different contexts, experiences over time, and the myriad factors that impact disability including greater cultural, institutional, and social influences [Chess *et al.* 2004]. Critics argue that empathy built through immersion may steer designers toward narrow and inaccurate conceptions of disability experiences, subverting firsthand experiences in favor of the simulator's interpretation.

Generally agreeing that design cannot be premised on empathy alone, several scholars offer alternative terms (e.g., compassion [Ladau 2014, Stewart 2016], humility [Creative Reaction Lab 2018], or noticing [Anaissie *et al.* n.d.]) along with techniques. Techniques include simulations guided by disabled people and the teaching of appropriate techniques to complete tasks [Burgstahler and Doe 2014, Silverman *et al.* 2018], codesign exercises in which designers enlist disabled people as partners [Spiel *et al.* 2017], and community service work led by disabled people [Chess *et al.* 2004, Kafer 2013].

Pervasive among recent critiques and correctives is a nearly uncontested belief in the power of empathy to provoke more inclusive designs for and with people with disabilities. cultural studies scholar Carolyn Pedwell described how, “precisely because it is so widely and unquestioningly viewed as ‘good,’ [empathy’s] naming can represent a conceptual stoppage in conversation or analysis” [2014, p. 14] For her, this stoppage involved not

“what is empathy?”, “what does it do?” or “what are its risks?”, but rather the more automatic refrain of “how can we cultivate it?”. She viewed its unquestioned promise as necessitating further investigation [Pedwell 2014]. But this stoppage is particularly problematic as she described, “When empathy is understood as the experience of ‘co-feeling’, it is suggested, this not only invites problematic appropriations or projections on the part of privileged subjects, it also risks obscuring their complicity in the wider relations of power in which marginalization, oppression and suffering occur” [Pedwell 2014, p. 29].

Pushing on this concern, scholars of African American literature [Hartman 1997] and Performance Studies [Anderson 2015] question the ethics and efficacy of empathy related to the valuing and understanding of life. For Saidiya Hartman, for example, the difficulty of empathy involved, “the dangers of a too-easy intimacy,” [Hartman 1997, p.20] wherein empathy upholds the workings of colonialism and oppression. Hartman and others pluralize empathy—using it as not merely a tool for understanding one another but as a tool rife with the histories, politics, and aims of those working with it. Feminist scholars Sara Ahmed [2010, 2013], Anna Tsing [2015], and Vinciane Despret [2004, 2013] held on to this tension between discovery and contamination by showing how empathy can open connections while predisposing the empathized as different and other. Ahmed, for example, contended that, “empathy sustains the very difference that it may seek to overcome. Empathy remains a ‘wish feeling’, in which subjects ‘feel’ something other than what another feels in the very moment of imagining they could feel what another feels” [2013 p. 30]. Attending to this “wish feeling,” Despret [2013] offered visions of feeling with another. Such accountability foregrounds shared experiences over authoritative narratives.

In what follows, I take to task this need to more deeply understand empathy within the context of disability and professional design. I use public accounts by representatives from

a professional design consultancy, IDEO, empathizing nondesigners with disabilities to illustrate how activities associated with empathy may turn disability into an unrelatable trait of the ‘other.’

3.3 Dispatches from Industry: Stories of Simulation and Personas in Design

Turning to IDEO, I use two public accounts of human-centered designers empathizing nondesigners with disabilities to help illustrate the complexities of empathy: one case involving simulation (an exercise in learning about disabled experience), and one case involving personas (an exercise in generalizing techniques for attending to disabled experience). With this analysis, I additionally rely on materials and prototypes released by municipal partners, media articles, and—although rarely available—firsthand accounts from disabled interlocutors. My focus on public vignettes stems from the ongoing influence of media narratives on HCI discussions of design (e.g., Irani *et al.* [2016], Rosner *et al.* [2018]) as well as the theorizing of feminist scholars such as Vinciane Despret [2004, 2013], and Saidiya Hartman [1997] who narrate against the grain in order to reveal under-recognized perspectives and uneven distributions of power. From the examples, I learn that designers can use empathy to conceptualize not only their own roles, but also those of people with disabilities, consequently delineating and defining differences between those identities. In this process, people with disabilities may be limited in the roles they can take up in professional design.

3.3.1 Simulation: The Case of the Voting Booth

In 2015, representatives from Los Angeles County contracted the large international design firm IDEO to assist in redesigning their voting booth. According to their blog [IDEO U n.d.], the firm conducted “empathic exercises” in which they consulted various people with

disabilities to understand and receive feedback on their prototypes from a wide cross section of intended users. “Early on, we did an empathy exercise about what it’s like to live with disabilities,” Matt Adams, the team lead, explained. “We visited one of the technical advisors, who is an electrical engineer and also happens to be blind. He lives in Santa Clara and took it upon himself to evaluate voting machines and write extensive reports about how they are incredibly frustrating for people who are blind.” According to Adams, the team visited the Technical Advisor’s house and spoke with him about his experience (“the stuff he was into and how he got around in the world”).

In a post for a disability advocacy organization, the California Council of the Blind, Noel H. Runyan, a blind member of the Voting Accessibility Advisory Committee, described spending time with the IDEO team at his house and at their facilities in Palo Alto, California, sometimes user-testing their prototypes [Runyan 2017]. Throughout the process, Runyan explained, he had to “press” those involved to,

repeatedly...make sure that the voting machine included an attached ballot box, to assure it would support hands-free ballot casting...When representatives of election poll workers' interests strongly pushed back against having those ballot boxes on each machine, we pressed them to describe the reasons for their strong concerns [2017].

Poll workers were concerned voters would not trust their ballot was submitted if they did not hand deliver it to a ballot box. According to the newsletter, Runyan, along with other disabled interlocutors remained assertive. The design team introduced a translucent ballot box which allowed a voter to transfer their ballot from the voting machine hands-free while hiding the ballot’s contents from view. Visual confirmation that a ballot was transferring while obscuring a voter’s markings pacified both those who wanted confirmation of the

ballot's transfer and who wanted to ensure ballot contents remained private [Runyan 2017, Voting Systems Assessment Project 2015].

To interleave this expanded perspective into their own work, the design team also built empathy without their disabled interlocutors present. Comprising disability simulations, the additional empathy building purportedly enabled the design team to encounter technologies with a temporary disability. Describing his own experience of this simulation, Adams explained, "I was blind in one exercise and had to buy a ticket at the Caltrain station. I also had to withdraw money from an ATM and figure out, without the benefit of sight, how do these machines work?" (See Figure 3.1) [IDEO U n.d.].



Figure 3.1: Matt Adams, Voting Booth Team Lead, attempts to purchase a ticket from a ticketing machine while wearing a blindfold.

The final voting machine incorporated several features directly aimed at addressing accessibility concerns, as outlined by Runyan [2017] and municipal records [Voting Systems Assessment Project 2015]. These included a touch-screen interface with adjustable height and angle, audio and visual output, adjustable text sizes, multiple languages selectable at any stage of the voting process, a built-in printer and scanner for people to check their answers before submitting their ballot, and mobile device support for remote voting prior to entering the booth (much like emerging passport control stations [Airside Mobile 2014]). A video depicted a light skinned hand flicking through preselected votes on an iPhone, resulting in a QR code to be presented at the precinct for ballot casting. (See images of the voting machine prototype and user testing in Figures 3.2 and 3.3).



Figure 3.2: Noel Runyan, Blind Voting Advisory Committee Member, testing a prototype of the voting machine with a participant.



Figure 3.3: A computer-rendered image of the final design for the voting machine, showing the machine’s digital and tactile interface.

The next account offers a window into what this work of empathy looks like as different human-centered designers from IDEO tried to build a toolkit for sensitizing designers across projects. In this effort to sensitize, we explore not just how empathy is communicated, but also how it can be generalized and circulated.

3.3.2 Personas: The Case of Adapt-o-Pack

IDEO employees dove into another public-facing accessible design with a description of a prototype brainstorming game called Adapt-o-Pack [Durlak 2018], still unreleased. (See some proposed cards in Figure 3.4). With this game, the designers hoped to serve two goals: first, to illustrate “the creativity of people with disabilities,” and second, to reveal “the unconscious bias of non-disabled people.” To play Adapt-o-Pack, players would randomly select a persona and livelihood, and ideate workplace adaptations to make the occupation accessible for the persona. Specifically, players would pair livelihood program cards (depicting a workplace setting such as farming) with persona cards (depicting persons with disabilities such as “Donella” who has Down Syndrome). Using simple

language and colorful vector illustrations, the cards prompted players to design for the overlaps: imagining ways of modifying the industry setting (also called “livelihood programs”) to serve the particular persona described. For example, a player might have to figure out how to design for a person who says, “It’s difficult for me to carry large objects. I have trouble grasping objects, like pens and doorknobs. I don’t write neatly. I struggle with tasks that require the coordinated use of two hands at once,” to complete farming tasks like, “Planting seeds or seedlings. Watering crops. Harvesting vegetables or grains. Removing weeds” [Durlak 2018].



Figure 3.4: Several sample cards from IDEO’s Adapt-o-Pack.

According to a co-creator of Adapt-o-Pack, the motivation for developing the game involved trying to find ways to ideate more inclusive solutions. She described personal experiences working with international organizations who sought to find employment for people with disabilities. Yet the research team also encountered pervasive disbelief among prospective employers and designers that people with disabilities could do competitive waged work. Interested in curtailing such belief, IDEO researchers observed how several

disabled workers adapt their tools and working environments. The Adapt-o-Pack comprised their summary of those observations [Durlak 2018].

The researchers got wind of one such observation in rural Nepal during a visit with Rajendra, a man described as having chronic pain and mobility impairments. Rajendra toured the researchers through a shop he owns and a farm he cultivates with some adaptations he has come up with along the way to maintain an income to support his family. The co-creator of Adapt-o-Pack described the impact of his inspirational everyday hacks:

While many people we spoke to had assumed it to be impossible for a person with a disability to be employed in a livelihood like farming, stories like Rajendra's completely discredited that. He'd made small changes to his farm, such as widening the paths between crops to make it easier for him to negotiate his space. It was a surprisingly simple solution. As the breadwinner for his family, he couldn't tell himself it was impossible—he just had to have the creative confidence to make his farm work for him [Durlak 2018].

Later in the blog post, the game's co-inventor highlighted an initial Adapt-o-Pack game played in Nepal, in which the design team tested whether pairing livelihoods with disabled personas could incite similar transformation from skepticism to ideation. Some players began the game disbelieving that the design challenge to make more accessible workplaces was possible. However, as during the visit with Rajendra, additional benefits quickly manifested. The blog post explained, "It was as though, for the first time, [the players] were seeing the world of possibilities in a place where they thought there were none. They were encouraged, even if for a moment, to think outside of their own lived experience" [Durlak 2018].

Thinking outside their own experience, according to the public-facing blog, meant that the designers found their interlocutors' creativity beneficial. It helped them undo their disbelief in the capabilities of disabled people and, in turn, render themselves capable of building empathy. The game designer described the inspiration and expanded creativity that the designers would gain from stories of adapting worlds to get by while living with disabilities [Durlak 2018].

Rajendra's story, which we assume informs the Adapt-o-Pack content, looked different on the livelihood card. The card depicts the word "Farming," set in large, centered, bold sans-serif type, accompanied by an abstracted corn-ear icon and a small-type description: "Planting seeds or seedlings, watering crops, harvesting vegetables or grains, Removing weeds." The back of the card illustrated a monochrome vector rendering of a scene at the farm. Describing the possibility of using the game to foster empathy-building, the IDEO blog post explained: It is impossible for a person without a disability to ever truly understand what it means to be disabled. Period. True empathy, however, can often take the form of human connection over a shared emotion or experience. The Adapt-o-Pack creates this moment of connection by tapping into the creative potential of the participant (Adapt-o-Pack player), and encouraging them to, even for a moment, empathize with the type of creative necessity people with disabilities display on a daily basis [Durlak 2018].

This account resembles other design guides [Creative Reaction Lab 2018, Microsoft 2016 B] in recognizing limits to empathy. It relinquished any attempt to "truly understand" the disabled experience. In its telling, I nonetheless read the possibility of a certain kind of empathy work: a capacity to create "human connection" without direct engagement. In this connection through common affective identifications perceived by the player or designer, that person may believe they understand "the type of creative necessity" that those living

with a disability regularly perform. With this reference, the blog situated Adapt-o-Pack in the promotion of mutual understanding between the player and disabled worker [Durlak 2018].

3.4 The Slipperiness of Empathy

The above snapshots of design activities helped me see what mattered to a range of people and institutions (community advisors, disabled activists, municipal actors, a design consultancy) involved in cultivating and performing empathy around disability. In partnership with interlocutors, a design firm prototyped a voting machine with the promise of broad accessibility, and brought new attention to the creativity and challenges of the disabled people with whom they spoke.

However, in each story I also find what Saidiya Hartman names the, “slipperiness of empathy” [Hartman 1997, p.18], an expression denoting the paradoxical nature of drawing the other closer. In the first account of empathy-building towards the development of an accessible the voting machine, I see an example of successful outcomes despite concealed authorship. Although the coalition in charge of the machine’s development appeared to take seriously the perspectives of people with a range of disabilities, their public-facing narrative sometimes failed to credit the disabled people or stories involved. In the second account of developing empathy with Adapt-o-Pack, I find a story of the prototyping of a toolkit designed to disseminate empathy exercises but ultimately also encoding ways of supplanting firsthand disabled experience. Through supplanting the other’s experience, the cards depicting disabled people’s stories (like Rajendra’s) could jump-start different (and perhaps unrealistic) solutions. The accounts show us, as professional designers, how being empathetic can be a lesson in displacement. By drawing the other near, the designer may unwittingly erase them.

