

“Trying On” Disability: Simulating, Performing, and Embodying Identity in Hungary

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Abstract

In a post-socialist context and a changing understanding of disability, several Hungarian organizations have sought to educate the public and raise the visibility of disabled citizens. The Invisible Exhibition introduces visitors to a blind guide and asks them to pretend to be blind for an hour in order to understand what it means to be disabled. This relies on a concept promoted by phenomenology: individual bodily experiences shape worldview, therefore simulations can provide people with other worldviews by changing their bodily experience. Disability theory, however, asks us to balance this emphasis on individuality with prioritizing social constructions and barriers. I draw on both fields, in addition to feminist theories like performativity, to analyze the narrative set forth by the Invisible Exhibition and its visitors and the contradictory narrative from tour guides and the disability community, including myself. I also use ethnomethodology and autoethnography to describe my experience as a disabled researcher and my own experiences. Using data from interviews, observations, and participation, I argue that simulations are founded on assumptions about embodiment, identity, and knowledge, and that these debates and conflicting narratives require an equally complicated network of theories to discuss their importance.

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Introduction

The Invisible Exhibition is a successful and popular simulation and the only permanent tour of its kind in the area. It provides visitors with the opportunity to interact with a blind person and participate in a tour that is intended to mimic the daily experiences and life of a blind person, while purporting to open their eyes, promote inclusion, and foster societal change. In a country that is still learning how to represent and care for its disabled citizens, a company that hires disabled people and asks them to participate in their own representation and public education is unique. The Invisible Exhibition rests on the concept that by pretending to be blind, an individual will use their senses and body differently. In combination with asking questions and meeting a blind person, the experience allows the sighted visitor to understand what it means and how it feels to be blind. As the company expands, and disability simulations experience an international resurgence in popularity, the methods, goals, and effects of such tours need to be analyzed in depth.

Phenomenologists have long discussed the idea that bodily and sensory experiences shape individual knowledge and worldviews, and the concept of performing identities and the politics that surround these acts is rooted in performativity. Disability theorists have historically drawn from these fields and others to contextualize debates around disabled bodies, identities, and knowledge in cultural shifts regarding how people understand disability. Each field often engages the other in dialogue, which strengthens their relevance to my research. The result is a tense network of theories that alternate prioritizing individual experience, cultural constructions and barriers, and a body-mind-society balance. In acknowledging these debates and foregrounding the experiences and perspectives of disabled individuals, I place myself within disability theory and argue that these webs allow for a better understanding of the complexities of the narratives and experiences of the Invisible Exhibition. These theoretical approaches exist in deep connection with my choice of

methodologies, which also exists in the tension between prioritizing individual bodies or experiences and emphasizing societal constructs and deficits. I do not think it would be possible to act as a disabled researcher studying the simulation of disability without addressing this position as an individual. This requires bridging sensory ethnography and ethnomethodology, while incorporating more traditional theories as mentioned previously.

Taking into account my theoretical and methodological approach, this raises several research questions: How do visitors experience certain dimensions of disabled knowledge and identity through these simulations? What assumptions do simulations make about embodiment? Are there differences between the proposed narrative of the Invisible Exhibition and the experiences of its guides and visitors? In Chapter 1, I evaluate the multifaceted criticisms against disability simulations, as described by scholars and activists. In Chapter 2, I summarize my theoretical and methodological approaches, and discuss their interplay and my own positioning. Next, in Chapter 3, I introduce the Invisible Exhibition, providing a summary of its history, design, and the narrative it constructs around disabled identities and knowledge. Following this, Chapter 4 focuses on the event of visiting and performing at the Invisible Exhibition. Chapter 5 addresses the sensory experiences and emotional labor, as well as an analysis that ties together theory and ethnography. I will conclude with thoughts about the potentials of this research and its broader contributions.

Historical Context

Over the past few decades, most countries have undergone a transition in how they describe and accommodate disabilities in society, while also undergoing political and cultural shifts in understandings of disability. For Hungary, this has occurred primarily in the post-socialist period, as the disabled population has become progressively younger, with fewer physical disabilities and more mental disabilities. Hungary has primarily addressed this by

developing laws and working with the United Nations for new legislation, while also cooperating with the UN Convention on the Rights of Persons with Disabilities. Few studies on disability in Hungary and Central Europe have been published in recent years, and largely focus on the immediate post-socialist period (roughly 1990 to 2000), as state socialism had prevented scientific research on marginalized social groups and the post-socialist period was the first opportunity to recognize the difficulties that disabled people face. There was also a surge in advocacy and rights organizations, who began to seek societal visibility. Darja Zaviršek has outlined the recent changes in Hungary and Eastern Europe as of 2007: while the country remains loyal to traditional understandings of disability, there were slow changes in how disability was represented in the public sphere (Zaviršek 2007). Zaviršek characterizes the post-1990 period as a state of “arbitrariness and fluidity of disability diagnoses which depend on welfare regimes, value systems, political constellations and individual struggles” (Ibid., 8) There have been slow changes for disabled people in Hungary, but by most accounts, their situation has not significantly improved.

A report released by the European Union’s Monitoring and Advocacy Program, associated with Open Society’s Mental Health Initiative, compared statistics from 1990 and 2001, finding that, despite the work of advocacy groups, significant numbers of disabled people live in institutions or residential care and fewer intellectually disabled people are attending school (Open Society Institute 2005). Disabled children who do attend school are frequently segregated out of mainstream schools, particularly if they are intellectually disabled (Ibid.). Another report, written in 2001, focuses on the “highly segregated school system” in Hungary, and the extremely slow reaction to newer legislation regarding integration (Csányi 2001, 301). Both the author and the Hungarian Disability Caucus argue that children in Hungary are systematically misdiagnosed or under-diagnosed, evidenced in part by the statistical difference between estimates from the UN or UNESCO, and the

proportion of disabled children in Hungary (Ibid., 303). The recent increase in organizations that seek to advocate for disabled people in Hungary have somewhat raised the visibility of disability rights, but these groups typically exclude disabled citizens from managing their image or legal battles. This further contributes to the invisibility of disabled individuals, as they are either misrepresented or not represented at all, and often segregated entirely from society. One organization that involves disabled people, seeks to to raise awareness, provide opportunities for disabled individuals is the Hungarian Federation of the Blind and Partially Sighted, which maintains an email server, shares job opportunities, and holds annual events to combat the invisibility of disabled people in society.

