

The Promise of Empathy: Design, Disability, and Knowing the “Other”

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ABSTRACT

This paper examines the promise of empathy, the name commonly given to the initial phase of the human-centered design process in which designers seek to understand their intended users in order to inform technology development. By analyzing popular empathy activities aimed at understanding people with disabilities, we examine the ways empathy works to both powerfully and problematically align designers with the values of people who may use their products. Drawing on disability studies and feminist theorizing, we describe how acts of empathy building may further distance people with disabilities from the processes designers intend to draw them into. We end by reimagining empathy as guided by the lived experiences of people with disabilities who are traditionally positioned as those to be empathized.

KEYWORDS: Empathy; design methods; disability.

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1 INTRODUCTION

Understanding users has constituted an important and even radical facet of computing practice and education since before the founding of the Human-Computer Interaction (HCI) discipline [[22], [50]]. Within HCI and related fields, designers often call activities associated with

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understanding users ‘empathy-building’ [[27], [99]]. These activities are part of a phase of the design process comprising a range of background research, interviews, and observations [[13], [99]]. Some design professionals credit empathy for supporting positive customer relationships and cultivating a successful business culture (e.g. [[13], [61]). Others highlight the systematic marginalization and low representation of certain people employed in design fields and frame empathy as a useful corrective: transferring experiences of nondesigners to designers in order to shape more inclusive futures [[8], [21],[45]]. In these calls for empathy, the domain of disability represents an especially potent site. Designers use empathy to frame their attempts to understand disabled nondesigners across a range of empathy-building activities, from the observation of people with disabilities to the temporary simulation of bodily impairments [5], [37], [45]].

In this paper, we examine 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, we draw from public accounts and popularized toolkits 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, we illustrate how designers may privilege their interpretation of the disabled experience over firsthand encounters, a position that further contributes to the prioritizing of normalcy over disability [[38], [66]].

Responding to and intervening in this design space, we argue for letting go of empathy as an achievement—something to build, model, or reach within design. Instead, we draw from decades of disability scholarship and activism [[20], [33], [48], [49], [51]] to recover empathy as a creative process of reciprocity. Specifically, we suggest that what it takes to “be with” someone should come before what it

takes to “be like” someone, a refrain borrowed from feminist theorist Vinciane Despret [[24], [25]] to describe a shift from transferred to shared experiences. In this reworking, we explore how designers may productively grapple with and against empathy by recognizing the range of emotional, political, and historical relationships of which empathy is a part. As Saidiya Hartman, a scholar of African American literature and history, writes 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” [[39], p. 20].

Our analysis draws from a growing body of literature examining design’s promise and idealism [[46], [47], [56], [79], [85]] as well as disparate strands of theorizing within disability studies, feminist philosophy, and participatory design (e.g., [[4], [6], [39], [54], [55], [72]]). Our understanding of the term ‘disability’ borrows from Alison Kafer [[48]], who describes how disability arises relationally when people with impairments are not anticipated, producing encounters inaccessible for people with body/mind impairments. Within disability studies, scholars such as Kafer [[48]], Michelle Nario-Redmond [[67]], Arielle Silverman [[83]], and Rebecca Garden [[34]] trouble the practical simulation of bodily impairments and call for more direct interactions with disabled people, without aiming to directly understand their experiences. In parallel, recent feminist scholarship 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 further entrench dominant forms of storytelling [[3], [39], [70]]. We thread this thinking through recent accounts of design practice to offer new perspective on the popular empathy-building activities that HCI scholars and practitioners employ today.

Our project makes three central contributions to recent conversations on disability, empathy, and design methods. First, we show that disability offers a crucial empirical site to expand current HCI conceptions of empathy in ways that reveal important and often unintended consequences of empathy activities such as the simulation of motor impairments with a wheelchair. Second, we show how empathy gets used to diminish disabled perspectives, separate the roles of disabled people and designers, and stage the disabled experience as a spectacle. Lastly, we explore what it might mean to shift understandings of empathy in design from a position that rests on “the ability [to] ‘put oneself in the other’s shoes’” [[70], p. ix]. to one that foregrounds shared experience and historicity.