At stake in these narratives is not just the functionality of an empathy toolkit or a voting machine, but also the status of people with disabilities within design. Like any story, accounts of the design process inevitably leave out the perspectives of people potentially affected by it. Drawing on theorizing from feminist and disability studies, we now look to these absences as possibilities for generative critique. Attending to the work done to narrate disabled perspectives, we examine three modes of displacement threaded through the accounts:

- (1) denying the authority of disabled experience,
- (2) treating the empathized as spectacle, and
- (3) separating disabled and designing bodies.

With these thematic threads, I show how empathy's gaps work as sites for reckoning with wider configurations of power in design.

3.4.1 Displacement 1: Denying the Authority of Disabled Experience

Notable in the design scenarios described above is the presence and absence of detail—the pairing of invisibility and authorship. From the design firm's blog post on the voting machine, for example, I learned how a design team may interview people with disabilities (like the "Technical Advisor") and ask people with disabilities to test versions of their technology (*vis-à-vis* photos) while never naming them or giving voice to their ideas. I also get a glimpse of the disability simulation activities that a design team may do to complement these interviews and how they could perceive the activities as beneficial. However, as decades of disability scholarship have shown, such a benefit depends on a wider environment complicit in neglecting disabled experiences [Moser 2006]. It is not

until we hear from the disabled activist Noel Runyan that we learn the name of a contributor with disabilities and what the design staff may have learned from or about disabled activists and interlocutors. Designers may engage directly with interlocutors through interviews and user testing, and still choose to simulate disability.

The first account illustrates that firsthand experiences and accumulated knowledge (here, on inaccessible voting) may evoke empathy, but not enough belief in the contributor's abilities or knowledge of their processes to make a simulation unnecessary. We know little about the research subjects involved or the research that the designers conducted into how a blind person might purchase a train ticket or withdraw cash (resources that exist widely online e.g., Vista Center for the Visually Impaired [2011]). Instead, the accounts leave the voices of those with disabilities for the nondisabled designer to explain. They position the many people interviewed for the project (e.g., the "Technical Advisor") as useful but insufficient.

Recalling Carolyn Pedwell's discussion of "co-feeling" [Pedwell 2014 p. 29], these accounts render the appropriation of the empathized's emotions as one's own. In this restaging of the disabled experience, designers can rely on their own experience, effectively displacing the experiences of those with disabilities. As Rebecca Garden warns, this slip from trying to be alongside the other to trying to become the other is dangerous: "Thinking that empathy is more first-person experiential knowledge than first-person observation, that 'I am you' is a more ethical way of framing 'I and you,' risks denying the subjectivity and agency of the patient" [2007, p. 560]. What begins as displacement follows through as replacement. Empathy becomes a mechanism through which designers demonstrate their professional judgment by responding to their personal reactions and subverting the experiences they intended to uplift.

3.4.2 Displacement 2: Treating the Disabled "User" as a Spectacle

The above accounts describe the impact of disabled people on designers (such as Rajendra on his visitors). How that influence reflects the complex identities of disabled people remains less clear. Without its complexity in full view, disability may become something to gaze on with amazement, rather than a condition of possibility.

Returning to the Adapt-o-Pack cards, the accounts discredit skeptics who question the capabilities of people with disabilities. They instead depict disabled people (such as Rajendra) as able to defy negative stereotypes about disabilities with their creativity, and they present disabled people's ingenuity as urgently necessary for their own family's well-being. Through these observations, a disabled person's livelihood could transform the researchers.

Yet, in transformations like these, designers may not have made themselves more caring or, in Saidiya Hartman's words, "ameliorated indifference" [1997, p. 19]. Instead, they may have, "only confirmed the difficulty of understanding" [Hartman 1997, p. 19]. In other words, empathy activities such as simulations and personas may allow designers to choose aspects of experience (e.g., occluded vision or imagined farming tasks with limited mobility) to isolate, and then inspect those experiences for their capacity to inspire designs. By putting on a blindfold, for example, designers might elevate the experience of their vision being suddenly occluded, while reducing other aspects of living with a vision impairment (such as the nonvisual techniques blind people use every day).

Casting this state as "spectacle," Hartman wrote of the power and utility of such stories when transferred from their tellers onto the empathizers or "spectators." In rereading the accounts of John Rankin, a white American who derided the "very dangerous evil" of

slavery Hartman recounted a letter he wrote to his brother to depict the horrors of Trans-Atlantic slavery [2017, p. 17]. In the letter, Rankin invented an empathetic account, a story in which his own family became enslaved. She wrote, “Rankin makes apparent that the crimes of slavery are not only witnessed but staged. This is a result of the recurs to terms like ‘stage,’ ‘spectacle,’ and ‘scene’ in conveying these horrors.” Her point is that empathy emerges not as an authentication of atrocity, but as a staged or exoticized display, an account that relies on vivid and theatrical prose in order to depict violent acts for people to extrapolate for their own understanding. As she stated, “the problem is that in the very effort to ‘bring it near’ and ‘inspect it closely’ it is dissipated” [2017, p.20].

With Hartman, we see that the design accounts of empathy work create their own scenes of dissipation. They help elucidate how designers may have a particular interest in accessibility and disability but are open to narrow understandings of their interlocutors’ identities. In retelling the story with disability brought close for inspection, designers may frame disability as the defining characteristic. From this perspective, people with disabilities serve as spectacles for designers to look upon for inspiration. They become important for evidencing that designers built empathy, and that they found such empathizing beneficial.

3.4.3 Displacement 3: Rendering Designers as Nondisabled and People with Disabilities as Nondesigners

I now consider how denying the authority of the disabled experience and treating the disabled user as a spectacle shapes relationships between disabled and designing people. Public accounts, voting machines, and illustrated abstractions depict shifting connections among designers and disabled interlocutors. These depictions may ultimately render designers and disabled people as inherently different.

The Adapt-o-Pack vignette provides a helpful illustration. It described how designers could bring disabled people's stories near during fieldwork, erased their interlocutors' ingenuity with their creation of the more generalizable Adapt-o-Pack cards, and recovered their stories to evidence the game's potential impacts. With simple renderings of a generic farm and farm activities, the cards put aside some of the contingencies of the original setting (here, Rajendra's reliance on his adaptations to care for his family). The list of job duties and stock illustrations communicated the livelihood programs as a yet-to-be-enacted accessibility design space. The accounts described the cards as allowing designers to bring themselves closer to anonymous extracts from Rajendra's everyday experience by, "thinking outside... their [the designers'] own lived experience" [Durlak 2018]. In invoking the phrase "thinking outside," they framed the designers themselves as having no relevant experiences to draw from—that is, no disabilities.

According to the accounts of the voting machine, designers may similarly gloss over the design insights led by disabled people in the face of disability advocacy. The designers implemented some of the machine's crucial features after continued advocacy by the interlocutors. However, just as the Adapt-o-Pack cards made no mention of the existing disabled workers' insights, the voting machine design story overlooked the contributions of those advocates in favor of highlighting decisions made by the design team. They presented designing people as non-disabled people, and they position disabled people as non-designing people.

While well-intentioned, empathy exercises of simulation or persona creation may help designers distance themselves from disabled people, framing the disabled identity as one distinct from, and non-overlapping with, that of the designer. They may appropriate disabled people's techniques and experiences while rendering them non-designers through

their disappearance. When designing for disabled users, such empathy work configures designers as different and isolated from the empathized. Designers may, after Garden, “subtly discount” the experience of those empathized, just as they give themselves (the designers) “the comfort of fictive distance” [Garden 2007, p.560].

This paradox of “empathetic proximity,” according to Pedwell, has as much to do with space as with agency [2014, p. 115]. Pedwell asks, “What about those so-called others who cannot be encountered or known as individuals, precisely because structural relations of power enforce absolute distance or segregation?” [2014, p.31]. With the cards and the simulation activities, designers aimed not only to prompt themselves to think outside their own experiences, but also to distinguish disabled bodies from their own—in this case, locating them outside of the design process. Whether through local organizations such as the Voting Accessibility Advisory Committee [Voting Systems Assessment Project 2015] or from global travels [Durlak 2018], we learn that the people to be empathized live not inside, but at a distance. The resulting narratives paradoxically uphold a distinction between designers and non-designers. In the words of Sara Ahmed, “empathy sustains the very difference that it may seek to overcome” [2013, p.30].

3.5 Discussion

I have so far provided glimpses into empathy’s pitfalls as cautioned by Hartman, Ahmed, Garden, and others. I exemplified how designers may conceal authorship and credit while sharing their own journey of coming to understand something unfamiliar. I described how empathy-building exercises may reify existing power differentials and further separate designer and nondesigner, disabled and nondisabled experiences. Together, these pitfalls help supplant and devalue disabled experience. They elevate nondisabled designers while rendering them unaccountable to the firsthand, disabled, and plural narratives they

initially sought.

Thinking more broadly, I argue that the displacements that occur as a consequence of empathizing people with disabilities, or attempting to understand what it is like to be them, impose necessary differences that may cast disabled people as outsiders (in this case, primarily users who will receive design outcomes) from professional design. This seeming contradiction, as the interlocutors were specifically recruited to become part of the design process, demonstrates how interwoven inaccessibility and misunderstanding the disabled experience are with professional design. These cases show that accessible activities and good intentions alone may not increase recognition of people with disabilities in professional design, if their very experiences are deemed outside its auspices. As such, reworking professional design may require a recasting of people with disabilities altogether. To do this, I turn to disability activism [Jackson 2018] and related scholarship [Rosner 2018, Sayers 2015]. This work posits that a recasting that inverts people with disabilities as already meaningful contributors to, rather than passive recipients of, the design profession may be a promising starting point.

3.6 Conclusion

By examining cases of professional designers attempting to understand people with disabilities, I have argued that well-intentioned empathizing may paradoxically impose necessary differences between the empathizing and the empathized. When the designers we studied focused on the practical and achievable qualities of a task (here, the act of simulating disability or using personas with disabilities), the subsequent accounts glossed over a wider history of ableism and activism that they could have meaningfully drawn upon. Taking up the recognition work of Rosner [2018], Sayers [2015] and others [Jungnickel 2018], in the next chapter I examine how professional designers might invite

in and listen to stories of crip technoscience by disabled people, and how such storytelling might affect our professional design practices and culture to become more accessible.

Chapter 4. Biographical Prototypes: Reimagining Recognition and Disability in Professional Design

4.1 Introduction

This chapter is based on [Bennett, Peil, and Rosner 2019].

In Chapter 3, I argued that professional design communications may cast disabled people as nondesigning, and designing people as nondisabled. But reading these stories alongside disability studies accounts of crip technoscience instead suggest that these popularly circulated accounts of designing for people with disabilities may well hide the fact that people with disabilities invent, modify, and repurpose in response to their lived experiences and encounters with inaccessibility [Hamraie and Fritsch 2019, Hamraie 2017, Williamson 2019]. In other words, they do uncredited work that has been professionalized as design.

With this chapter, I begin to address my second research question: how can lived experiences and creative practices of people with disabilities impact professional design in regard to who can design, what counts as design, and how design should be done? To begin exploring this question, I gathered stories of crip technoscience by people with disabilities and read them with the language and practices of professional design. As a result, this chapter introduces the concept of biographical prototypes: material demonstrations of how individuals with disabilities have made, adapted and repurposed their environments and objects to work for them. As this intervention aimed to take up the language of design to frame these stories, I adopted phrases to characterize what we learned from interlocutors with disabilities including, ‘stories of design’ and ‘stories of making things work’ to rhetorically position crip technoscience as design (and, as we will conclude, more broadly

as contributions to design).

For example, recalling the story of Betsey Farber's under-credited contributions to OXO's products [Jackson 2018], a biographical prototype could be fashioned to recognize Farber's work by covering the handle of a conventional peeler in foam to enlarge the area a user could grip, and then pairing it with her first-hand account of her role in the prototype's inception (see Figure 4.1 and caption). I take up the language and practices of prototyping, and intentionally entangle them with first-hand stories to amplify historically silenced design contributions. With this intervention, I sought to do more than uncover omissions; I also aimed to bring under-recognized stories back into exclusionary professional design processes.



Figure 4.1: Betsey Farber's OXO biographical prototype could illustrate her work by depicting the handle of a conventional peeler covered in foam or Play-Doh paired with a vignette describing her firsthand experience coming up with the idea to adapt the peeler to be comfortable for her grip. Photo by Daniela Rosner.

4.2 Empirical Research

In the sections that follow, I describe the creation and sharing of biographical prototypes across a series of workshops that my team facilitated with disabled activists, designers, and technology developers in the downtown public library in Seattle, Washington. During the

workshops, the biographical prototypes opened discussions about the types of stories that get told and suppressed within design settings. Furthermore, individual stories led to discussions about potential consequences of elevating particular forms of work as contributions to professional design when the title “designer” felt unmerited or unwanted.

To develop the term ‘biographical prototypes,’ I drew on several literatures to arrive at a phrase that would:

- (1) emphasize the personal nature of stories of design by people with disabilities,
- (2) acknowledge the partial and incomplete nature of stories which are situated in greater sociocultural arrangements, and
- (3) directly take up language of professional design.