Internationally, many countries have used various means to increase public knowledge and understanding of disabled citizens, including national media and education campaigns, as well as new legislation that promotes school and business integration. The primary disability advocacy organizations in Hungary are international rather than Hungarian. This results in a very general understanding of disability and provided an opportunity in recent years for these organizations to develop events and media campaigns. For Hungarian organizations specifically, however, they often rely on other methods, such as disability simulations that replicate certain aspects of various physical, developmental, intellectual, and psychological disabilities. Because most Hungarians are not disabled, and many do not know anyone disabled, the primary approach to promoting acceptance combines introducing the public to disabled people while asking the public to understand disabilities from a first-hand perspective using these simulations. The ultimate goal of these simulations is to encourage social inclusion and participation of disabled children and adults in schools and workplaces. These simulations are faced with the same problems as legislation and advocacy groups, however, and often exclude disabled people. National campaigns such as the Médiaunió Foundation's "Get Closer!" in 2010, which asked popular public figures to

mimic disabilities (Médiaunió Foundation 2010), and the Council of Europe's Human Rights Education program promoted "See the Ability!" activities for schools and offices (Brander et al 2012). More permanent efforts include the Invisible Exhibition and its former counterpart, Ability Park. Ability Park did not just focus on one disability but offered visitors the opportunity to become acquainted with "the life of people with disabilities in an interactive and entertaining fashion that facilitates social inclusion" (Ability Park 2010). However, it recently closed its permanent location and exists only as a traveling exhibit upon request. At present, the Invisible Exhibition is the only permanent disability simulation in Budapest.

1. Critiquing Simulations: Perspectives from Disabled Scholars, Activists, and Supporters

Disabled theorists, scholars in disability studies, and activists have critiqued disability simulations, arguing that not only are they deeply problematic in several ways, but ultimately there are no long-lasting positive effects. While some have argued that with significant changes, simulations can remain useful and educational, I do not believe in the potential of redesigned simulations, as these changes do not fully address the critiques raised by disabled activists and the concept seems inherently ineffective. Activist Lydia Brown provided similar criticism regarding the use of a simulation in university classrooms, labeling it “fundamentally problematic, potentially dangerous, and certainly counterproductive” (2013, 1). In addition, simulations are not designed or managed by disabled people, and therefore cannot be realistic or effective. Simulations are temporary experiences that are rarely accompanied by in-depth information about disabilities, and are not educational. In a response to a Washington Post article about the popularity and benefits of simulations, blogger Anna Palindrome wrote that more effective educational experiences would be to invite disabled guests and “ask them to talk about their lives and lived experiences,” which can be paired with books written by disabled authors (2009). She identifies the primary reason for the popularity of disability simulations as the fact that people do not “trust people with disabilities to talk about their own experiences,” and therefore must experience disability first-hand (Ibid.). She continues:

I'd love to stick someone from City Council in a wheelchair for an afternoon and push them around my neighbourhood. I'd like to think the curb cuts would be fixed, the sidewalks replaced, and the snow cleared faster... if they're not going to believe *us* when we talk about it, maybe they'd believe their own experience of being almost tipped out of a chair because of how nasty the curb cut is (Ibid.)

When simulations exclude disabled people from representing themselves or their disabilities, they contribute to the invisibility of disabled people and a misunderstanding of their identities

and lives. The broader identity politics surrounding disability are similarly present in the debates surrounding simulations: what does it mean to identify as disabled, and how is this identity represented and consumed by nondisabled visitors? Agency is also important for disabled activists in the fight for self-representation and visibility. In line with Palindrome, I believe that a more realistic and efficient way of getting people to understand the barriers they face is to accompany and have conversations with disabled people throughout their daily routines.

Disability simulations also portray disability as a burden or undue challenge with no recognition of the community and culture associated with disability. As Tobin Siebers describes, visitors ultimately leave simulations with a “thoroughly negative and unrealistic impression of disability” (2008, 29) Siebers continues with this line of thought, suggesting that visitors focus on bodily changes rather than how disability influences identity, and get caught up in a game of “what is worse?” where visitors rank different disabilities (Ibid.). Along the same lines, Emily Ladau argues that disability simulations are “more likely to evoke empathy or pity than true acceptance” because they offer a brief, “temporary glimpse into disability” (2014) She also highlights that disability simulations have been used for decades and societal barriers have not been dismantled, which she believes is proof that “trying on” a disability does not lead to social change (Ibid.). Therefore, she argues, the invisibility and discrimination that disabled people face is not lessened by the temporary but inaccurate visibility of their disabilities in a simulation. Another author, Toby Olson, wrote that “simulations actually reinforce the inaccurate negative stereotypes that often limit opportunities” for disabled people seeking jobs. He continues:

If you participate in a simulation, what you experience will not be at all like a slice from the life of a person who has lived with that disability for any time... without any of the coping skills and techniques people with disabilities create and master throughout their lives, the best you will be able to manage will be to emulate the experience of being the single most hapless, incompetent individual with that particular disability on the face of

the planet. Participants in disability simulations experience their adopted disabilities as a series of discoveries of things they can't do... Those of us who have had a disability all our lives haven't experienced our disabilities that way (Olson 2014).

Simulations like the Invisible Exhibition do not include the “positives” of disability, such as the strong cultural history and communities that emerge from shared experiences. Kuppers agrees with Siebers and describes that there is nothing “real” about problematic simulations and they serve to “merely reinforce negative stereotypes” (Kuppers 2007, 81). When discussing simulations that specifically mimic vision impairments, such as blindness, she argues that simulations are unable to “[bring] a blind person’s life nearer and [show] it as a dignified life full of potential and specialized skills” (Ibid.). Siebers believes that simulations result in “emotions of loss, shock, and pity at how dreadful it is to be disabled” (2008, 28) while other writers have noted the themes of “frustration, isolation, humiliation, insecurity, and apprehension” – which typically build upon existing feelings regarding disability (Herbert 2000). These are similar descriptions as what I received when interviewing visitors; a common theme in simulation reviews is a sense of gratitude that they are not disabled, coupled with pity for blind people.