In what follows, we first put empathy in historical context. We briefly trace the roots of empathy work in HCI and user-centered design, reviewing in particular the literature around disability and empathy. Attending to the theorizing of feminist scholars (Sara Ahmed [[3], [4]], Vinciane Despret [[24], [25]], Saidiya Hartman [[39]], Carolyn Pedwell [[70]], Anna Tsing [[93]], among others), we then analyze public accounts of empathy around disability shared by a celebrated global design firm. We end by discussing efforts to reimagine empathy as the work of attuning – noticing and realigning different bodies and relationships to one another toward respectful connections. In this sense, our work picks up where Rebecca Garden leaves off in her incisive critique of empathy in the medical profession, examining “the development of sophisticated paradigms of empathy as a means of reframing the discussion of ethics in medical education and in clinical practice” [[34], p. 564]—as well as in the parallel fields of technology design.

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 Pedwell, “empathy is everywhere and is viewed, by definition, as positive” [[70]].

To understand this positive valence, we turn to empathy’s roots, a genealogy tied up with earlier vocabulary. Bioethics scholar Rebecca Garden, for example, reports 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) [[34]]. For Enlightenment philosophers David Hume and Adam Smith, she points out, sympathy and sensibility came naturally to certain bodies (those of members of the educated, upper classes), and not to others [[34], [52]]. In the late 1800’s, this concern for sensory capacity resurfaced with empathy’s introduction into the German language [[34], [70]]. According to historian Susan Leigh Foster, the aesthetic theorist Robert Vischer devised the German term *Einfühlung* (empathy, or “feeling-in”) to explore the process of observing arts such as sculpture [[70], p. 191]. Following this usage, the early 20th century translation of *Einfühlung* into English referred to the sharing of sensory experiences with other people and objects. 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 body and mind [[52], [70], [76]]. Its meaning contrasts with empathy's usage within contemporaneous European psychiatry wherein the concept of empathy signaled a solution to over-sympathizing [[52]]. Psychiatrists such as Ludwig Binswanger positioned empathy as a technique of empiricism, using therapeutic interviewing to get at the intangible thoughts and feelings inaccessible by traditional medical instruments while avoiding complete immersion into a client's thoughts and feelings, ostensibly keeping an empirical distance [[52], [70]]. Across the later decades of the 20th century, this mix of concepts—on the one hand, creating an affective, less fully conscious connection and, on the other hand, developing a removed scientific understanding—formed the activities that have come to characterize empathy in design.

2.1 Empathy in Contemporary HCI

While less studied, the roots of empathy in HCI date back as far as 1974, when Koberg and Bagnell articulated the “analyze” stage in their widely circulated volume *Universal Traveler* [[50]]. 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 [[27], p. 4]. Such valorization took place not only in HCI research but also in business schools [[23]] and other popular design thinking resources (see, for example, [[8], [12], [43]]) “Find (or create if necessary) ways to immerse yourself in specific environments to understand first hand who you're designing for,” one popular empathy-building guide suggests [[27], p. 5]. In another celebrated tool called the “empathy map,” designers synthesize intended users' behaviors, feelings, and thoughts (see [[36]]). This and similar empathizing exercises can serve as justification for subsequent design decisions.

Turning to empathy in HCI research, several scholars have developed the concept with methods and ethics-oriented contributions [[16], [26], [59], [99]]. In a widely cited 2008 CHI paper, Wright and McCarthy [[99]] identify empathy as an emerging trend within HCI studies involving attempts to more deeply understand and interpret user experiences. Surveying empathy-building activities employed in HCI research, they review a variety of techniques of empirical inquiry: from observations and interviews, to narrative resources comprising diaries and art pieces, to roleplaying with simulations and personas. Across this set, they argue 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 [[99]].

2.2 Empathy-Building Around Disability

Recent design guides frame empathy-building as even more important when users have disabilities [[1], [17], [45], [58]]. By making the assumption 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.