I began by consulting literatures which investigate the ways in which objects tell stories of peoples’ lives. Anthropologist Janet Hoskins’ [2013] term biographical objects and STS scholar Sherry Turkle’s [2007] anthology of people’s evocative objects helped us to characterize material representations of stories as pivotal to their biographical retellings.

Prototypes occupy a precarious place in professional design, which positions them well to describe the momentary and experimental quality of these crip technoscience stories.

While they get designs out into the real world, they are not meant to be permanent or final [IDEO.org 2015], in line with our framing of the stories themselves as moments rather than whole biographies. Further, we took up the language of prototyping in deference to Jentery Sayers and colleagues’ work on prototyping pasts [Sayers 2015]. Building prototypes of historic technologies, they shared accounts of under-credited designers such as Mary Jamison, a blind inventor of the optophone, a reading machine that used

sonification to communicate printed text audibly. Their prototype responded to and resisted many other accounts that emphasized the male, sighted inventors' perspectives while relegating Jamison's role to a public demonstrator of the device. Chan and colleagues wrote:

Like translation more generally, prototyping does not seek a straightforward, 1-to-1 equivalency, nor does it seek to replicate past devices or embodied experiences. Instead, it highlights smaller gains or losses over time and across versions. That is, it foregrounds difference and absences: what we cannot retrieve, repeat, or translate in the present [2018, p. 6].

We took up this interest in foregrounding difference and absence by specifically crediting crip technoscience practices by people with disabilities.

As exemplified by Chan *et al.* [2018], Jungnickel [2018], Rosner *et al.* [2018] and others who re-presence historic objects while highlighting under-credited inventors, our materials and prototypes were not intended as replacements, beginnings, or endings, but instead as openings for elevating forgotten, untold, and uncredited design contributions. This renewed attention to gaps in storytelling—a counter-storytelling [Solorzano and Yosso 2002]—underpinned our conceptual development of biographical prototypes.

4.2.1 Biographical Prototypes

Biographical prototypes are material manifestations of people's oral or written personal counter-stories of 'making something work.' They combine the language and practices of prototyping with a person's under-recognized stories of design (called counter-stories [Solorzano and Yosso 2002]) to establish such work as meaningful to professional design

practice. Notably, as for our inquiry, designers can use the prototypes to foreground people with disabilities as the fashioners of their own stories and associated representations in design contexts. The prototypes take a wide variety of forms, from representations of artifacts that people invent, to illustrations of rooms that people modify, to mock-ups of digital applications that people repurpose or put to a new use. Their forms and contents range from provisional sketches to full replicas that reflect pasts and imagine futures (see Figure 4.2). In short, we hoped this kind of prototyping would offer a potential means of addressing long-standing challenges around conceptions of design and disability.



Figure 4.2: Selection of prototyping materials and narrators' biographical prototypes brought to the workshop. Nikki's back scratcher on the far left, Diana's jeggings and sequins and wax-covered pen in the middle, and Nikki's embroidery holder featured on the far right.

4.2.2 Workshop Preparation

The initial phases of the study comprising interviews and literature review which underpinned the creation of example biographical prototypes are overviewed in Chapter 2. In this chapter, I skip to the workshops and their preparation.

To create example biographical prototypes for workshop attendees to examine, the research team reviewed the collection of stories I gathered during my interviews with the four narrators, and developed an initial set of 14 biographical prototypes made of store-

bought and found artifacts (see Figure 4.2 and caption). Consider the six examples described below.

Nikki's Tupperware grabber comprised a back scratcher with tines. Nikki described using a back scratcher to hook onto the lipped lids of Tupperware they keep on high shelves. The tines helped them pull the items down. With relatively short arms, Nikki wanted to extend their reach. The back scratcher enabled skillful extension.

Nikki's embroidery holder comprised several embroidery samples, including: a large wooden hoop, a broken wooden hoop, a large plastic hoop sewn to a cushion, and a small plastic hoop. Together these elements illustrated the story of effortful trial and error involved in Nikki's work to learn embroidery with one hand. Describing their embroidery course, Nikki told me how their instructor held a large, wooden hoop in midair with one hand and stitched with the other. Unable to follow their instructor's inaccessible technique, Nikki experimented. They first tried sitting on a similar wooden hoop to free their hand for stitching but, in the process, broke the wooden hoop. Nikki then tried a plastic hoop and found it more durable but not perfect: they sometimes embroidered into their wheelchair seat cushion while sitting on the hoop. They finally switched out the large plastic hoop for a much smaller one in order to neatly balance the hoop between their torso and the wheelchair's arm.

Diana's bead gatherer comprised a spatula wrapped in double sided tape with a box of beads. Diana, who has motor disabilities and uses a wheelchair, told me about her bead crafting. Once, after dropping beads, she found objects in her vicinity to collect them. She wrapped a spatula in double sided sticky tape to extend her reach and catch the beads as she swept.

Diana's rhinestone transporter comprised a wax-covered ballpoint pen with a plate of rhinestones. When Diana added smaller beads such as rhinestones to her projects, she covered the ink end of a pen with wax. With this tool, Diana could lift the intricate items she wanted and place them precisely onto her work.

Diana's altered jeggings comprised a pair of stretchy jeans with hair ties sewn into either side of the waistband. With motor disabilities impacting her reach and grasp, Diana found it hard to pull up her pants. After a long day of not having access to a restroom, she sought out flexible pants in maternity sections. The maternity pants worked for a while, but Diana grew tired of unsolicited questions about pregnancy. As jeggings were coincidentally gaining popularity, she tried on a pair and learned that she needed a bit more assistance than the stretchy material gave. In response, she altered jeggings with hair ties that she sewed into the left and right sides of the waist band for easier tugging. The adaptation represented moments of learning what clothing did not work for her over time.

Julia's calendar comprised both paper and digital schedules. Allocating time allowed Julia to prioritize her medical appointments and work first before choosing which social activities to attend. The structured documentation came in handy when she had difficulty remembering what she should do next.

As we grappled with how to materialize vignettes from interview transcripts, we learned to see the provisional illustrations not as biographies in themselves, but as biographical moments. Generally ephemeral and short-lived, the experiences that narrators shared could never encompass a biography in full. Instead, they materialized particular, often deeply personal memories. We built on this concern while preparing for our workshops: holding onto a sense of provisionality by treating connections between stories as incomplete as well as generative [Sayers 2018, Strathern 2005].

The following sections summarize what happened at the workshops and what we learned.

4.3 Lessons at the Workshops

At each workshop's outset, people took their time to arrive, grab snacks, and find their place at a long conference table stationed in the middle of the room. Some attended carefully to where they sat in relation to others. A few participants already knew one another through their disability communities. Those participants used the set-up period to rekindle connections and introduce themselves to new neighbors.

All workshops comprised four main parts, described next:

- (1) introductions and set up,
- (2) encountering stories and autobiographical prototypes,
- (3) co-creating biographical prototypes, and
- (4) a concluding discussion.

4.3.1 Introductions and Set Up

After establishing the access commitments (detailed in Chapter 2), we invited attendees to share their names, pronouns, and reasons for attending. At this point, facilitators announced themselves available to assist. We then asked participants to reflect on whether they felt they were outgoing or not and to step back or step up respectively. (We repeated these communication considerations before each group discussion, reminding participants that we sought everyone's stories and reflections.) Facilitators noted when people shared and called on those who remained quiet, offering them time to share if interested.

4.3.2 Encountering Stories and Biographical Prototypes

Following participant introductions, we told a few directed stories including one about OXO founder Betsey Farber (see Chapter 1). We then drew participants' attention to the narrators' biographical prototypes displayed on the conference table and felt the excitement in the room intensify. The prototypes' proximity seemed to encourage participants to reach forward and explore the objects in front of them. To contextualize the stories, we guided participants through a few biographical prototypes before asking them to engage freely with the artifacts. However, we discovered this free engagement required additional scaffolding by circulating facilitators. Though eager, some participants only engaged with biographical prototypes near them, and we learned that expecting participants to move around the room presented significant access barriers for some. We also learned that finding and reading biographical prototype story cards and examining the corresponding objects took longer than anticipated. Upon noticing this, we began to intentionally pass objects around to ensure that each participant learned about each biographical prototype. With this passing-along, we took care to give each examiner time to read the accompanying story. After participants had a chance to explore several prototypes passed around the table, we asked them to share with the whole group any biographical prototypes that resonated with them. These reflections often sparked personal and sometimes humorous anecdotes.

For example, a biographical prototype prompted Tali—who uses a cane to assist with balance and who has difficulty reaching shelves—to share their recent experience grocery shopping and finding no employee available to assist them. They told the group: “I’ll have my cane with me, and I’ll be using one of those motor carts. If there is something on a high shelf, I’ll use the hook [of cane] and knock it into my cart. Sometimes the employees get a

laugh out of it.” Tali’s story emerged in response to Nikki’s Tupperware grabber prototype that we created from their interview. While describing Nikki’s back scratcher, Tali found humor in their own everyday activity.

During a similar moment in the first workshop, Ari mentioned the eye strain they experience while engaging in their crafting hobbies. Ari shared this experience while pointing to Diana’s bead gatherer and rhinestone transporter,. Learning from Diana’s prototypes, Ari speculated that similar workarounds might help reduce their own fatigue.

Much like Tali and Ari, several workshop participants used the biographical prototypes to not only share personal stories but also learn new ways that people with disabilities adapt their worlds to get by. Looking across the table, participants variously called the prototypes “remarkable” (Ari), “impressive” (Shay), “simple solutions” (Carrie), and “ingenious” (Ray). “I’m blown away,” said one participant (Tai). Carrie captured this sentiment when she noted, “One of the things I keep thinking about is [that] the way I was taught to talk about disability was about what accommodations do you need. But that didn’t come up here[...]It feels like a set of skills that’s a bonus and not something to apologize for.” As conversation pieces, the biographical prototypes and their examiners drew appreciation and praise from participants, and also began to help frame disability differently.

4.3.3 Co-Creating Biographical Prototypes

After sharing responses to the example biographical prototypes, facilitators divided participants into groups of two or three people and asked them to share something they made work for themselves as well as to collaboratively prototype that story (the object made, the practice of making it, or associated emotions). We selectively intervened to encourage participants to meet new people, or to pair hesitant participants with

participants who seemed to provide openings for others.

In their small groups, participants dove into the variety of arts and crafts supplies available on the table in front of them. Particularly useful items included the braille and print writing utensils and a variety of molding tools such as Play-Doh, Wikki Stix (string covered in wax for easy sticking), pipe cleaners, tactile foam stickers, felt fabric, and Sensational Blackboards that raise lines when drawn upon (see Figure 4.3). We knew that not all materials would be accessible to everyone. Our goal was instead to maximize choice by offering a variety of supplies in the hope everyone would find supplies they could and wanted to use.



Figure 4.3: Four participants working in pairs during the workshop. Each participant is talking with another and handling supplies on the table. Supplies shown on the table include pip cleaners, Play-Doh, colored paper, sheets of colored foam, Wikki Stix, foam sticks, felt fabric, and writing utensils.

In the next paragraphs, I overview a sample of the biographical prototypes that participants made at the workshops. These examples demonstrate the breadth of crip technoscientific practices shared according to themes including:

- (1) repurposing objects in ways unintended by manufacturers,
- (2) inventing objects,
- (3) reconfiguring spaces, and
- (4) mental and emotional labor done in response to inaccessibility.

These examples begin to respond to questions of what counts as design.

First, a number of the biographical prototypes showed how people put objects to use for purposes that were not explicitly intended by the manufacturer. Katherine—who has memory loss—sketched a dinner delivery subscription box out of Play-Doh. Presenting the prototype, Katherine described the chronological instructions and prepackaged ingredients that made comprehending recipes easier; empty ingredient containers were useful reminders of whether steps were completed. Ahsoka and a few other participants made 2D and 3D drawings of calendars and note-taking apps that they repurposed as essential tools for staying focused and managing stress. Ahsoka’s choice of app was particularly informed by her sensitivity to alarm noises; she preferred silent, color-coded notifications. These participants repurposed existing objects to work with their access needs, elevating these resources from convenient to essential tools for ‘making things work.’

Second, other prototypes depicted objects participants invented. These stories often foregrounded provenance: the need or interest that instigated their interventions such as a scarcity of accessible objects or resources to obtain them. Alex—who uses a feeding tube and is Deaf—worked with their partner at the workshop to create a prototype from a plastic water bottle and pipe cleaners to depict their inventive approach to eating. While waiting on insurance funding to purchase a pump that delivers food to their feeding tube

automatically, they received a small syringe from a healthcare provider. Requiring manual filling, the syringe made eating more laborious and time-consuming. In response, Alex created their own interim feeding tube pump by incorporating the syringe into a plastic water bottle. They cut the bottom off of the water bottle, punched a hole through the lid, and threaded the syringe through the hole, connecting it to their feeding tube. They then filled the upside-down water bottle with more food than could fit into their syringe so that, as the syringe emptied, food dripped into it. They additionally taped the bottle to a nearby surface making it possible for Alex to eat while multitasking. Using the prototype—and communicating through an American Sign Language interpreter—they told their story of building the actual system.