Another common criticism of disability simulations highlights their exclusive focus on bodily experience while ignoring societal barriers. This was mentioned previously by the activists who would find a field trip around their neighborhood more effective than playing on a wheelchair obstacle course, which does not reflect daily inaccessibility or how their difficulties are a result of absent services. Gary Kiger notes that “disability simulations do not reflect real-world experiences... going on a “blind walk” for an hour does not give a participant the ‘feel’ for experiences of discrimination, rejection, or pity” (1992). Temporary experiences of disability therefore cannot approach the lived experience of being disabled. Petra Kuppers, in a discussion of pop culture performances of disability, writes that simulations are also inauthentic performances, emphasizing and making even more visible

the “nondisabled differently-adapted bodies” of visitors rather than learning what an actually visually impaired person experiences when navigating the world (2007, 80). By prioritizing the bodily experience of being disabled, guests cannot truly understand what it feels like or means to be disabled.

Finally, simulations emphasize the visitor and their expected transformation, rather than their guide or the disabled community. Siebers describes the popularity of disability simulations amongst those who work with disabled individuals, such as occupational therapists and rehabilitation scientists, as a means of consciousness-raising (2008). Rarely do people come with the sole reason of wanting to understand a blind person’s perspective, and because they are so focused on their own difficulties in the simulation, they ignore the social causes of disability and its invisibility in society. While simulations could be modified to include more information about disability, they would remain flawed, and I am not sure if they can be changed enough to truly help the disabled community.

Beyond their design problems, when studied for effectiveness, it becomes clear that, in addition to being unrealistic, simulations do not work. Sally French, a social scientist, analyzes the use of “disability awareness” trainings that often incorporate simulations (1992). She argues that these exercises are both ineffective and inadequate, largely because they ignore the social and mental effects of ableism. She suggests replacing simulations with other activities that could be created and run by disabled people, to best provide a well-rounded understanding of disability (Ibid.). In French’s research, she concludes that success occurs under highly specific conditions, but more often there are no lasting attitudinal changes (Ibid.). Sheryl Burgstahler and Tanis Doe write that disability simulations “represent only a negative experience rather than a whole, contextual one” and serve to reinforce the medical, individual model of disability, which will be described in the following chapter (2004, 11). In suggesting how to create effective simulations, they provide the following guidelines: “state

objectives clearly, ensure voluntary participation, illustrate challenges and solutions related both to the system and the individual, demonstrate the value of universal design, include consumers [people with disabilities] in planning and delivery, support positive attitude change, debrief thoroughly, and reflectively acknowledge discomfort” (2004). Dean Dorn in particular discusses the effects of simulations, writing that students became more interested and motivated in comparison to lectures, but this did not translate into changed attitudes or actions (1989). Depending on the type of simulation, Laura West Steck et al found mild positive effects, while other scholars have determined that it can be impossible to assess the effects of simulations that do not have clear learning objectives (2011). Ultimately, it is difficult to determine whether there are long-term effects from simulations, yet simulations remain common today, much to the dismay of disabled scholars and activists.

2. Approaches: Theory and Methodology

Before any other academic theory, I prioritize disability theory and the work of disabled scholars on bodily experience, since it is their lives that simulations seek to mimic. Disability theory has quietly contributed to broader academia without much celebration, even as it slowly changes the world. One of the most important ideas to come from disability theorists is the distinction between the medical and social models of disability, which is one of the largest frames for my research. The medical model, as summarized by Siebers, focuses on disability as embodiment: an essentialist and biological orientation (Siebers 2008). It paints disabled bodies as defective, arguing that disability is an individual trait requiring medical intervention. The social model, in contrast, eliminates embodiment and defines disability as a social construct, “arguing that disabling environments produce disability in bodies and require interventions at the level of social justice” (Ibid., 25) Because of this shift, a strong debate is occurring about the level of importance that embodiment should hold. Theorists David Mitchell and Sharon Snyder have claimed that this over-emphasis on social constructs has eliminated disability from the social model, which is therefore limited by not recognizing the realities of disabled bodies and minds (Mitchell and Snyder 1997). Siebers argues for a “theory of complex embodiment” that has room both for disabling environments and body-centric disabilities: both influence the lived experience of the body, inherently essential to disability studies (2008, 25). This transition between models relates to a common critique of simulations: they prioritize individual experiences rather than balancing this with information about inaccessibility and societal problems.

As disability theory still holds many contradictions about the disabled body and the disabled experience, it is important to consider how bodies and experiences remain centric, particularly when discussing embodiment. Siebers, Ellen Samuels, and S. Kay Toombs each address the importance of the body in constructing the category of disabled in society,

acknowledging the aforementioned tensions in using social constructions (Siebers 2008, Samuels 2003, Toombs 1995). Siebers does not believe a simulation can provide visitors with “the embodied knowledge contained in disabled identities” (2008, 28). Toombs writes, “I am embodied not in the sense that I have a body but in the sense that I *exist* or *live* my body” and later references her “changed and changing embodiment” (1995, 10 & 22). Samuels analyzed her “coming out discourse” as it related to her “praxis of embodied identities,” including disability: her lived experiences and embodied identity were what brought her to the disabled community (2003, 250). Even as these authors use the concepts of disabled bodies and disabled experiences, they acknowledge the difficulties in emphasizing the individual while also favoring the social model, a challenge also faced by simulations.