Activities for building empathy largely overlap with user research methods. A unique empathy-building method 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 rudimentary tools like blindfolds and gloves to occlude vision and tactile sensations and then complete a daily task with these unfamiliar bodily constraints (for a range of work, see [[5], [17], [29], [40], [53], [57], [58], [67], [69], [73], [77], [83]]). 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 [[5], [37], [42], [45], [73], [77]]. For example, researchers have created personas with disabilities [[82]] and Microsoft's Inclusive Design toolkit offers situational impairments [[63], [64]] to bring disability closer to designers. According to the Inclusive Design Manual [[64]], 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 impairments, 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).

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., [[1],[41],[46]]), a phenomenon Lilly Irani aptly characterizes as the “design savior” complex [[47]]. In a widely circulated critique [[95]], media historian Lee Vinsel likened 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 [[14], [60], [68]]. Across these critiques, commentators grapple with how to minimize harm while still reaping the benefits of human contact that inform design.

Decades of scholarship in rehabilitation and social psychology [[33], [49], [67], [83], [84]], education [[18]], disability studies [[48], [51]], and popular design blogs [[1], [86]] caution certain types of empathy-building around disability. Scholars argue that simulations, an especially controversial empathic modeling activity, reproduce negative stereotypes and fail 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 [[48], [67]]. Empathy built through immersion, critics argue, may steer designers toward narrow and inaccurate conceptions of disability experiences.

Generally agreeing that design cannot be premised on empathy alone, several scholars offer alternative terms (e.g., compassion [[51], [89]], humility [[21]], or noticing [[6]]) along with techniques. Techniques include simulations guided by disabled people [[18], [35], [62], [84], [88]], codesign exercises in which designers enlist disabled people as partners [[32], [35], [71], [87], [94]], and community service work led by disabled people [[20]].

Pervasive among recent critiques and correctives is a nearly uncontested belief in the power of empathy to provoke more inclusive designs for/with people with disabilities. Feminist cultural studies scholar Carolyn Pedwell describes how “[p]recisely because it is so widely and unquestioningly viewed as ‘good’, [empathy’s] naming can represent a conceptual stoppage in conversation or analysis.” For her, this stoppage involves 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 sees its unquestioned promise as necessitating further investigation [70].

Pushing on this concern, scholars of African American literature [39] and Performance Studies [9] question the achievability of empathy related to the valuing and understanding of life. For Saidiya Hartman, for example, the difficulty of empathy involves “the dangers of a too-easy

intimacy” [[39], 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 [[3], [4]], Anna Tsing [[93]], and Vinciane Despret [[24], [25]] hold onto this tension between discovery and contamination by showing how empathy can open connections while predisposing the empathized as different and other. Ahmed, for example, contends 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” [[3], p. 30]. Attending to this “wish feeling,” Despret offers visions of feeling *with* another. Such accountability foregrounds shared experiences over authoritative narratives.

In what follows, we take to task this need to more deeply understand empathy within the context of disability and design. We use public accounts of empathy to illustrate how activities associated with empathy may turn disability into an unrelatable trait of the ‘other.’ With this argument in mind, we attempt to break through Pedwell’s “stoppage.” As she describes, “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” [[70], p. 10].

3 DISPATCHES FROM INDUSTRY: STORIES OF SIMULATION AND PERSONAS IN DESIGN

Turning to an elite design consultancy, we use two public accounts 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, we additionally rely on materials and prototypes released by the municipal partners, news media articles, and—although rarely available—firsthand accounts from disabled interlocutors. Our decision to focus on public vignettes stems from the ongoing influence of media narratives on HCI discussions of design (e.g., [[46], [47], [78]]) as well as the theorizing of feminist scholars such as Vinciane Despret [[24], [25]] and Saidiya Hartman [[39]] who narrate against the grain in order to reveal under-recognized perspectives and uneven distributions of power. Rather than represent how empathy

gets built and evangelized, we use these cases to illustrate its possible paths, particularly how those paths require more consideration than designers may call for in their practice or pedagogy. From the examples, we see that designers can use empathy to not only conceptualize their own roles, but also those of people with disabilities, consequently delineating and defining differences between those identities.

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 [[44]], 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”) [[44]].