A third set of prototypes shared how participants redesigned and reconfigured spaces to work for them. For example, Aaron and his group drew a map of his apartment demonstrating his strategic arrangement of furniture to align paths so he could grasp sturdy objects while walking. This rearrangement of furniture allowed Aaron to forego using crutches at home, as they became cumbersome to manage in the small space. A similar story came from Karen who cultivated several species of lavender, each of which requires unique care and harvesting. Being blind, Karen could not discern the different species since they had similar scents and textures. The garden's spiral shape, preferred for its aesthetic, meant that after a while, counting plants for the purposes of identifying one in particular became unwieldy. At the workshop she shared these challenges and worked with her group to produce a tactile representation of the garden from pipe cleaners and foam, re-materializing the paths she designed through each row of plants. Karen explained that she alternated materials as she laid down the curving paths (one with brick, then one with stone, then one with brick, etc.) so that she could discern species by associating them with the nearby path's material. Together, these design choices helped her produce a desired

aesthetic while keeping care and harvest tasks accessible. For Aaron, Karen and others, negotiating inaccessible spaces felt inevitable. As such, they reshaped spaces in their homes and gardens to work for them, and their biographical prototypes honored those spaces.

Looking beyond physical material, a fourth and final set of prototypes depicted mental and emotional work. For instance, Raphael made a heart and hammer out of Play-Doh to represent the anxiety he felt not expressing his gender before transitioning. The hammer represented “tools” like therapy, coming out, and stress management, each of which he felt alleviated negative symptoms of mental health conditions. Grant made paper versions of the multiple schedules he creates and manages. Rather than feature the tools he leverages, Grant illustrated his creative and difficult processes for keeping responsibilities in check—both for himself and his caregivers. He explained how he organized his schedule by allocating time between his classes to complete tasks requiring a caregiver. He would then examine three caregivers’ availabilities and schedule their work hours. For Raphael, Grant and others, biographical prototypes of making things work augmented stories of expending mental and emotional energy. Although material objects themselves, the prototypes also worked metaphorically to depict aspects of emotional and mental labor.

4.3.4 Concluding Discussions

Upon completion of the prototypes, the small groups reconvened as a larger group. We invited each participant to share their biographical prototype and we posed a series of reflection questions that set up a discussion around who counts as a designer. Questions included: do you often have opportunities to share stories of making things work for you in your own life? What types of stories get told more often? What stood out about the workshop? Is the story you told today a design story? Why or why not?

During these discussions, participants tended to vocalize appreciation for the example biographical prototypes and the sharing and honoring of personal stories. But some participants (Andrea, Genevieve, Matt, Ray, Shiori and Viraj) expressed difficulty thinking of a story from their own lives to share. Andrea, Matt, and Viraj preferred to come up with new designs more than revisiting existing experiences. Further reflecting on these responses, we now examine broader themes and limitations emerging across our encounters.

4.4 Workshop Reflections

These concerns for producing stories echoed comments I heard while circulating among participants before and during the prototyping phase of the workshop. For example, when asked to work with partners and share her own story, Genevieve explained, “I’m looking at them [biographical prototypes] and I’m thinking, ‘Oh, look at this!’ I feel like these people can do everything right and then there’s me.” Hearing this concern, I engaged with Genevieve one-on-one and learned she had not encountered Nikki’s embroidery biographical prototype, which featured setbacks and successes (elaborated above). Together, we reviewed Nikki’s biographical prototype and Genevieve began describing the braille and tactile labels she writes and adheres to home appliances and products. Her frustration subsiding, she soon began writing braille in demonstration to her partners. In this sense, the biographical prototypes didn’t foster an easy connection to a personal story for everyone evenly. Next, we examine these limitations to help us calibrate the conditions for recognition that biographical prototypes make possible.

4.4.1 Challenging Confined Stories: On Pressure to Tell Happy Stories

One of the most salient themes that emerged during both the prototyping and reflection

phases of our workshops concerned the frequency and nature of the stories that their prototypes represented. Participants reflected on their personal experiences and agreed they were rarely asked to tell stories about getting by with disabilities. The opportunity to tell these plural stories of plural lives broke through the far narrower misconceptions they reported others having about life with disabilities. However, they noted often feeling pressured to tell stories with happy endings. While prototyping, I noticed that the workshops gave participants space to question that pressure and explore alternative types of stories.

Many participants viewed the prototypes as marking a rare and welcome occasion for recognizing the personhood of people with disabilities. As Katherine explained, “I don’t think I’ve ever—and I was injured 30 years ago—been asked to share around making things work for you with your disabilities.” Katherine’s experience signified general agreement among participants that they seldom shared stories about disability and ‘making things work.’ Feeling similarly stripped of opportunity, Tali speculated about connections between absent forms of storytelling and wider patterns of discrimination: “[who is credited with design] depends on who is given the most agency or seems to have the most... If you assume that everyone else is doing something for this person you won’t think of that person [as] possibly coming up with that [design] for themselves.” For Katherine, Tali, and others, being asked to share stories about getting by with disabilities was rare. Informed by their personal experiences, they posited that they were not expected to tell such stories because many nondisabled people assume that people with disabilities receive, not design, technologies.

However, when given the opportunity, participants appreciated sharing parts of their lives and personalities through biographical prototypes. Genevieve’s biographical prototype, for

instance, exemplified how storytelling could present multiple facets of our participants. It featured a book cover made from felt fabric inside which rested a page with a braille alphabet she wrote. The object symbolized a literacy technique that she uses to access reading material and identify items around her house. But the biographical prototype also created a means for her to share her ongoing advocacy for braille despite text-to-speech alternatives which in her experience, have led to a misconception that braille may become obsolete. Genevieve went on to share that as a member of the American Council of the Blind, a civil rights organization of blind people, she raises awareness about braille to policy makers in order to preserve its instruction in schools. Genevieve's biographical prototype helped to pluralize her life experiences by offering not only one way she 'makes things work,' but it also provided her an opening to share how advocating for braille instruction in schools has become a passion, which she channels through her community service.

During discussions, participants conversed at length about a pressure to share stories with happy endings. Though well received by everyone, many stories took the form of Genevieve's, ending with successful objects and techniques. But Trinh described how these stories might not be representative. She mentioned strategically choosing among stories she could tell about her disabilities: "When I tell stories about spinal cord injury, I tell [people that] I used to be in a wheelchair and now I use crutches. But then problems [such as chronic illness] I don't talk about. It opens up vulnerability. It isn't an inspiration story." By telling an "inspiration story" (in Trinh's case, focusing on transitioning from using a wheelchair to walking rather than on the ongoing challenges of managing a chronic illness), she and others could relieve what she felt to be a paternalistic desire to fix things on the part of nondisabled people, as well as potentially avoiding feelings of vulnerability. Other participants with chronic illnesses especially connected with this struggle. Lee—who

has motor disabilities and chronic pain—walked through a hypothetical conversation he avoids: “So, what have you been up to these days?’ [people ask]. I hate that question, [so I respond], ‘I only had 6 migraines this week instead of 7, so one day I got out of my apartment.’” Despite what most people want to hear, he explained, “None of my conditions are going to get better. They might get worse.” Finally, Parker corresponded with me after their workshop. While some participants felt comfortable sharing the messier aspects of disability, Parker realized they hadn’t included that in their retelling: “A missing part of my ‘story’ was the drama—the pain, the loneliness, the despair, the failings that came before my victories. I’m still learning to make and take space to illuminate the ‘ugly— parts and not just the wins.” Though rarely asked to tell stories, participants felt pressure to share the “wins” when we invited them to tell their stories. Yet for Trinh, Lee, Parker, and others, these wins did not represent their experiences. Their experiences contained much pain and sadness in ways they may never want resolved (or have the ability to resolve). They instead sought to complement celebration of disabled creativity with invitations from others to be vulnerable.

4.4.2 Disempowerment, Exhaustion, and Disinterest

With biographical prototypes, I began to see not only the workings of recognition within design but also its potential pitfalls. While participants generally appreciated interacting with biographical prototypes, some also voiced skepticism. Telling their own stories of making things work and making space for such tellings could feel insufficient and obligatory.

Some participants found the work they represented exhausting and felt disinterested in calling the work ‘design.’ Parker, who is autistic and visually impaired, shared that they decided not to do a variety of tasks such as wear makeup since devising an accessible

solution felt too arduous. During workshop discussions, they opened up about the fatigue that informed their decision not to wear makeup: “It’s valid to be over it or exhausted. I can have all of the feelings that I have about it. As a disabled person it’s [making things work] compounded.” Carrie—who uses a wheelchair—similarly questioned whether people with disabilities should want to be cast as designers, elaborating, “I don’t really want to be the designer, I want someone else to do the designing and I want to benefit from it. I think the Pollyanna part of it is, ‘well we’re all designers!’ But is that the optimum condition for people with disabilities? Should I be making stools [biographical prototype of using a stool as a lower, easier-to-reach cooking surface] for myself forever? That feels like a job title I don’t want.” Parker and Carrie felt disinterested in being credited as designers, and instead preferred professional designers to take on the task of prioritizing accessibility as standard design practice.

A few participants felt biographical prototypes put too much of a stake in individuals. Andrea’s biographical prototype relayed her difficulties viewing small screens on video cameras with a vision impairment, a task essential for her job filming and publishing disability rights campaigns. She prototyped a model camera with a new feature. The foldable LCD screen would remain compact for transport but enlarge during use to increase the visibility of onscreen menus and what is in the camera’s focus. During the final discussion, Andrea expressed that her urgent access needs would only be known inside the workshop. “I guess I can start a social media campaign...but I’m feeling a bit disempowered in that it’s not actually changes that I can make [to cameras].” Andrea found her strengths in activism irrelevant to the development of a more accessible video camera. This sentiment resurfaced when Carrie offered a nuanced critique: “I want to make a distinction between the power that comes from sharing the things we have to do versus the fact that we have to do them. [These things we have to do] shouldn’t have to

happen...Nobody [when presenting their biographical prototype] talked about systemic things or larger, broader structure things. It's all micro. How can we broaden that in thinking about linking all those things together as a process across all of us?" To Parker, Carrie, and Andrea, stories of invention, adaptation, and repurposing could foster negative feelings of inadequate skill, place too much focus on individuals with disabilities, and erase the complicity of wider structural forces that keep disabled people disadvantaged.

4.5 Discussion and Conclusion

Across the workshops, attendees illustrated a means of recognizing design contributions by people with disabilities. I saw that the workshops also signified a deeper transformation for design practice and research. By facilitating the creation of biographical prototypes, we took seriously the notion that disabled people are always already meaningful contributors to professional design practice. We materialized forms of counter-storytelling [Solorzano and Yosso 2002] in order to change the circumstances by which the circulation of those stories might take place. The workshops exposed how prototypes worked not just as objects for eliciting feedback but also as ways of rehearsing particular and under-recognized forms of authorship (see Sami Schalk on crip futuring through speculative fiction [2018]). Through engaging with varied personal stories, participants began to imagine what they did not experience and reflect on the limitations of their imagination. For those who engaged with them, biographical prototypes helped shed aspects of a pejorative understanding of disability in favor of one that pointed to potentials for creativity. Additionally, they helped us to challenge wider silencing in design research and even to critique my methods of representation and recognition.

But the most poignant of participant critiques cautioned that biographical prototypes could focus narrowly on individuals in ways that risk asserting that people with disabilities

should be responsible for their own adaptations. Celebrating design stories, then, may obscure the oppression underpinning their necessity. In other words, recognition alone can still promote assumption that disabled people can or should come up with their own accommodations. My attempt to address wider structural issues in professional design made some headway to resist the valorization of predominantly nondisabled professional designers speaking on behalf of disabled people. But this resistance left much work to be done. In particular, I learned that biographical prototypes could not engender assumptions that people historically under-recognized within design fields would be overjoyed (or even willing) to join the ranks of designers. As a first step to dial back enforcement to necessarily cast crip technoscience as professional design, I take up the language of contribution with the hope of opening up who can count as a designer and what can count as design, while ultimately recognizing that disabled people are already and always meaningful contributors to professional design, but should not need to enroll into the design profession to be recognized.

I offer these lessons as a means of emphasizing the significance of both creating space for people with disabilities (as designers or otherwise) and those working on design projects learning about one another through prototyping. In helping us to explore sites for recognizing often-hidden design legacies, they lay the groundwork for the refinement and elaboration of biographical prototypes in domains of work. But I learned from crip technoscience that disability, and the stories that illuminate the knowing-making of disabled people, necessarily reveal frictions. As they are told in a world that still dismisses access to the periphery, disability studies scholars argue these frictions must be held rather than disappeared. In other words, while recognition by intervening biographical prototypes into professional design practice may be a partial response, it does not provide an easy or straightforward solution to long-standing inequities.

As such, in the next chapter, I explore how lived experiences and creative practices by people with disabilities might be recognized and classified more broadly so as first, not to bound them by professional design language and practices and second, to better illuminate the frictions of crip technoscience that structural ableism upholds.

Chapter 5. Interdependence as a Guide to Recognize Access Work

5.1 Introduction

This chapter is based on [Bennett, Brady and Branham 2018 and Bennett, Rosner and Taylor 2020].

In the previous chapter, I introduced biographical prototypes, an activity for bringing crip technoscience counter-stories by people with disabilities into professional design. Through their examination, creation and sharing, biographical prototypes opened moments for people with disabilities to recognize their creativity and ingenuity, and to discuss their rare opportunities for sharing such stories of invention, modification and repurposement outside the workshop. But in celebrating one another's creative adjustments, workshop attendees also noted the exhaustion and extra labor the stories their biographical prototypes represented, aspects of their stories which we had not explicitly sought.