Disability theory also draws regularly from phenomenology, which also emphasizes the individual. Maurice Merleau-Ponty’s *Phenomenology of Perception* describes how perception is central in understanding the world around us. The importance of the senses and bodily experiences has obvious connections to the methods of disability simulations like the Invisible Exhibition: if people experience the world in particular, embodied, and individual ways, it is necessary to replicate these bodily experiences to understand their worldview. Although he focuses primarily on nondisabled sensory perception, Merleau-Ponty references how blind people engage with the world, referring to canes as “an area of sensitivity, extending the scope and active radius of touch, and providing a parallel to sight” (2012, 144). Canes, therefore, mediate absence of vision with touch, and become an instrument of or for perception. In the Invisible Exhibition, however, visitors and guides use their hands rather than canes. It is important to apply Merleau-Ponty’s interest in bodily experiences as a way of mediating the world, in combination with his descriptions of how blind individuals perceive, to a context where the instrument for perception can be the same for both blind and sighted people.

My other primary reference for phenomenology is Alfred Schutz's book *The Phenomenology of the Social World*. Schutz is concerned with consciousness and how the act of perceiving can differentiate between experiences. He also discusses the difference in experiences, describing how perception provides individuals with their own understanding of the world (Schutz 1967). From Schutz, disability theorists like Toombs are able to describe their experience as disabled academics. Toombs writes,

The *lived body* is the basic scheme of orientation... I experience myself as the Here over against which everything else is There. As orientational locus in the world, my body both orients me to the world by means of my senses and positions the world in accord with my bodily placement and actions... the *lived body* is the locus of my intentions. I actively engage the world through the medium of my body. (1995, 10-11).

Phenomenology's emphasis on lived bodies and how each person orients themselves in the world, as well as the influence their senses have on their interpretation of reality, provides disability theorists with the language to bridge the medical and social models.

Since phenomenologists frequently discuss performance as a site of sensory experiences and identity construction, I also draw on emotional labor and performativity from feminist theory. Although emotional labor originated in sociology, it was quickly adopted by feminist scholars to address the management of emotions in the public sphere, as expected from workers in typically feminized jobs. In *The Managed Heart*, Arlie Hochschild describes how flight attendants were trained to suppress their emotions on a daily basis, as well as to manage the feelings of passengers in dangerous situations. Hochschild ties this management, or emotional labor, to the rise in service industry jobs and labor feminization (1983). I use the concept of emotional labor in the context of disability to describe how guides at the Invisible Exhibition are expected to manage their emotions and the emotions of visitors while performing disability. I also discuss my own emotional labor as I perform ability. Butler's work on performativity is directly related as a way to understand the concept of performing

an identity. She characterizes identities, like gender, as a performance produced and sustained by acts, building a “true” but socially constructed identity (1990).

Both phenomenology and feminist theories like performativity are regularly drawn on by disability theory, often with some alterations. In agreement with disability theorists, I believe that these contradictions benefit from coexisting and being fully argued. Siebers and myself incorporate theories from several authors as a way to discuss debates within disability studies in alternative contexts. Siebers believes that it is important to incorporate non-disability centric theories, such as Butler’s identity politics, which “remains the most practical course of action by which to address social injustices... and to apply the new ideas, narratives, and experiences discovered by them to the future of progressive, democratic society” (2008, 15). Because of this potential to broaden theories from feminist scholars and phenomenologists, Butler’s insights into the social construction of the body have been popular in disability studies for several years, although disability theory provides an alternative way to interpret theories of the body. As Samuels writes, feminist and queer theories addressing the body need to be adapted or contextualized to include disabled experiences (2002). Applications of Butler in disability theory also exist in the aforementioned tense place between the medical model and the social model of disability. This anxiety necessarily reflects reality, and it allows for new evolutions of traditional academic theory when applied to disability.

Disability studies’ use of phenomenology also allows scholars to prioritize meaningful engagement with embodiment. Performativity opens the possibility for simulations to be a reasonable option for understanding the embodied knowledge particular to being disabled, therefore justifying their creation. Samuels, Tom Shakespeare, Mairian Corker, and Kevin Paterson have similarly discussed the importance of phenomenology and performativity when applied to the social model of disability (Samuels 2012, Shakespeare

2006, Corker 2001, Paterson 1999). Paterson specifically argues for a “radical phenomenological approach to the impaired body” as a way of mediating the transition between models (1999). Phenomenology is central for many disability theorists as a way to introduce identity politics to the tension between the social and medical models of disability: Kay Inckle appreciates how “embodiment... operationalizes new and challenging forms of representation and articulation” for disabled individuals, but Inckle finds fault in phenomenology and performativity’s ignorance of disability, a common problem in feminist theory (2014, 389). Feminist theories like performativity provide new directions for phenomenology, but need to be taken up by disability theorists before they become fully functional and representative of all bodies and all lived experiences.

Departing from disability theory, phenomenology, and feminist theory, I use ethnomethodology to concretely link my theoretical and methodological approaches. There are three primary authors that I draw on to address my own experiences: Harold Garfinkel, Graham Button, and David Howe. Garfinkel is the foundation for this network of ideas: drawing on phenomenology, he defined ethnomethodology as a way to understand how people make sense of their world through their experiences. Button uses similar approaches but addresses how embodied practices are part of the larger social practice: out of “the structure of individual experience” comes a way to understand the world for individuals and society (1991, 65). Garfinkel’s student Albert Robillard used ethnomethodology to understand his own disability and how his body was changing. He wrote that only ethnomethodology could “address the concerted, bodily accomplishment of ordinary tasks” (1999, 31). It is no coincidence, therefore, that the subtitle of his book is “The Lived Experience of Paralysis.” Howes bridges ethnomethodology and sensory ethnography, arguing, “cultural patterns are embodied through everyday sensory experience” (2003, 14). This emphasis on cultural patterns and embodiment connects with the individual lived

experiences of people and how sensory experiences provide structures to navigate the world. Howes references theorists such as Edward Hall, who suggested that not only did people from different cultures speak different languages and experience reality differently, but they also “inhabit different sensory worlds” which then affects how they experience the world (Hall 1966, 2). Sensory ethnography, ethnomethodology, and disability studies explain why people with disabled bodies and minds experience and understand the world differently, as their senses and bodies do not perceive in the same ways. This rationalizes the interest in and popularity of simulations: if worldview and knowledge are a matter of perception and bodily experience, an individual could understand difference through another way of experiencing and understanding the world.