In a post for the California Council of the Blind [[80]], 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. 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,” he explained. Poll workers were concerned voters would not trust their ballot was submitted if they did not hand deliver it to a ballot box. Runyan, along with other disabled interlocutors remained assertive resulting in the design team introducing a translucent ballot box which still hid markings from view, pacifying those who wanted to see their ballot feed as they cast their vote [[44], [97]].

To interleave this expanded perspective into the design team’s work, the design team also built empathy without their disabled interlocutors present. Comprising disability

simulations, the additional empathy building would purportedly enable 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?” [[44]]

The final voting machine incorporated several features directly aimed at addressing accessibility concerns, as outlined by Runyan [[80]] and municipal records [[97]]. These included a touch-screen interface with adjustable height and angle, audio and visual output, adjustable text sizes, and 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 [[65]]). A video depicts 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.

The next account offers a window into what this work of empathy looks like as different members of the design consultancy try 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.

3.2 Personas: The Case of Adapt-o-Pack

In 2018, IDEO employees dove back into public-facing accessible design with a description of a prototype brainstorming game called Adapt-o-Pack [[28]], still unreleased. 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” [[28]]. To play Adapt-o-Pack, players would randomly select a persona and livelihood and must ideate workplace adaptations to make the occupation accessible for the persona. Specifically, players pair industry cards (depicting a workplace setting such as farming) with persona cards (depicting persons with disabilities such as “Donella” with Down Syndrome). Using simple language and colorful vector illustrations, the cards prompt 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 tasks such as “Planting seeds or seedlings. Watering crops. Harvesting vegetables or grains. Removing weeds” while serving 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" [[28]].

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 job placement specialists and designers that people with disabilities could actually 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 [[28]].

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 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" [[28]].

Later in the post, the game co-inventor highlights an initial Adapt-o-Pack game played in Nepal in which the design team tested whether pairing livelihoods with disabled personas could insight similar transformation from skepticism to ideation. Some players began disbelieving the design challenge to make more accessible workplaces possible. However, like the visit with Rajendra, additional benefits quickly manifested. The blog post explains: "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" [[28]].

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 disability [[28]].

Rajendra's story, which we assume informs the Adapt-o-Pack content, looks 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 illustrates 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" [[28]].

This account resembles other design guides [[21], [63], [64]] in recognizing limits to empathy. It relinquishes any attempt to "truly understand" the disabled experience. In its telling, we 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 understand "the type of creative necessity" that those living with a disability regularly perform. With this reference, the blog situates Adapt-o-Pack in the promotion of mutual understanding between the player and disabled worker.

4 THE SLIPPERINESS OF EMPATHY

The above snapshots of design activities help us 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 built a technology 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 we also find what Saidiya Hartman names the "slipperiness of empathy" [[39], p.18], an

expression denoting the paradoxical nature of drawing the other closer. In the first account, the voting machine, we 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, the Adapt-o-Pack, we 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 jumpstart different (and perhaps unrealistic) solutions. The accounts show us how being empathetic can be a lesson in displacement. By drawing the other near, the designer may unwittingly erase.

At stake in the 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 necessarily leave out the perspectives of people potentially affected. 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) differentiating disabled and designing bodies, and (3) treating the empathized as spectacle. With these thematic threads, we show how empathy's gaps work as sites for reckoning with wider configurations of power in design.

4.1 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, we 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. We also get a glimpse of the disability simulation activities that a design team might do to complement these interviews and how they could perceive the activities as beneficial. Yet, as decades of disability scholarship have shown, such a benefit depends on a wider environment complicit in neglecting the blind experience [[38], [66]]. 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 his 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., [[96]]). Instead, the accounts leave the voices of those with disabilities for the non-disabled 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 discusses of "co-feeling" [[70], p.10], the 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" [[33], 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.

4.2 Rendering Designers as Nondisabled and People with Disabilities as Nondesigners

Now we consider how those same inspirations shape relationships between disabled and designing bodies. Public accounts, voting machines, and illustrated abstractions depict shifting connections among designers and disabled interlocutors. In this depiction, they may ultimately render designers and disabled people as inherently different.