With this caution, I wanted to think again with disability activism to rework recognition of contributions by people with disabilities in a way that does not enforce the language and practices of professional design onto crip technoscience. I also wanted to explicitly recognize tensions among the work people with disabilities do to build access while recognizing that the structural ableism this work responds to is unacceptable. In so doing, in this chapter, I leveraged interdependence, as recent research is beginning to do [Middleton and Byles 2019], to structure my analysis of fieldwork during which I observed people with disabilities. Specifically, I positioned interdependence as an analytical tool to examine three pairs of people with different vision working together to co-construct accessible worlds in common. Drawing on disability justice activism, interdependence not only foregrounds work done by people with disabilities but offers a structure for

understanding this work while holding onto the resource scarcity and pervasive inaccessibility that necessitates community-built access.

This chapter takes cases of people with different types of vision working together as a starting point for thinking with interdependence to complicate how access is understood in professional design. As I mentioned in Chapter 1, access is often depicted as a fixed achievement. But crip technoscience, biographical prototypes and interdependence from disability justice activism tell a different story. They point to ways in which access comprises ongoing, effortful work that gives rise to crip technoscientific practices, or the knowing-making that happens in the frictions of being disabled and living in an inaccessible world. While crip technoscience warrants recognition and celebration exceeding the praises of professional design labels (as critiqued in Chapter 4), it also entangles with the ableism it resists—ableism such as assistive interactions that presume that nondisabled people care for disabled people.

5.2 Independence and its Limits in Disability Activism

I will begin by providing some historical background to clarify what I mean by interdependence, and particularly how taking it up according to disability justice articulations demands recognition of, and holding on to, frictions.

During the greater United States Civil Rights Movement in the 1960's and 1970's, disability rights activists, who largely consisted of white and physically disabled people, led a specific disability rights movement and independence became its cornerstone. By demanding independence, disabled activists asserted that people with disabilities have the right to make choices about how to live their life. This assertion pushed back on the widespread institutionalization of disabled people, which often entailed egregious human rights

violations at worst, and at best, extremely restrictive environments that limited disabled people's whereabouts and general societal participation [Johnson 2003]. Earning rights to make choices and trainings that prepared disabled people for competitive employment became known as 'gaining independence' [Barnes 2003, Kafer 2013, Longmore and Umansky 2001, Scotch 2000, Shapiro 1994].

Accessibility research has taken this call seriously and in the relevant case here, assistive technologies have been developed with the aim of increasing independence of people with disabilities [Wobbrock *et al.* 2011]. However,, independence can place the credit of providing access on the technologies and infrastructures that enable participation by people with disabilities, and may cast people with disabilities as passive recipients of such provisions.

5.3 Interdependence

Recent disability justice activism has pointed out the community-based and collective character of much access work, which can be obscured by an independence framing. Specifically, disability justice activists have, over the past 15 years, shifted how they talk about access. Evidence of this shift is marked by a transition in terminology from independence to interdependence. Notably, these activists, largely from the Bay Area Disability Justice Collective and Sins Invalid performance project, credit their multiply marginalized identities for informing the shift in naming and focus from independence to interdependence, which they believe more accurately characterizes and credits the extensive relational networks they build and maintain to get their needs met and to meet the needs of others in return. Being primarily disabled people who are also queer, trans, Black and Indigenous people of color, they argue that government programs like post-World War II veteran rehabilitation programs, from which current design for accessibility

principles like universal design are derived, mostly met the needs of white disabled working people and stay-at-home parents. Meanwhile, the defunding of already racist and transphobic healthcare, rapidly gentrifying urban areas, and gatekeeping health and rehabilitation services for those who can show proof of insurance have instead kept multiply marginalized disabled people reliant on collectives of care [Mingus 2010 A and B, 2011, 2017, Hamraie 2017, Piepzna-Samarasinha 2018, Sins Invalid 2016, Williamson 2019]. For example, in their disability justice primer, Sins Invalid activists offer collective access tips including sharing routes home to stay safe, dividing access-related tasks according to group members' strengths, and being flexible to dynamic access needs that may change over time [Sins Invalid 2016].

However, interdependence is not a utopia. Though it points to moments of distributed labor that, at best, honor the capabilities of disabled people without normative expectations of what counts as access and care, interdependencies are rife with complications, communication breakdowns, and the difficulties of maintaining a relationship when you wish to know someone for companionship but have come to rely on them for some sort of access provision. At a larger scale, events like the 2019 California wildfires and subsequent power shutoffs exemplified the types of injustices that necessitate interdependence. This event specifically catalyzed on-the-ground organizing to crowd fund and crowd distribute generators, air purifiers and other devices essential for staying alive with disabilities that require breathing assistance and clean air. In response, Stacey Milbern, a key disability justice activist in this organizing project and in the movement as a whole, deplored the romanticizing of interdependence, noting that, as with our unthought celebration of biographical prototypes, such valorization obscures and absolves institutional-level accountability and reparation [Milbern 2019]. In other words, according to disability justice activism, interdependencies do not substitute for structurally

supported access like funded healthcare, and interdependencies do not live outside the largely ableist world they try to resist [Wong 2017, Piepzna-Samarasinha 2018].

Research in feminist STS provides useful tools for deeply unpacking and complicating care work, a term describing the affective labors of keeping others well and being well together [Despret 2004, 2013, Giraud and Hollin 2016, Murphy 2015, Puig de la Bellacasa 2011, 2012, 2017]. I consider care work a companion to interdependence and access work for their frequent application to describe attendant care for people with disabilities [Kelly 2013, Piepzna-Samarasinha 2018]. Though this literature rarely engages disability explicitly, some notable exceptions include work by disability studies and feminist STS scholars Kelly Fritsch [2010], Christine Kelly [2011, 2013], Laura Mauldin [2017] and Ingunn Moser [2011]. For example, Christine Kelly drew out these complexities with her term ‘accessible care’ or, “an unstable tension among emotions, actions, and values, simultaneously pulled toward both empowerment and coercion” [2013, p. 790]. Writing of her “frien-tendant” relationship with a man with disabilities, she shared how care is multiple. It is in their mutual friendship, in her assisting him with daily tasks, and in the ways these acts seamlessly blend. But care also threaded through her discomforts with the ways she is simultaneously perceived as superior to her disabled friend and undermined through the feminized devaluing of care work, marking complex tensions that may be subverted if the focus remains on efficient completion of care-related tasks.

For my research, taking up interdependence as a tool for analyzing access work may provide some promise for complicating the ways in which contributions by people with disabilities are(n’t) recognized, and a concept through which we can imagine holding onto the possibility that access provision may problematically band-aid structural ableism, and may itself be conducted in an ableist manner. Guided by interdependence, I then turned to

the aforementioned complications of care by feminist STS to unpack moments from the field observations I describe next.

5.4 Empirical Research

The materials I present below take the form of detailed transcripts of fragments from video I recorded while interning at Microsoft Research. The video was captured while my mentor, Alex Taylor, and I accompanied pairs of people who had consented to be filmed, and also in some cases to wear small cameras during routine, everyday outings.

After data collection, small groups of researchers discussed the observations, alongside reviewing fieldnotes, video excerpts and transcripts. This helped us prioritize the deeper analysis of what we thought were moments where access work seemed particularly important. We were especially drawn to what we observed to be the ways the pairs actively collaborated through a combination of conversational talk and bodily gestures, and where specific questions arose around: how people with different degrees of sight use talk and fine-grained movements to coordinate with each other, how pairs make their actions mutually intelligible to unproblematically (or sometimes problematically) get on with an activity, and where troubles arise in these interpersonal interactions.

5.5 Findings

To investigate more deeply how interdependencies build access, I present three cases—one from our time with each of the aforementioned pairs. As I recount the cases, I borrow from feminist STS and disability studies scholarship to help enliven what might at first glance be viewed as partnerships in which someone with more abilities assists someone with fewer abilities. In the first case, I establish how to read an interdependency from a transcript

depicting the completion of a short task. I show that it is not only what seems like the direct acts toward completing the task, but also mutual investments in one another to enable each other's action, to not only build access but ensure everyone is building it together. In the second case, I show how contributions shift among actors to maintain the interdependency. In the third and final case, I draw out how interdependencies can shift in and out of operating in ways that privilege certain senses—like vision—over others. Together, these cases show that paying attention to relationships of people and things that build access while assuming people with disabilities are important contributors may illuminate new ways of thinking about access.

5.5.1 Building Access Interdependently

To begin, I turn to an excerpt from video we recorded of William and Jason. I use the excerpt to illustrate how access is not something given (or received) but rather co-configured by the pair through their encounters. In particular, I highlight how the conditions for access come about through interdependencies.

The video is of William and Jason in a meeting room. But rather than sitting at its conference table, the twosome, along with other meeting participants and a group facilitator, Sandra, are standing in an open area. Sandra has instructed the group to form teams of two in preparation for an activity where each team will pass a ball back and forth. As a team, William and James place themselves to one side of the room, facing one another, and ready themselves to throw and catch.

Before turning to the details of this scene, it is worth noting that William contracted a vision impairment seven years prior to the observation. With a full field of vision, he sees large objects and colors within a few feet from him. Jason, William's guide (who has full

sight), is employed via a government scheme to assist with work activities upon William's request. Their throwing and catching is one exercise in preparation for an upcoming event in which they will be working with young vision impaired children, helping them to improve their confidence by participating in sports activities.

Let us then turn to the short excerpt in which William and Jason work to throw and catch, as instructed.

- William* *F1* *[Holds yellow oval-shaped ball out towards Jason and taps on it with fingers]*
- Jason* *I think you should drop-kick it. [Turns and faces William and looks to ball.]*
- William* *F2* *I could do a drop-kick. [Hands ball to Jason.]*
- Jason* *F3* *[Says something inaudible while tapping hand against ball and handing it back to William.] We're sort of limited, though.*
- William* *F4* *Yeah, we are a bit. [William hands ball back to Jason.]*
- Jason* *F5* *I think you should try a drop-kick. [Jason takes ball with two hands then taps on it with right hand. Turns to Sandra and back to William.]*
- William* *Ha, I'll try throwing it. [Steps back as Jason hands him the ball. Then takes ball in both hands readying for throw.]*
- Jason* *[Steps back, readying for catch.] Yeah, alright, do*

that, do that...

William

[Draws ball back towards him slowly, then throws to Jason, who's standing about 2 meters away.]

Jason

[Sound of Jason catching ball.] Yes.

William

Go on, try throwing it at me. [William holds his hands open and out.]

Jason

Haha. [Nods head to one side and tosses and catches ball gently in his hands as he readies to throw it from one side of his body.] Right, do you want it properly with a bit of spin? [Throws ball in spinning motion as he says, "spin."]

William

Give it a go. [Grasps ball as it reaches him, but it falls between his hand and body. Moves towards fallen ball.] Aww.

Jason

Aw. [Reaches down to get ball that has rolled towards him.] You should have had that.

William

Okay, try again, try again.

[Moments later...]

Jason

That's defeating the point. [Throws ball up and catches it twice before throwing towards William.]

William

[Catches ball.] Yes.

In this transcript, we find that William and Jason participate in the exercise by gradually establishing a rhythm. They begin, tentatively, by handing the ball back and forth—

signaling their movements with taps of the ball and gross gestures to ready one another (See Figure 5.1). This back and forth also corresponds to verbal cues such as, “are you ready?” and confirmations like, “yes,” and, “oh, that was good.” The passing of the ball is then synchronized with that “simplest” unit familiar to conversation analysts, turn-taking [Sacks *et al.* 1978, Schegloff and Sacks 1978]. William and Jason come to first pass the ball to one another, then throw and catch it, and finally (beyond the short window we present) accomplish a drop kick.

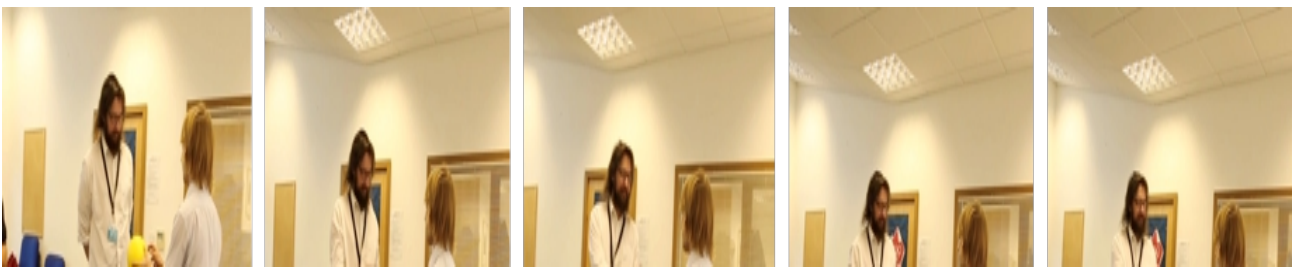


Figure 5.1: Video frames F1 through F4, corresponding to spoken turns between William and Jason.

It is this turn-by-turn interaction, and what emerges as a combined set of capacities, between William and Jason that I point to as an interdependency that creates conditions for access. I find that the capacity to throw and to catch does not reside in any one actor—William or Jason—but comes about through actions that are made mutually intelligible between the pair. Notably, these are not explicit or crude declarations like, “I’m passing the ball now,” but built into the unfolding interaction—agencies shift fluidly. Certainly, to speak of access here, and to presuppose agency residing in one member of the pair but not the other, would belie what is achieved by William and Jason together. In other words, it would be to elide how they come to be interdependent.