I have outlined some of the ways in which these multiple theories connect to each other, either explicitly, as disability theory actively uses phenomenology and performativity to understand bodily experiences, or more implicitly, as theorists in ethnomethodology acknowledge their interest in phenomenology but do not regularly reference it in their work. There are other means of communication amongst the mix of theories however, such as their tension in prioritizing social constructions or individual bodies and their lived experiences. This debate is most prevalent in disability theory, during the transition from the medical model to the social model that left many theorists uneasy with the repercussions for non-physical disabilities and the lack of interest in people. Performativity relies more heavily on the idea that the world is socially constructed. In contrast, ethnomethodology uses individual experiences to build more collective structures to interpret reality. Ethnomethodology is also influenced by phenomenology, which draws on the body and senses to situate people as embodied subjects with shaped perception. This reflects the inherent stress between prioritizing individual experiences and senses over larger structures and societies: is it more important to address disability as socially constructed or to acknowledge the individuality of

lived experiences, at the risk of tying disability too much to the body? Disability theory can provide a means to interpret these debates while letting the theories exist in contradiction. It also supports a more thorough analysis of the Invisible Exhibition that addresses the conflicting ideas behind its creation and methods. I believe that these tensions are essential for understanding the conflicting narratives of the Invisible Exhibition. Simulations are founded and become popular because, as phenomenology argues, individual experiences shape our worldview and the only way to understand another's worldview is to share in their experiences. It is also useful to consider performativity, emotional labor, and disability theory to discuss peoples' experiences in the tour and what information they are gaining.

Out of the context of these theories and their debates, a variety of methodological approaches arise. It is necessary to engage in ethnomethodology, in order to best address my role as a disabled researcher studying disability, as well as to understand the tensions inherent in prioritizing individual experiences. Autoethnography is a key part of my methodology, because it is essential to discuss my own experience in the tour to analyze its reliance on embodiment. I participated in the simulation twice and recorded my experience, and wrote reflections on what it was like for me to experience the tour. As a disabled researcher, it is not possible for me to separate my experience and sensory knowledge as a disabled person from the research process. It is essential to include my own perspective of embodied knowledge and identity in this regard. The primary problem with this method is that it must be secretive: the Invisible Exhibition does not allow most disabled visitors to take the tour, and in many cases, the potential of "insider" information poses more risks than benefits. However, this raised an interesting question about to whom this experience and its embodied results are accessible, which will be discussed in a later chapter.

In addition, I interviewed and observed staff and visitors. My interviews with the manager focused on the design and intentions of the simulations, while in my interviews with

the guides we discussed their own identities as disabled people, their embodied knowledge, and how they think the simulations reproduce disabled experiences. The business manager was the highest-ranking person and my primary contact, as the original creator is no longer with the company and the owners do not live in Hungary. I was to formally interview her three times, for one to two hours per interview, about the company's design, method, and goals. I was also able to observe her in daily activities at the site and how the company is run, as well as the changes it is undergoing. I was not allowed full access to any part of the tour, to see it with the lights on, or non-tour events at the site. I also received comments on what does not reflect the official position of the company. This was clearly a potential ethical issue here if she became too involved in editing my data, but ultimately I made all decisions about what would be included. I had to be careful that although it is necessary to share some materials with the business manager to maintain that relationship and gain her trust, I could not let this influence what I recorded or my analysis.

Because I could not observe the guides during the actual tours, I used my experiences as a tour participant to understand their methods. I observed guides in the first portion of the tour, in the light, and their interactions with the visitors and each other. I also interviewed the guides to ask about their own embodied knowledge and identity, and how they try to convey this during a tour. I conducted two interviews during tours and two outside of the tour, which typically occurred in segments of 20 to 30 minutes when they had breaks. There were further ethical risks here, as whenever a researcher works with disabled subjects, since many of the guides are completely blind and I was careful to be honest when recording or taking notes. Because of this, I tried to maintain a high level of honesty with the guides and build their trust so that I was able to conduct interviews without concerns about what I might do if no one can see my actions. Ultimately this was more difficult than expected, which will be addressed later on when I describe what I learned from interviewing and observing guides.

With visitors, I relied on a combination of observation and interviews. I observed nearly a hundred visitors prior to the tour, when they were introduced to different tools and games designed for blind users and they initially met their guide. After the tour, I interviewed dozens of visitors about their experience. These interviews were between 10 and 45 minutes long, depending on the number of people involved and availability. In interviews with the participants, I asked about their bodily experiences in the simulations and what knowledge they gained about disability. Unfortunately, as the tour is entirely in the dark, it was impossible to observe visitors during the main part of the tour or use this information to structure their interviews. I took the tour twice myself and was familiar with the tour process, so I have used my experiences to guide these interviews. I was also reliant on visitors being willing to speak with me immediately after their tours, although I supplemented this information with reviews and guestbook entries. The changes made to these approaches will be further delineated in other sections, and their collected data shared and analyzed as well.

3. Introduction to the Invisible Exhibition

History of the Invisible Exhibition

When he was a teenager, the founder of the Invisible Exhibition visited a similar simulation, where blind guides took visitors through activities designed to mimic their everyday experiences. This left a deep and lasting impression on him, as it was his first interaction with anyone blind. As an adult in Budapest, he was inspired to create a temporary exhibit that would recreate the experience for Hungarians. In 2007, he asked his friend Ágnes¹ to help set up the exhibition. As Ágnes tells it, there was no particular trigger that encouraged him to found the company, “he just had the feeling” that the time was right. At the time, Ágnes had another job and neither of them had any experience working with disabled people. Nevertheless, the two began hunting for locations and tools to establish the company. They settled on a rental space on the outskirts of Budapest that also held a nightclub. Without any relevant experience or research into the life of blind people, the two organized a for-profit exhibition with the intention of hosting it for one year and then moving on with their lives. Surprisingly, the original iteration of the Invisible Exhibition was immensely popular and the two decided to continue on a more permanent basis. He later left the company and the country to work abroad, and new people bought the company. The original location was small and inconvenient for most visitors, so they began seeking another building and developing relationships with the Hungarian blind association and blind community in order to hire more guides and expand the popular exhibition.