Our Adapt-O-Pack vignette provides a helpful illustration. It describes 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 recover 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 original settings (here, Rajendra's reliance on his adaptations to care for his family). The list of job duties and stock illustrations communicate the livelihood programs as a yet-to-be-enacted accessibility design space. The accounts describe 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" [[28]]. In invoking the phrase "thinking outside," they frame the designers themselves as having no relevant experiences to draw from—that is, disabilities.

According to the accounts of the voting machine, the designers may similarly gloss over the design insights led by disabled bodies 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-Cards make no mention of the existing disabled workers insights, the voting machine design story overlooks those contributions of those advocates in favor highlighting decisions made by the design team. **They present designing bodies as non-disabled bodies, and they position disabled bodies as non-designing bodies.**

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 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" [[34], p.560].

This paradox of "empathetic proximity," according to Pedwell, has as much to do with space as agency [[70], p. 115]. Pedwell asks, "[W]hat about those so-called others who cannot be encountered or known as individuals, precisely because structural relations of power enforce absolute distance or segregation?" [[70], p.31] With the cards and the simulation activities, designers not only aimed 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 [[97]] or from global travels [[28]], 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" [[3], p.30].

4.3 Treating the Disabled "User" as a Spectacle

The above accounts describe the impact of disabled people on designers (such as Rajendra on his visitors). But 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 have, in Saidiya Hartman's words, "ameliorated indifference." Instead, they may have "only confirmed the difficulty of understanding" [[39]]. 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 occlusion of vision 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 writes 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 [[39] p. 17], Hartman recounts a letter he wrote to his brother to depict the horrors of Trans-Atlantic slavery. In the letter, Rankin invented an empathetic account, a story in which his own family became enslaved. She writes, "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 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 states, "the problem is that in the

very effort to ‘bring it near’ and ‘inspect it closely’ it is dissipated.”

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 only partial understanding 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 empathy was done and that its benefits could be reaped.

5 FROM “BEING LIKE” TO “BEING WITH”

We have so far provided glimpses into empathy’s pitfalls as warned by Hartman, Ahmed, Garden, and others. We exemplified how designers may conceal authorship and credit while sharing their own journey of coming to understand something unfamiliar. We described how empathy-building exercises may reify existing power differentials between designer and non-designer, disabled and nondisabled person. We finally discussed how empathy work may stage disabled bodies as spectacles, further dissipating the disabled experience. 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.

But then what to make of empathy’s successes? Well-meaning attempts to support disabled people through the prototypes that designers build and the empathy activities they devise result in important interventions. Recalling the advocacy of Runyan, an advisory committee member who noted critical shortcomings in the voting machine design process, we find it notable that he later praised the voting system as “an excellent finished prototype” [[80]]. The prototype provided multiple accessibility features and evidenced a desire on the part of privileged designers to respond to a broader diversity of potential users. Empathy activities, in this sense, may be imperfect but they may also raise awareness among those already empowered to design.

Rather than solve empathy as a problem or dismiss it altogether, we propose three commitments that work *within* and *against* empathy. These concerns are not guidelines, but rather orienting responsibilities inspired by disability activism. Despret explains, “Empathy allows us to talk about what it is to be (like) the other, but does not raise the question ‘what it is to be “with” the other” [[24], p.128].

Taking up this latter question, we offer the commitments as techniques for “being with” rather than “being like” other social actors in the design process (see also [[7], [78], [90], [92]]).

5.1 Commitment 1: Rather than seek to represent another’s experience, we seek partnerships in imagining the design encounter.

Building on decades of work in participatory design and disability activism (see [[10], [15], [32], [54], [55], [71], [72], [94]]), we argue for developing partnerships in ways that animate new types of collective futures, what Shaowen Bardzell calls “an ambitious, even literary, imagination” [[11]]. Disability studies scholar Alison Kafer and colleagues similarly propose coalition building in response to disability simulation activities. Their work documenting restroom safety and access shifts forms of individual immersion such as steering a wheelchair toward interventions guided by disabled and LGBTQ+ volunteers. Investigating bathrooms across a university campus, they used measuring tools to document the presence, placement, and accessibility of resources. As the group forged new partnerships, they looked beyond their initial interest in access barriers to identify additional concerns such as whether gender neutral bathrooms offered (working and stocked) tampon dispensers and diaper changing tables [[20]].