Something that is harder to get a handle on in interchanges like that between Jason and William is that a certain sensibility appears to be at work between them. On viewing the sequence above, what feels abundantly clear is that there is a care between them; they

seem not only invested in successfully throwing and catching the ball, but also to share a concern for how well they are doing together and whether they are achieving the most from their combined capabilities.

Paying closer attention to the video and transcript, there is an affective interchange threading through their acts of connection. A care is made observable in Jason's hesitation to throw the ball at first, in William's persistence, and in their voiced compassion, with verbal cues like, "aww," and in humorously suggesting a drop kick when they aren't clear how they will accomplish the task at all. The seemingly functional acts of throwing and catching are then entangled with gestures signifying a will, a hope, and the investment to throw and catch a ball well together.

Below, I give closer attention to this presence of care, and its entangled relations with the practical acts of doing things with others. What I consider is how not only agency, but also caring, continually shift in these interdependencies. In so doing, I show how interdependencies might also open up moments for another to act.

5.5.2 Shifting Labors of Access

Below I rejoin William, this time shopping with his long-time, romantic partner-sometimes-guide, Emily. William uses his white cane and partial sight to navigate, and Emily, who has had little sight since birth, is accompanied by her guide-dog Jazz. The threesome is in a pharmacy and the transcript captures their search for an exit in a maze of crisscrossing aisles.

Emily

You want me to find the door?...William?

William

Yeah. [Keeps walking.]

Emily You want me to find the door?

William Find the door? [Stops and turns to one side as Emily approaches.]

Emily Do you want me to find the door?

William Yeah, go on then, yeah.

Emily Where have we gone now? [Emily and Jazz take the lead, and begin to walk right down an aisle.]

William I think we've...Oh, we've headed up to the perfumes.

Emily 'Scuse me. [Walks around someone, then walks in silence.]

Emily [Talking to Jazz.] Good girl. [Sotto voce, as they continue walking ahead.] Where are we going?

William [Inaudible.] Lost?

Emily Yeah, err... [Turns left.] Straight on. Find the door. Good girl, find the door. Find the door, good girl.

Emily [Talking to Jazz.] Good girl, find the door. [Door is approximately four meters in front of them. Jazz and then all three stop.] Oh, it [the door] doesn't open.

William It's not an automatic door. [Walks around Emily and Jazz and opens a swinging door.]

Emily Oh, isn't it? [Walks through as William holds the door open.] Oh, hahahahahaha. We got stumped by

a door. Good girl. [Pats Jazz on the head.]

William

Hehehehe. [Continues walking.]

In a flow and intermingling of forces, William, Emily and Jazz work together to navigate obstacles like shelving units, other shoppers and the larger floorplan to locate the exit. There is a form of access at work; agency is distributed across a heterogeneous assortment of actors in order to make exiting the store possible for the group. William, Emily, Jazz, the harness, the shop's floorplan, the aisles, and so on, comprise an interdependency which produces the conditions of access through which they are able to respond to each other.

Importantly, though, these capacities shift continuously among actors as they progress and work together. Different relationships to another's touch, to lighting, to space, thresholds, words, interactional sequences, open up possibilities for new ways of sensing. But these openings are not only material. While things are getting done, William, Emily, and Jazz notice how things are (or are not) getting done. There is a sensibility to who is capable of what, and how the flows and shifts can work together. Indeed, Emily and William spoke of other occasions in which they walk side by side, combining their ways of 'seeing' to compose a field of potential co-action in common.

In working interdependently, each is caring for how the others are able; their access is thus made possible as much by who can do what as by how one can open an opportunity for someone else to do something. In showing caring and doing as co-constitutive, I point to a sensitivity William, Emily and Jazz have for one another that makes this intermingling much more than finding the exit or completing the task. To see what is unfolding in purely instrumental terms—as problems of navigating bodies from point A to B, or of

mechanically throwing and catching—is to lose all that has gone into how actions and abilities are mutually constructed and shared. Much effort is given to ensure everyone can contribute.

From philosopher of science Vinciane Despret, I learned that developing a rapport like this, a sense of each other’s capabilities, requires one to give these capabilities, “some worth, some affective values” [Despret 2013, p. 55]: a sensibility that everyone is attuned to William being good at this, Emily that, and Jazz something else. Much of the work done in these interdependencies is in enabling this fluid flow of forces to happen. As I will show, this caring labor may not only authorize others to act, but importantly, may also determine what types of sensing are most recognized in a given moment.

As such, in the next section I establish how interdependencies do not necessarily presuppose good. I show that some of what goes into building access forecloses some types of labor from being recognized, and sometimes this can occur along lines of disability.

5.5.3 Uneven Access-Building

To explore in more detail some of the troubles that may arise in building access, I turn to another video recording we have made, in which I find our third pair, Joseph and Gwen, using a trolley to transport some tables they have borrowed from a church next door, for an event Joseph is hosting at his workplace. Joseph is completely blind and Gwen is his long-time sighted guide. Unsurprisingly, both have come to be close friends over the years. In this example, we skip to the end, when Joseph and Gwen are bringing the trolley back to its storage place in the church. Though they no longer have need for the trolley, upon arriving at the church, Joseph and Gwen have loaded some more tables onto it, and they look to be rolling it back outside.

Gwen I'm just going to open the door here. [The pair wheel the trolley into the church.]

Joseph Okay.

Gwen Can you just go straight ahead?

Joseph Yeah, ish. Hahaha.

Gwen ...Leaning to the right...

Joseph I am? Or you want me to?

Gwen You, hahaha.

[A few minutes later, they have begun to wheel the trolley back outside, navigating it through two different doors. In the midst of this, they realize they've done this unnecessarily.]

Gwen Okay, we're going to swivel it [pause] to your right.
[Said slowly as if contemplating direction.]

Joseph [Inaudible. Both swivel the trolley as Gwen directed.]

Gwen You ready?

Joseph Yeah.

Gwen [Inaudible.]

Joseph [Scratches head. Both move the trolley toward the door, then stop at the door.]

Gwen I'm going to push against this door. [Opens door.]
Okay, straight ahead.

Joseph [Pushes the trolley forward.] Okay.

Gwen [Inaudible.]

Joseph Okay.

Gwen Okay, and turn right. Joseph, just stabilize it, please. [Gwen lets go of the trolley.]

Joseph Okay.

Gwen [Inaudible.] I think, I'm going to unlock the door.

Joseph Yeah. [Pause.] Sorry, where...Where are we going with this?

Gwen Pardon? [Laughs. Both laugh and say a few inaudible things.] The trolley goes in the corner.

Joseph Yes. [More laughing from both.]

Gwen [Inaudible.] It could be like Groundhog Day; we could just keep going back and forth.

As Joseph and Gwen walk with the trolley between them, it is at first hard to be sure who is guiding whom. Both are exerting different forces on the trolley, Joseph pushing, Gwen pulling. Joseph momentarily pushes alone, Gwen issues words that help to orientate him. Even when they have realized the mistake, Joseph's subtlety in action and dialogue: in turning toward the door and in asking "Where are we going with this?" (see *) compassionately makes Gwen aware of their unnecessary efforts. Working together, it seems fair to say there is an interdependency between the two, the trolley and church.

Admittedly, this interdependency seems to default to positive affect and presuppose political and ethical good. However, in this reading, I am not complacent about the

distributions of authority and power it allows. Gwen and Joseph seem to be very much attuned to one another, and noticeably there is a caring in their voices, pauses, hesitations, and bodily interchanges. And yet the distribution of work leans markedly to one side. As STS scholars Ingunn Moser and John Law [1999] described, “good passages” conceal others. They and other STS scholars who complicate care work are emphatic, and rightly so, that the work to make room for another, or build access, cannot be outside of this [Giraud and Hollin 2016, Kelly 2011, 2013, Mauldin 2017, Moser 2011, Murphy 2015, Piepzna-Samarasinha 2018, Puig de la Bellacasa 2011, 2012, 2017].

To be sure, Gwen is guiding Joseph here. She exhibits her expertise as a guide, issuing a series of orientating turns to anchor Joseph as they move from outside to inside, through a series of doors. “Straight ahead” indexes the open door, the passing through the doorway, the movement of the trolley. Joseph’s, “I am? Or you want me to?” is a query to the prior turn, but also a question about the line he has followed or must follow. More precisely, he is reassessing the line he is making with the trolley as he passes through the threshold, moving from before the doorway to after it. This is an altogether more complex affair than the ‘standard’ guiding formation between a vision impaired and sighted person. People, things and spaces are changing, so that what is invited is an active and collective sensing, what we might call a sensing-with, much more than a sensing-for or -of. But this unfolding, as mutual as it may be, also demands recognizing Gwen’s placement in front: she moves Joseph’s hand, she vocalizes the actions. It is Gwen sensing in a-world-for-the-sighted and giving Joseph the capacity to act in this world. This certainly allows for more to happen; for Joseph to, for example, reorient the pair when plans go awry. But he is being afforded a capability that highlights his absence, that highlights what he cannot ‘see.’ In this moment, their interdependency orders ability in a distinctive way [Moser 2005]. It is performed along the lines of disability.

I do not do justice to the troubling and historically contingent complicities that come with providing assistance, as others do so richly in complementary work on caring relations [Giraud and Hollin 2016, Murphy 2015], but I propose that the interdependencies we find enacted between William, Emily and Jazz provide another way of approaching how access can be built. Between and around them, there are to be sure power differentials. On the shop floor, for example, there are: large typefaces marking out aisles, regulated levels of illumination, standardized aisle widths and automated doors (or not, as the case may be). All these designed items materialize a structural access for people who can use their vision to find the exit. But still, the threesome provides a way to understand how interdependencies might flow in ways that authorize acting through non-normed sensibilities.

Let us think a little more with William, Emily and Jazz to consider this. True, they are making do in a setting designed for sighted people, but conditions for access also seem to come into being through their openness to authorize different types of capacities. Being capable here is much more than a literal ‘seeing’, it comes through an interdependency resistant and responsive to dominant visual cues. Their work together shows how creating uneven conditions for access does not preclude more equal and generative forms of being together. Indeed, they illustrate how an attention to interdependency, which foregrounds their ways of sensing, may help deepen understandings of the particular forms of work on which access depends.

Even in the most ordinary occasions with what may seem the most banal consequences, attending to interdependencies provide an alternative way of complicating how “historically and spatially layered distributions” [Murphy 2015, p. 721] of power and capability entangle with access. Understanding access in this way is not to dismiss Gwen’s

guiding or Joseph's guiding; it is to accept that this difficulty is often the way access is built. Joseph, William, Emily and Jazz come to be able in these always-shifting modes of uneven ordering that must be pieced together. The fact that building access comes with seemingly inevitable structural inequalities does not imply turning away from the trouble. Instead it suggests attending to it closely [Haraway 2016]: making room for multiple and alternate types of sensing that resist prevailing norms.

5.6 Discussion

I have used the above encounters to begin to complicate a conventional focus in professional design on considering access as a fixed quality of design solutions meant for users with disabilities. By paying attention to people living with vision impairments, and to the mutual capacities enacted with each other, I have sought to exemplify a variety of processes for creating access. Among each pair, above, we saw threaded through interdependencies not only definite acts toward building access, but caring relations which could open up or foreclose different types of sensing. Since interdependencies foreground work done by people with disabilities in such relations, I began to notice when authorizations occurred along lines of disability, privileging some ways of sensing, like vision, over others. But by attending to the work done by people with disabilities, I also learned new ways of sensing that were integral to building access together. With William and Jason, I noticed this with the tapping of the ball to signal its location, and their slowness to figure out the best way to throw and catch together. With William and Emily, I noticed access-building in the ways they used their memories, smell, sensing of Jazz's movement through a guide-dog harness, and in their back-and-forth information sharing, which opened up moments for them to re-assert the other as an active participant. With Joseph and Gwen, I found access-building in Gwen's instructions, opening doors, and

pulling on the trolley, and in Joseph's pushing (and sometimes steering) the trolley, his gestures which invited shifts in their activities, and his compassionate demeanor when he asked Gwen where they were going when they had intended to secure the trolley back in place. But I also saw this access-building unfold in uneven ways that privileged a caring for vision impaired people that relied on 'seeing for' another. As much as they cared with one another, William's difficulties accessing throwing and catching were markedly greater than Jason, who smoothly threw and caught during his turns. Similarly, Gwen's exacting instructions for moving the trolley enabled Joseph to act in a limited way, responding to a narrow, verbal interpretation of visual surroundings whereas had space been made, he may have had much to offer from what he was sensing nonvisually.

Turning to the literature to make sense of these interactions, I also saw how interdependencies were entangled in these everyday actions—how, as feminist STS scholar Maria Puig de la Bellacasa wrote, care is brought into being through “a hands-on doing connected with neglected everydayness” [Puig de la Bellacasa 2017, p. 111]. With an attention to care, we made out the difficult-to-identify-in-action but ever-present investment the pairs have in doing well together and opening up opportunities for each other to act. This concern helped me articulate the varied forms of work it took to create access while recognizing such work as inseparable from the task completion I set out to learn from. I saw how the interdependencies produced through and with access worked in distinct and important ways.

In closing, I want to look more closely at these emergent interdependencies in the context of interactive designs. Our analysis points to how I might widen the emphasis on achieving discrete outcomes, and place greater importance on the work going on in the interdependencies. Specifically, I imagine what it might mean to recognize these

interdependencies as routine, including the always present and meaningful work done by disabled people as a guide for new ways of designing. And in recognizing this work, I also consider the roles actors have in authorizing one another in ways that may or may not make possible crip technoscientific practices, or disabled ways of sensing and doing toward building access. In so doing, I suggest considering specific approaches to designing that are sensitive to the routine work of care access enacting particular (and never entirely innocent) versions of disability and ability.