By 2010, under the leadership of the new owners, the Invisible Exhibition was flourishing and Ágnes was asked to quit her existing job to work fulltime. The company was looking to expand internationally so Ágnes began to direct this project, scouting cities and contacting various associations. At the time of my research, the Invisible Exhibition was well

¹ All names have been changed.

established in Budapest, Warsaw, and Prague, and was looking to expand into more countries and possibly overseas as well. From the beginning, the tour had been popular with local schools who wanted hands-on, educational experiences for kids, but after the company became popular within Budapest, people recommended the activity to their friends and guests. The marketing team had also begun using websites like Trip Advisor in order to advertise to international visitors and tourists. This grew their audience even more, and the Invisible Exhibition quickly climbed in popularity online. As of 2015, the Invisible Exhibition markets itself throughout Budapest with print ads in the metro and in magazines or newspapers, statues in parks, and other means. It also uses its high ranking on Trip Advisor and similar websites to draw more visitors from abroad. The company does, however, remain popular with school groups within Hungary and is committed to its goal of education, which it defines as providing children with an introduction to disability and the opportunity to meet blind people, so that as they grow up, they understand disability as natural human diversity.

Because Ágnes and her friend did not have any experience with disabilities or simulations, beyond the single visit by her friend, the tour was designed based on their own ideas and priorities. Neither did any research into the lives of blind people, universal design, or societal inaccessibility, but instead designed the tour to replicate what they understood as the daily experience of someone blind. The tour has evolved over time and is different in each location: while the basic set-up and included rooms are the same, the design changes as needed and different tools and toys are included in the lighted room based on the city. Many of these items are bought from companies who specifically design them for blind people. The guides also contribute, often suggesting particular games that are fun or easy to understand for visitors, and they will occasionally bring in new items to add in order to more effectively

create rooms that mimic reality. The result is a somewhat haphazard approximation of reality for blind people that has become extremely popular with tourists, students, and other visitors.

Design of the Invisible Exhibition

The current design of the Invisible Exhibition in Budapest is one that has evolved over time into a highly structured and ritualized experience. When visitors arrive, there is a large open room with displays, a video, couches, information about a tandem bicycle association, and a do-it-yourself obstacle course. This area and the reception room are divided with a large, translucent wall that has the name of the company in both Hungarian and Braille 3D lettering. Once inside reception, there is a wall-sized bank of lockers, the reception desk, and three tables that have different objects on them. The walls are covered in enormous displays about Braille and various blind celebrities, televisions with video information, or other items. Typically, visitors spend 10-20 minutes in this area with their guide before entering the dark part of the tour, which is connected by two doors to the reception area. Once out of the light, the tour consists of a series of rooms that are intended to replicate normal environments that a person would experience. This includes an apartment (a kitchen, bathroom, and living room) as well as a street scene and market, a forest, a cabin, an art gallery, and a bar. Many of the rooms have sounds and scents added, and consist entirely of real objects; the bathroom holds a donated shower, toilet, sink, and washing machine, for example. The tour was not designed with the input of blind people, but Ágnes did mention asking the guides for assistance when choosing new objects for the lighted room, and regularly seeking their feedback. When asked about the original development of the tour, and about its evolution over time, however, she repeatedly stated that the founder and she had designed the tour with anyone blind, done research, or made any effort to collaborate with blind people.

It is necessary here to explain the structure of the Invisible Exhibition and what the standard tour is like for visitors. Most visitors book tickets ahead of time, which is mandatory for those who want tours in any language other than Hungarian. Visitors are given limited information on the design of the tour beyond the rules, but have often heard of the tour from their friends or online, which influences their expectations. The Invisible Exhibition hires guides who speak English as well as other European languages, but it can be difficult to reserve tours with languages other than English. Typically visitors arrive, check in with the receptionists, and leave the reception area to wait outside. When their guide is ready, they go outside, collect the visitors, and bring them inside to put their things in a locker. Most visitors spend 10-20 minutes in this part before entering the dark, although it depends on the tour schedule: for larger groups, some sections skip this room in order to get a head start in the dark. The guides use this time to meet visitors, discuss their existing knowledge and expectations, and educate visitors with a short introduction to Braille and basic information about different types of blindness. Once in the dark, visitors move throughout the tour until they reach the bar scene at the end, where they are able to sit down, order drinks, and have conversations with their guide.

The Invisible Exhibition's Official Narrative

I previously summarized the origins and design of the Invisible Exhibition but I would also like to describe its purpose and approach in more detail. Teodor, a guide who had previously worked at Ability Park, contrasted the two simulations' approaches. Ability Park, in a section designed to replicate blindness, used a detective story where visitors were asked to find clues and solve a mystery in the dark. Ability Park included simulations for multiple disabilities as opposed to just vision impairments like the Invisible Exhibition does. It also advertised itself as an educational experience, whether for students or workers who sought to

understand disability. Teodor acknowledged the differences in approach but also admitted, “the style is different, the purpose is the same.” The goals or intentions of the exhibition, however, are concretely linked with the structure of the tour experience, which I will detail next.

It is important to include how the Invisible Exhibition’s website, Ágnes, and the guides describe the intent and design of the tour prior to discussing my own experience and understanding of their intent and design later. When it comes to the purpose, there is no official statement for the Invisible Exhibition, but given the repeated language used by the website and employees of the company, there is a definitive message. The common thread across each is that the Invisible Exhibition is meant to be educational. Their idea of education focuses largely on the importance of first-hand experience and being able to meet a blind person, as there is limited information on site about Braille, different types of vision impairments, or what people can do to improve society. The website makes claims of education and understanding as well with phrases like, “[the tour is] how we can help them, even understand them” and “you will be able to understand what life is like without one of the senses” (Invisible Exhibition 2015). This idea was present in a few of my interviews with visitors as well; one woman specifically mentioned that “now [she] understood it [herself]” and this gave her more information than simply meeting blind people. The “understanding”-focused narrative of the Invisible Exhibition closely matches what phenomenology has long argued: perception shapes how people understand the world, and different forms or abilities in perception (such as blindness) result in a different worldview. This opens up the possibility that changing a sighted person’s perception, by taking them through a tour in the dark, can shape their worldview and provide new perspectives. The Invisible Exhibition echoes this in a less theoretical way, arguing that a changed sensory experience can concretely improve society and encourage integration.