The empathy-building exercises we have so far described do a type of preparatory work that contrasts with disability activism and related forms of partnership-development. Although wearing a blindfold offered a pathway into thinking and speaking about vision impairment, the activities threaded a seemingly inevitable path from understanding particular experiences (that of disability) toward design outcomes. Accepting other types of connections, the restroom activists widened their initial concerns. They lengthened the list of things worthy of measuring but also expanded their original vision with the enrollment of new partners. In other words, the activists were open to revealing their learning process as partial and continual, a stance resonant with Marilyn Strathern’s phrase “partial connections” [[91]] and taken up in other feminist HCI interventions [[31]]. This form of connection makes available many things including, crucially, the potential for framing others social actors as partners in empathy. Orientating designers to expect reciprocity might shift empathy building toward opportunities for mutual sensemaking, multiple first-person narratives, and shared accountability.

5.2 Commitment 2: Rather than achieve an understanding, we seek a process of ongoing attunement.

Upon establishing partners in design, we draw from feminist care ethics [[74], [75]] to call for continual acts of *attunement*, embodied adjustments and realignments of relationships that may inform design. Showing how partnerships remain vulnerable without continued care, feminist care scholars describe attunements as noticing practices [[24], [25], [93]], what Amrute (drawing on Kathleen Stewart [90] calls “training the senses” [[7].

Media historians Jentery Sayers, Tiffany Chan, and Mara Mills [[19], [81]] illustrate such attunements in their creation of the early 20th century optophone, a device that communicated printed text through sound. Through prototyping, they examine the efforts of Mary Jameson, a blind woman who helped design the device, recognizing her for innovations attributed to sighted, male engineers. In their retelling, they do not recover Jameson’s experience but glean insight into its creation while holding on to what they do not know. They seek not to fill absences but to question them—asking why certain stories are not told. Following attunements—the ways people sensitize themselves to one another through design—entails imagining what might happen differently by rendering social actors capable.

5.3 Commitment 3: Rather than attempt symmetry, we recognize and work with asymmetry.

In reimagining empathy, we hold onto its inevitable asymmetries. With this responsibility comes opportunities to question what we are doing when we develop affective relationships with others (human or nonhuman). For design researcher Laura Forlano [[30]], this asymmetrical sensibility prompts a challenge to her insulin pump and the frequent and intimate interfacing it demands between her skin and machine. In recounting her experiences with her diabetes monitoring and management equipment, Forlano describes experimenting with ways of resisting continual intervention and elevating more affordable and environmentally responsible forms of medical care. Attending to asymmetries helps, in Forlano’s words, “decenter the human” [[30], p.43] to widen possibilities for recognizing and responding to the uneven capabilities of actors. By accounting for asymmetries between her body and her device, Forlano shows what it might mean for designers to connect with other people, nonhumans, and environments.

Sitting within wider design relationships (economic and ecologic), this line of questioning could examine how our acts to come to know and understand people also predispose them to occupy certain spaces in design. As we have showed

through our case studies, well-intended learning has consequences, as any attempt to empathize differently will. Reworking design empathy as “being with” could raise asymmetries not as things to be avoided but as things to be ongoingly accountable to.

6 CLOSING THE LOOP

By re-examining empathy around disability, we have argued that it is not something to be done, built, or modeled within design. When designers focus on the practical and achievable qualities of a task (here, the act of simulating disability or using personas with disabilities), they may gloss over a wider history of disability, activism, affective understanding, and personal capacity that they could meaningfully draw upon. In rejecting empathy as an accomplishment, as a means to an end, we look back at what that determination entails. We call for “an undetermined articulation of ‘being with’” that involves learning to be affected and attending to difference without reifying that difference once again [[24] p. 131]. In so doing, we make room for an affective partnership that may help designers destabilize and reimagine imposed boundaries (e.g., between categories of “disabled” and “designing” or “designer” and “user”).

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