In the following, I respond to this prompt by thinking through two notable ways in which interdependencies gave rise to access in these cases:

(1) mundane attunement, and

(2) non-innocent authorization.

5.6.1 Mundane Attunement

Captured above, the interlocutors exposed interdependencies knitted into the ordinary course of life events, into continually shifting relationships of things and people mutually sensing in common. Through the collaborative acts of tossing balls, finding exits, and pushing trolleys, a routine kind of access was continually negotiated. Such access was not made possible, or even likely, just from completing tasks. Instead, authorizing others was an essential part of this routine work [Despret 2004, 2013].

Thus, threaded through these interdependencies was not a preoccupation with the completion of a task *per se*, or indeed the steps necessary to achieving it. Instead, there was an investment in establishing what mattered and what was meaningful between those involved. What counted as accessible was, in other words, held open, attuned and

negotiated between actors. Whether dropping or drop-kicking a ball, it was an unfurling care for such mundane acts that made moments matter, that gave them worth and the direction for what to do next. Building access [Hamraie 2017] is not a special achievement here, but the ordinary, mundane attunement of people's acts, wills and hopes—of how to move on.

5.6.2 Non-Innocent Authorizations

Across the vignettes, the work of access was not only continually constituted through mundane attunements; it also shifted and sometimes did so unequally. In building access together came the inevitability of producing relationships inflected with moments of awkwardness, hesitation, and dominance. Consider how Gwen and Joseph moved between providing access and attuning access; in their unfolding relations, they exposed skewed capacities. For them, their interdependency could not be “reduced to [the] smoothing out of differences,” but was instead a practice of working with differences [Puig de la Bellacasa 2012, p. 204]. And in some cases, these differences were cast by long histories and troubling normative presumptions about the values of certain bodyminds and abilities [Davis 1995, Piepzna-Samarasinha 2018].

This signaled the non-innocence of care that feminist STS scholar Michelle Murphy wrote of in the context of the transnational movements of a vaginal self-exam [Murphy 2015]. To care—even to care for another's access in a sight-dominant world—is to exert a politics, for example, a politics of who has the authority to decide what bodyminds should guide other bodyminds, what abilities should be the ones to invite other abilities to act. What I found on occasions like Gwen and Joseph's is that the authority—the capacity to authorize these politics of bodyminds and abilities—was entangled in the mundane work of care. To guide and take the lead using a textbook formation, to translate the visual into the audible, were

acts that did not point to an absence of access, but rather which showed how this work, in the very practical ways movements are afforded and authorized, came to be marked by structural inequalities and discrimination. To authorize is always to perform a disconnect, “we cannot possibly care for everything, not everything can count in a world” [Puig de la Bellacasa 2012, p. 204].

The implications for professional design must then be to accept that in making decisions, in choosing to disconnect some worlds from others, in authorizing particular versions of the careful work of building access, there must come responsibilities—taking responsibility for and specifically resisting the foreclosure of certain acts in ways that uphold the structural ableism that keeps disabled people from professional design.

5.7 Conclusion

In this chapter, I have sought to widen the conditions through which people with disabilities are recognized for their contributions to building access. Whereas celebrating crip technoscientific practices through biographical prototypes may importantly push back on a lack of disabled voices in professional design, disabled people’s work exceeds the professional design studio. To recognize contributions of people with disabilities in everyday activities, I drew on interdependence from disability justice activism which describes access-building as collective and comprising work, of which disabled people’s contributions are integral. But while interdependence hints of futures where work done by people with disabilities is recognized, and where access is attended to collectively and continually, interdependencies are premised on reliance that is often itself necessitated by structural ableism that keeps healthcare and support systems unavailable to many disabled people.

Thinking with interdependence, I analyzed how three pairs of companions with different vision built access together. From their interactions, I uncovered two sensitizing concepts that draw out characteristics of access-building. The first, called mundane attunements, refers to interactions that fall in and out of access-building. In this way, building access is not remarkable or fixed. Rather, it is part of each pairs' ordinary activities to get by and enjoy each other's company. The second sensitizing concept, called non-innocent authorizations, points to the complexities of access-building where moments of working together subvert people with disabilities in favor of normative sensing like Gwen's 'seeing for' Joseph. Together, these concepts and the three pairs teach professional design that access-building is continual work that becomes knitted into and inseparable from other relations. As such, access-building is also non-innocent, and is not located outside of the inaccessibility it resists. Instead, access-building may always exert a politics that at time privileges certain labors over others. By looking for these moments of awkwardness and subversion, professional designers might seek out the histories and conditions that produce such inequity, and support interlocutors' negotiations of these complex realities over attempts to design ourselves out of inaccessibility.

Chapter 6. Toward Centering Access in Professional Design

6.1 Introduction

In this dissertation, I set out to answer two research questions:

- (1) How are people with disabilities cast in media which communicate the methods and experience reports of professional design? and,
- (2) how can lived experiences and creative practices of people with disabilities impact Professional Design in regard to who can design, what counts as design, and how design should be done?

To address these questions, I drew on disability studies and other critical perspectives. To address the first question, I learned that professional design communications and experience reports tend to relegate disability to a descriptor of potential users. While professional designers empathized with users with disabilities, they imposed separations between designing and disabled people. Despite their contributions to projects like the design of voting machines and empathy-building cards, the work of disabled interlocutors in those cases was illegible to professional design. But the theoretical underpinning to my research gave me tools to offer a different perspective. Counter-readings of design thinking experience reports, accounts of disabled people from the history work of scholars such as Aimi Hamraie [2017] and Bess Williamson [2019], and autoethnographic accounts from scholars like Jillian Weise [2018] and Laura Forlano [2016] show elisions not with the work characteristic of design or building access, but with the professional design field and how it characterizes disabled people specifically.

These practices, collectively called *crip technoscience* by disability studies scholars Aimi

Hamraie and Kelly Fritsch [2019], teach us that access is an ongoing work of resistance, pushing normed boundaries of what it means to move through space and know through materials while constrained. Recall how Laura Forlano [2016], for example, experimented in the friction that was participating in the medical industrial complex. For her, this participation was necessary to sustain life but within those confines, she resisted masculine and mass-produced technologies by exploring how to clip her diabetes monitoring equipment onto feminine clothing and use supplies longer than recommended. Forlano and others demonstrate how crip technoscience may structure the systematic discovery and recognition of disabled people's long histories and expansive practices.

Taking up these insights, I developed two responses to the narrow casting of people with disabilities in professional design to explore my second research question.

The first, called biographical prototypes, overviewed in Chapter 4, aimed to widen conceptions of user, designer, disability and design work in professional design by bringing stories of crip technoscientific practice into the field. Working as counter-stories, moments of invention, modification and repurposement defied the roles people with disabilities were often assigned in professional design contexts to show they regularly do work that could be read as design. That is, they countered dominant narratives circulated through and beyond professional design which tend to depict people with disabilities as auxiliary recipients of technologies, and which are also seldom authored by people with disabilities themselves.

The contributions of this study were three-fold. First, biographical prototypes scaffolded a record of access-building by disabled people. Taking up the activities and language of professional design through prototyping, they explicitly drew attention to the ways people with disabilities can and do undertake design work. Second, biographical prototypes also

importantly inverted prototyping, and professional design, more broadly as an opportunity for disabled people to tell stories, and for people already empowered to design to listen. This positioning contrasts with many professional design activities which poise professional designers to enter user engagements with preplanned activities and design solutions in mind. Biographical prototypes exemplify the possibility for professional designers to step back and redistribute power of voice and credibility to people, like those with disabilities, who have systematically been configured outside the field.

Third, I learned that although imperative, intervening a record of biographical prototypes into professional design was insufficient. Recognition of contributions by people with disabilities needed to exceed the language and practices of professional design and better reckon with structural ableism, ideally shifting the burdensome access work more onto the people who may be empowered to affect infrastructural change, like those of us among the ranks of professional design.

In Chapter 5, I drew again from disability activism in search of a framing that might more widely recognize contributions to access-building by people with disabilities, without enforcing that they take up professional design's language and practices. I chose the term 'interdependence' as it has been developed in disability justice activist writing. This form of interdependence celebrates disability culture for its collective work to provide access for people with disabilities by people with disabilities. These texts are also forthcoming that community-based assistance responds to structural ableism and insufficient service provision by healthcare, education, and other government and charity-sponsored programs [Mingus 2010 A and B, Mingus 2017, Piepzna-Samarasinha 2018]. That is, much community-based assistance is done out of necessity rather than by choice, access collectives take immense labor to maintain, and the labor of access is disproportionately

burdened onto disabled people.

By taking up interdependence as an analytical tool, I aim to foreground the work people with disabilities do without disappearing some of the negative aspects of that labor. Taking three cases of people with different vision working together as examples, I unpacked two facets of access work that we observed. The first is mundane attunements, which describe momentary negotiations of access among actors—the people, objects and environments involved. These adjustments were ongoing, intertwined with other actions, and importantly comprised both actions toward direct access-building as well as openings for others to act. The second facet of interdependencies that I unpacked is non-innocent authorizations, or access work done along lines that privilege certain abilities, like seeing, over others that are traditionally subverted, like nonvisual cues. Recall Gwen’s verbal instructions directing Joseph’s movements with the trolley. While efficient, the pair chose a division of labor that easily fit into narrow but normed hierarchies of ability that presume paths are best carved with vision. In so doing, an interdependence lens taught me that access-building can be ableist.

Interdependence offers a structure to examine relationships that impact professional design. Like biographical prototypes, it offers a window into access-building that foregrounds people with disabilities as capable and intentional actors. But interdependence uniquely focuses on relations rather than individual accomplishments as biographical prototypes did. With relations in focus, I could find frictions. From them, I learned that authorizing nondominant sensing takes, among other things, care, time, patience and resistance. These are labors in and of themselves, which make non-innocent authorizations such as seeing for another tempting, for their easier fit into expectations of how people should relate with one another.

What I propose the field of professional design can learn from interdependence is that inviting perspectives that reckon with, rather than disappear, non-innocent authorizations might be approached with continual attention, rather than one-time, static changes. Given the inevitable uneven experiences of what access might be for one person or another, and how it is built differently from moment-to-moment, professional design might instead consider access as a fluid, rather than a static process, one that needs ongoing and collective attention.

Biographical prototypes and interdependence extend the ways by which professional design configures who designers can be, what counts as design, and how design gets done. Regarding who can design, though some interlocutors cautioned unthought application of design labels, artifacts from the biographical prototype workshops and indeed the workshops themselves, as well as the continual remaking worlds in common with companions during my field work, exemplified skills that design thinking toolkits aim to cultivate in designers. In line with crip technoscience's assertion that we orient to the frictions, for example, to the ways William, Emily and Jazz made do and did well with limited resources, there is an opportunity to read such work as design. Indeed, creativity with constraints stimulates good design, according to popular toolkits, as several activities both aim to expand thinking outside the box while keeping feasibility in mind [Doorley *et al.* 2018, IDEO.org 2015]. Additionally, biographical prototypes demonstrated ideation, prototyping and testing (phases in the aforementioned design processes) as attendee stories often included trial and error, thinking of new ideas, gaining inspiration from their own experiences and others, and trying things out in real life. If enforcing design is too heavy-handed, these practices suggest, as others have [Kane *et al.* 2014, Ladner 2015], that important steps should be taken so people with disabilities can, if they wish, join the design profession.

Second, biographical prototypes expand what counts as design. Where accounts from IDEO detailed in Chapter 3 anchored the voting machine and Adapt-o-Pack cards in the careful, iterative work of professional designers, disabled interlocutors suggest something different. Sensory gardens and rhinestone transporters evidenced introspection into their designers' bodyminds and experiences, and their (mis)alignments with their environments. As with practices of modifying medical equipment, adapting home appliances and reimagining museum experiences [Finnegan 2017, Forlano 2016, Profita *et al.* 2016, Weise 2018, Williamson 2019], disabled interlocutors combine getting by with creativity and resistance. For example, in the cases of Karen's garden and Diana's craftwork, they blended aesthetics and access, which are often separated during the design of assistive technologies [Shinohara and Wobbrock 2011]. Their constructions did not just provide a type of needed function; they appropriated the practices of design to combine access work with their hobbies to play with form, aesthetic, and pleasure [Kafer 2019]. These examples challenge and extend assumed material boundaries of design to encompass the labor, stories, resistance, and even pleasure they represent [Rosner 2018].

Third, this research extends how design should be done. Recall William, Emily, and Jazz's trek to the exit. They shared information with one another as it became available to them. Joseph kindly asked Gwen where they were going when they continued steering the trolley although they meant to secure it. There are many other ways these situations could have proceeded. Any companion could have acted for the other, but instead, in these moments, they opened opportunities for their companion to notice something that seemed important and to act on it. This type of access-building that authorizes another raises questions about what roles professional design can play in inviting or making possible for others to act. Research on scaffolding professional design activities to train or make more accessible some aspect of professional design [Buehler *et al.* 2015, Giles *et al.* 2018, Hurst and Kane

2013, Li *et al.* 2019, Siu *et al.* 2019] are making important strides to welcome people with disabilities into design fields, and widening the modes by which design is expected to be done. But as building access is continual, the cases from this research suggest that partnerships with people with disabilities might not only prompt the remediation of existing activities. Such invitations might first motivate professional designers to step back, to make more space for disabled people to get resources they need to amplify the designs they have already come up with. Second, such invitations may also involve a much more moment-by-moment checking-in whereby the modes through which access is built are as important to iterate on as any traditional design outcome. Though many of these directions remain open questions, my research suggests opportunities to widen what counts as design.