This key theme of understanding was present in nearly all interviews with guides and Ágnes, who prioritized the humanizing aspect of the tour. These goals were brought up by Teodor, who said, “Our key word is that people should look at us like humans” and mentioned that he wants visitors to learn how to interact with him in everyday life. He referred to a major construction zone near the building and his difficulty in navigating the constant changes, but people are too scared of him to offer any help even when he is alone. He used the concept of sensitivity several times, asking for people to become more sensitive to blindness. Other guides used similar language, particularly the ideas of fear and sensitivity, when describing what changes they anticipate from people who complete the tour. One guide mentioned that people have a better “appreciation toward the blind” after experiencing blindness first-hand and can feel more sympathetic. When I interviewed Ágnes each time, she referred to the “message” of the exhibition, that it can “teach us not only to be a bit more open with the blind” but also to “change people’s minds.” She used the concept of humanity, arguing that when people can meet someone blind in person and ask questions, they come to understand “you are the same but different,” which is what she defines as “the main point.” She believes that after visiting the Invisible Exhibition, people are more open and helpful towards blind people, and “can see things from their point of view... it improves human’s souls or ways of thinking.” This emphasis on change exists primarily on an individual level but Ágnes also mentioned that the Invisible Exhibition can bring about social change on a larger scale simply by educating people about disability.

When it comes to the structure of the tour, particularly how it connects to the purpose of the tour, there are similarly strong consistencies across responses. The concept of first-hand experience is repeated often with the metaphor “stepping into their shoes.” There is an expectation by the Invisible Exhibition that visitors have no experience with disability, but visitors also hold particular expectations of the company and the tour. This duality is noted

on the website, where the importance of having a blind guide is emphasized: “you will be lead by blind or partially sighted people on a journey that will change your life” and “The Exhibition brings the world of the blind and the seeing closer to each other and teaches through positive experiences” and relates to their stated goal of integration (Invisible Exhibition 2015). This emphasis on the bodily experiences of visitors also reflects what phenomenology argues: individual perception shapes how people understand the world, so it becomes necessary to have new bodily experiences in order to gain new, particular knowledge. This same language was also present when I interviewed Ágnes, who referred to “seeing things from the other side” and the importance of an experience that cannot be found anywhere else. She also mentioned the role of entertainment in the tour, or that it is essential for people to be “having fun but they are learning a lot without even noticing” and slowly overcoming their misconceptions about disability. Similarly, Teodor referred to the importance of asking curious questions and building a relationship with his visitors is the key to education, which are topics that Ágnes mentioned as well. She said that it is important to allow questions in the dark so that the visitors are not scared of being rejected or mocked for their questions and that they can get information in a safe environment. This relationship between the design of the tour and the Invisible Exhibition’s goals is essential.

I also received parallel answers to questions that were solely about the design of the tour. Both the guides and Ágnes praised the organization, particularly that people could be slowly eased into the dark by spending time in the light and talking with their guide before entering the tour. One guide, Mária, mentioned that she puts extra effort into the time in the lighted room to help people get ready for the tour. She said that it is important to have conversations with the visitors about any previous experiences they have had with simulations or disabled people and what they are expecting. She does not set a time limit on this part of the tour, but waits until she can “feel if someone is ready or not” and will spend

extra time encouraging them to relax before entering the dark. She acknowledges, “Some people need a bit more in the [lighted] location.” This also builds a relationship between the guide and the visitor so that in the dark the visitors are trusting and dependent. Another guide, Teodor, and Ágnes both mentioned the adaptability of the tour and the willingness of the guides to answer questions that would make the experience more worthwhile for visitors. Teodor described how he likes to “go with the flow” and accommodate their unusual requests, often working to manage visitors’ expectations with his reality. He also changes parts of the tour based on the visitors; he told me about letting a visitor smell the drinks in the bar to help her understand what each one was and she wanted to learn how to fill glasses. Both Teodor and Ágnes referred to how the tour changes based on the guide and their personal style, as well as the visitors and their interests. Each also acknowledged that because their visitors can come from any country in the world, it is necessary to be aware of cultural differences, visitors’ expectations, and how these can influence sensory experiences. This is similar to Howes’ belief that “cultural patterns are embodied through everyday sensory experience” (2003, 14). The guides are aware that each person has their own understanding of the world, shaped by factors like their senses, cultural context, and preconceived ideas or expectations. Guides are also aware that the tour could be adapted slightly to make the experience more effective and the changes that visitors go could be stronger.

4. Visiting and Performing (at) the Invisible Exhibition

The Researcher in the Tour

I first visited the Invisible Exhibition in February 2015, simply to meet Ágnes and confirm that my research plan was acceptable and possible for the company. I was hesitant to participate in the tour myself, largely because I was fearful of the sensory impact that the tour would likely have on me, as someone autistic and with other disabilities, including a sensory processing disorder. On my first tour, the English-speaking guide was unexpectedly ill so the receptionist and a Hungarian-speaking guide accompanied me. I did not hear the guide speak at all unless it was in conversation with the receptionist-translator, but I could feel her moving around me and twice she touched my hand to make sure I was moving in the right way. A significant part of my initial fear was based on expecting someone touching me for an hour in the dark to lead me through interactions with strange objects, but I was rarely in physical contact with either the guide or the receptionist-translator. However, the tour was confusing, primarily because I did not have the relevant knowledge to understand what I was supposed to identify. Once I had been inside for a few minutes, the initial clumsiness and disorientation did not lift. Because of the language barrier, I did not ask any questions of the guide or try to hold a conversation in the dark, and I was in the tour for maybe 20 minutes (as opposed to the standard length of 20-45 minutes). Afterwards, I tried to diagram how the space was designed and the organization of the rooms and I was unable to do so. I left the Invisible Exhibition as quickly as possible, feeling sick and mostly frustrated that such a stressful experience had not resulted in any transference of special knowledge. I went home and reflected on the experience:

The tour was different than I expected. I wasn't nervous about being in the dark but I tend to walk into things and misjudge distances in a normal, well-lit room, so I was worried about kicking something or moving into a wall. I was so paranoid that I held my hands up and stuck out my elbows so I could try to maintain balance without hitting anything... The whole experience gave me

such a headache that when I got home I laid down for an hour and tried to cover my windows because it was exhausting...