Taking the ways we do design as a case, I spend the remainder of this chapter sketching out a first synthesis of how we might do one aspect of professional design work, building access, differently.

6.2 Centering Access

To begin, I will overview the work from disability justice activism that has guided my thinking on how to make our design practices more accessible. Specifically, I take up the term access-centered to outline initial thoughts on applying this praxis in professional design. As I am currently defining it, access-centered is a praxis for equitably, collectively and imperfectly attending to people's needs so they may meaningfully contribute and be adequately recognized.

Most importantly, situating the term, access-centered [Access-Centered Movement n.d., Schlesinger 2017] and honoring those who came up with it must precede and underpin its

usage and application. During biographical prototype workshops, I learned that disabled interlocutors were seldom asked to tell their stories of crip technoscience. They instead shared with us the pervasive assumptions that they did not have such stories to tell, or that they lacked agency in the worlds they occupy and move through. From this lesson, which aligns with the historicizing of scholars including Aimi Hamraie [2017], Daniela Rosner 2018, Jentery Sayers [2018] and Bess Williamson [2019], I learned the uneven character of archives. As I am now part of their creation, failing to credit under-recognized perspectives when I borrow from them will erase them, as in the case of the disability politics that are now often absent from universal design [Hamraie 2017]. As such, the stories we tell [Irani *et al.* 2016] matter; they help to define what will matter in the future.

Access is frequently used to describe the human right disabled people have to participate in the world, and the conditions through which such participation may be possible [United States Access Board 2002, World Wide Web Consortium 2008]. But disability justice activist and movement coach Jess Dene Schlesinger explained that using the term access, instead of accessible, shifts the work from making a claim to keeping a commitment [Schlesinger 2017]. From this characterization, the trial and error exhibited by biographical prototypes, and the moment-by-moment and mundane attuning that described access work in my fieldwork offer evidence both for recasting access work as ongoing, and for potentially underpinning rhetorical shifts in how the term may represent the labor people do on behalf of disabled others. Specifically, Schlesinger wrote:

The term ‘Access-Centered’ was given to me by a friend in response to so many non-disabled movement teachers using the phrases ‘accessible’ and ‘for all bodies’ for their classes without doing the work necessary to be available for people with disabilities. Although well-intended, the impact has been harmful

for those of us who are disabled, show up to a class, and quickly realize that it is not accessible for our bodyminds. Unfortunately, within capitalism and with limited resources, most environments are not accessible for all bodies. Using the phrase Access-Centered means that we are describing access as a verb instead of a state of being, that we are thinking about access intersectionally (meaning that we do not think about access solely in regards to disability: we also think of it in regards to our other identities such as race, gender, sexuality, language, class, etc.), we are constantly striving to be more accessible and using accountability processes when we are not [Schlesinger 2017].

To Schlesinger and other disability justice activists, claiming accessibility is often a fallacy, which can do harm by inaccurately messaging to disabled people that they can be in a space and by potentially narrowing conceptions of disability (such as the common assumption that disability access equals physical access). They use the term ‘access’ to instead establish meeting needs as an ongoing process that may respond to disabilities and other factors. Importantly, ‘access’ that shifts with local contingencies then emphasizes the roles learning, attuning, communicating and remaining accountable play in its development.

‘Centered’ from access-centered movement brings access into focus to resist its common relegation to the peripheries of design, as demonstrated in Chapter 3, which may be achieved through preconceived principles and practices created predominantly by professional designers for disabled users. In using the word ‘centered’ I do not mean a calculated, static point but rather, as Schlesinger explained, a type that is a verb, one that keeps access present. This type of centering opens up possibilities that access may be needed all around, including by disabled professional designers. For example, Schlesinger

offers coaching sessions in clients' personal spaces. Along with detailing things she can do to personalize the sessions to the ways the client moves, she shares her own access needs. Schlesinger argues this nudges movement instruction and other forms of fitness teaching from a hierarchy where teachers are presumed to be nondisabled. Instead, centering access makes space for disabled people to occupy ample roles, and to share their access needs irrespective of the types of labor they are undertaking [Access-Centered Movement n.d.].

But how might access be centered in professional design? The suggestions for centering access outlined below draw on things I tried during my own research, insights from literature and activism, and speculation based on my experience organizing events with people with disabilities for research and activism. Currently, this work draws on small disability justice movements and individual design activities. However, the main concern from biographical prototype workshop attendees, and disabled people more generally, is that change must be structural. As these suggestions may be starting points, it is important to implement them as high up or as widely as possible, and to expend some of our energy as professional designers on implementing wider-spread policy changes at our own institutions, and within those that govern.

6.2.1 Centering Access Must be Equitable

Like its roots in disability justice activism, access-centered acknowledges that some needs are met more easily and implicitly than others, and that some people's needs, like those of people with disabilities who are multiply marginalized at intersections of oppressed identities, are predictably not met given structural barriers that presume people adhere to a normed standard of bodymind capabilities [Davis 2005].

In their disability justice primer [2016], *Sins Invalid*, a performance project made up

primarily of disabled, queer, trans, Black and Indigenous people of color described how equity changes how activist events are organized. Considering protest marches, equity demands that the people moving the slowest, or those most impacted by the conditions (such as walking) enforced by the form of the event, should then take the lead. Access-centered movement coach Jess Dene Schlesinger centers access equitably by describing what might be considered modified movements first, instead of those that presume a normed range of motion, so they are not relayed as afterthoughts. Centering meeting the needs of those most impacted then resists forms of professional design which treat disabilities as extreme or specialized cases [IDEO.org 2015]. Instead, crip technoscience, and other forms of knowing-making based on marginalized lived experiences [Benjamin 2019, Rosner 2018, Williams and Gilbert 2019] may work as central starting points. Through activities like biographical prototypes, disabled perspectives may be foregrounded to ‘set the pace’ of design activities.

Equity can also thread through reports out from professional design. Recall the accounts of the accessible voting machine and Adapt-o-Pack cards from Chapter 3. I foregrounded perspectives from Noel Runyan, the disabled interlocutor who helped design the accessible voting machine, Rajendra, the interlocutor who toured professional designers through his garden full of crip technoscience adaptations born from farming with motor disabilities, and scholars of African American literature, disability studies and feminist theory. Within the bounds of one chapter, I certainly gave them more credit than did the perspectives from IDEO. But this response accounted for histories where disabled people’s perspectives have been silenced, as scholars including Aimi Hamraie [2017], Liz Jackson [2018], Jentery Sayers [2018] and Bess Williamson [2019] have demonstrated. To have given equal weight to all perspectives would have not been neutral or apolitical but would have actually continued a narrow retelling, ultimately privileging the professional design

perspective.

Centering access equitably may help prioritize meeting needs that are systematically not met. It can guide our decisions around which people to invite as partners, how to divide time in terms of who is sharing and who is listening, how our reports are authored, and what commitments we have to report back in ways that are legible to the communities we benefit from [Design Justice Network 2018].

6.2.2 Centering Access Must be an Ongoing and Collectively-Kept Commitment

From collectives like the Design Justice Network [2018] and Dombrowski *et al.*'s [2016] social justice-oriented interaction design, along with the aforementioned disability justice organizing, I have learned that commitments to access, and other types of recognitions such as the use of self-reported pronouns and the honoring of Indigenous lands carry power and expectation when they are made explicit at the outset.

As such, I made access commitments for the biographical prototype workshops which seemed to work well to facilitate communication about access and disability. I recommend these be incorporated into professional design events when organizers are willing to do the work necessary to uphold them. But access commitments are not just a list of things to keep in mind during an encounter. They began far before the workshops and continued as an ongoing dialogue and ongoing adjustments between workshop organizers and attendees. From recruitment fliers to the screener to emails back and forth building common understandings of access needs among all attendees, the list of commitments showed at each workshop's outset was only a curated culmination of what I learned beforehand. After reading them, however, I offered that attendees could share access needs that were not listed, at any time during the workshop or during access check-ins (as the

interlocutors from Chapter 5 attuned to one another regularly) [Mingus 2010 B, Sins Invalid 2016]. Explicitly committing to intentionally centering access as much as possible, and keeping open what access will mean in a particular moment, may help establish access as a set of needs that not only participants, but people in all roles may have and as a collective responsibility that will involve accountability and revision.

6.2.3 Centering Access Will be Non-Innocent

Recall Joseph and Gwen's adventure moving the trolley of tables back and forth from a church to the location of an upcoming work exhibit. During their walk, they changed paths, sometimes unintentionally, and their ways of relating with one another, whether by using words, gestures, or feeling the other through the trolley itself, was made possible based on what was available to them in the moment. Sometimes Joseph and Gwen's guiding shifted fluidly between the two and at other times, Gwen clearly took the lead. As non-innocent authorizations articulate, the very work of building access will fluctuate among moments when disabled people are subverted. Recognizing these imperfections is not to succumb to their inevitability but to accept that access is complicated. Multiple factors such as what support systems someone has access to (such as Gwen being hired as Joseph's guide) and what must get done to move on, present opportunities for working with the complexities of building access. By keeping continual tabs on access, anticipating mistakes, and building in time to communicate and revise practices, professional designers can position themselves as lifelong learners of what access does and does not look like, as well as stay open to opportunities for reworking moments that subvert disabled people.

Asking participants to share stories specifically about making things work during the biographical prototype workshops glorified solutionist thinking and disappeared painful or less solved, but still laborious, aspects of access work. Gratefully, some participants shared

their frustration. For example, Andrea lamented that her advocacy skills could not will into existence a video camera operable with low vision. I did not plan the workshops with a nuanced, frictioned understanding of access. These talking points made it into the biographical prototypes chapter, and remain among the first things I share about the limits of this technique. They impacted the way I thought about interdependence, and gave rise to the non-innocent authorizations sensitizing concept. Work to build and center access will be non-innocent, but continually checking about access to learn these imperfections as quickly as possible, acknowledging shortcomings, and being flexible to act toward their relief helped them not to become excuses for inaccessibility, but rather opportunities for me to be more accountable to the numerous disabled people who have entrusted me with their stories.

Centering access is foremost about moving access from the recesses and recasting it as an ongoing commitment. Rather than a set of standards, the practices of disabled people teach us to do design differently. As such, this chapter offers a starting point for praxis (thinking and doing) around access in professional design. Centering access should first acknowledge the disability justice activism from which it came, and influence ongoing recognition of the voices and perspectives who scaffold our work. Such choices may help preserve the politics and disabled intellect formative to its development. Second, centering access involves equitably attending to needs. Though everyone has needs, some are met more easily and predictably. Keeping access in mind, or centering it, means intentionally asking who is not centered with us right now, and working to invite those people in. Third, centering access requires a collective. A center implies surrounding supports, and access work will be most impactful when distributed according to what people can give in a particular moment. Finally, centering access is non-innocent. While something is in focus, other things are obscured. Keeping aware of how labor is distributed and who is recognized

may open opportunities for revising types of access-centering.

6.3 Conclusion

In this dissertation, I have expanded how disability and access are understood within professional design. In turn, I have offered the creative practices of people with disabilities as starting points for reworking who counts as a designer, what counts as design, and how design can be done.

I first showed how communications of professional design often cast people with disabilities primarily as users of technology. Calling them design for accessibility, I described a myriad of principles and practices aimed at sensitizing professional designers to the needs of users with disabilities. While many of these principles and practices open up the spaces and activities of professional design such that people with disabilities may participate in some professional design activities, disabled and designing identities rarely meld in ways that give disabled people power to affect the design, or credit for doing so. Additionally, the ultimate goal of these projects tends to prioritize the development of end products and attends less to ensuring the practices and cultures that produce such products could be occupied by disabled designers. In Chapter 3, I deepened this analysis by taking two accounts of professional design projects as cases for learning how disabled people were portrayed. Reports about these projects read alongside critical perspectives on empathy-building revealed that efforts to understand people with disabilities, often called empathizing, reinforced people with disabilities as outsiders to design.

Scholarship from disability studies, feminist STS, and media studies, as well as disability activism, have contrasts with design for accessibility. These literatures instead exemplify crip technoscientific practices, or regular alterations disabled people make to dismantle

inaccessibility and build access. Taking crip technoscience as a starting point, I offered biographical prototypes and interdependence as interventions into professional design that recognize work done by people with disabilities and intervene their creative practices into common language and practices of the field. From these interventions, I argued that crip technoscientific labors of disabled people and associated representative objects offer new ways of examining access work and boundaries of professional design.

Thinking on how crip technoscience and access work might rework how design can be done specifically, I offered a preliminary outline for centering access, or shifting the way access is practiced within professional design. Centering access aims to recognize that people with disabilities are already and always meaningful contributors to professional design, and that maintaining and encouraging further contributions rests on effortful and continual work to attend to access needs. Indeed, some participants from the biographical prototyping workshops did not want their stories recognized as design contributions. This stark finding cautions that continued sidelining of access and disability in professional design risks the field missing out on, and potentially further harming, people with disabilities who are experts at living within, while chipping away at, the frictions of a world not built for them.

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