The first tour did not leave me confident that I could argue anyone was gaining any understanding of disability by stumbling around in a faux forest and walking into walls.

The second time I took a tour was also out of necessity: as part of my Visual Anthropology class, I was asked to record the tour in order to share the experience with others and make a video that could try to mimic the simulation. I realized the irony of trying to simulate a simulation as well as the same anxiety that had made me delay taking the tour the first time: I did not believe I could adequately explain how my experience in the tour differed from a non-disabled visitor. I also expected the same experience as my first tour, and similar effects. Still, I went on the second tour with a recorder and tried to spend more time in the tour and ask more questions. The experience was completely different than my initial tour, although it had the same overwhelming and negative impact on me. I was able to book a tour with an English-speaking guide, and he and I spent more than an hour in the dark because we had so many long conversations:

There was so much more interaction between the two of us – not just the questions but he would take my hand or touch me in order to guide me through a room, he used more directions to tell me where to walk and what to watch out for, and he would sometimes snap his fingers so I knew where he was.

Unlike the first tour, the entire experience was full of conversation and contact, but it too left me deeply nauseated and exhausted. Once again, I went home and laid down before trying to write about the day.

The benefit to experiencing the tour myself was how it provided a frame reference and an easy way to interview visitors about their own time in the dark. I was able to identify the feelings that I had felt or that I assumed other people would feel, and I could ask about these specific emotions in interviews. I could also relate to any experience, expectations, or particularities of the tour when I asked visitors about their experiences – when I was coding

my interviews, I noticed the frequency with which I used “I” statements to relate my experience to the visitors’ or provide them with a way of processing their experience. I also had a better foundation for speaking with Ágnes and the guides since I had the particular experience of taking the tour and the staff/visitor dichotomy was how each was used to interacting with an outsider. I could not understand how anyone thought this brief tour was true insight into the life of blind people, although I was aware of the extreme impact that it could have on any visitor, based on my own experience.

I had expected ethnomethodology and my personal connection to my research topic to be punishing at times, but I found it surprisingly challenging to balance addressing my own position and “sensory situatedness” with the desire to understand the embodiment the Invisible Exhibition purported to offer. Throughout my Visual Anthropology class, I was drawn to sensory ethnography as a way of processing the research process. Throughout fieldwork, one of the authors I returned to was Sarah Pink, who refers to ethnography as “a reflexive and experiential process through which understanding, knowing, and knowledge are produced.” This is what I was waiting for at the Invisible Exhibition that never hit me to the extent that other visitors claimed. One of Pink’s other primary ideas is that, in preparation for sensory-based research, researchers must be aware of sensory biases. From the beginning, I had assumed that being sighted was my bias and that I would experience the tour like any other visitor. I discussed my changing understanding of this in a response for class:

Given that my tour guide was blind, and the exhibition is designed to make me empathize with “the blind experience,” I assumed my sightedness was my bias. I think now that it’s more complicated than this. I have my own sensory issues – a mix of over- and under-sensitivities as well as general processing issues, always in competition and directly tied to my own disabilities... I must address that beyond the differences in how my guide and I experience the tour, I am not experiencing it the same as any other visitor.

It took until the end of my research to fully understand why ethnomethodology was relevant in a study of bodily experiences, as well as how to best address my own position as a disabled researcher who is interested in both disability studies and traditional anthropology.

Laura Marks refers to Merleau-Ponty and his idea that vision allows us to “flatter ourselves that we constitute the world, while touching “adheres to the surface of our body, we cannot unfold it before us, and it never quite becomes an object. It is not I who touch, it is my body.” Other researchers have acknowledged the same centrality their body, identity, and embodiment hold in fieldwork, as a way of understanding larger processes and the tendency to interpret information through individual, first-hand experiences.

Guides in the Tour

There is limited data on how guides feel about the tour or what their experiences are like in the tour, entirely because they are hesitant to discuss it or put words to the feelings. I was only able to speak with 4 guides, in part because of scheduling difficulties with the company but, significantly, because many did not want to speak with me or were not interested. For the interviews I was able to complete, when I asked guides about what it feels like for them to take visitors in the tour and to share information about their lives, they answered simply, “I don’t know.” The interviews were awkward and full of miscommunications, as well as a lack of trust. Because of this, I have limited information from the guides on how they interpret the exhibition. Most guides would respond to questions where they could describe their job, but nothing more. One guide, Mária, described her job as “to show people our world” and to open her world to sighted people in order to help them understand. This was in contrast to how Teodor explained his job, he told me that he finds it difficult to represent all blind people and that it is not possible for him to show visitors all of his life in such a short period of time, although he acknowledged that he experiences the

world in a particular way through sensory perception and that visitors do expect this level of access and understanding. Other guides felt less strongly about their role and mentioned the positive aspects of introducing people to the blind community and educating them. When I asked guides about their relationship with other guides, since Ágnes had suggested they were all excellent friends and part of a tight community. Instead, I got answers such as, “We are fine, absolutely no problem... everyone is different, everyone has different strengths and weaknesses” or that one guide was friends with “all the group” and Ágnes added, “She didn’t name anyone in the group because they have good relationships.”

I received the most detailed and energetic responses when I asked questions about the types of things visitors ask the guides in their efforts to understand or educate themselves. Every guide had a story to tell. The only guide who insisted he had never been asked an offensive or ignorant question was Teodor, as he believes all questions come from genuine desire to learn and therefore cannot be inappropriate. He did, however, have stories from his colleagues and told me about a visitor who asked a guide who is also a mother of four children how and why she was having children if she was blind. She was extremely hurt and offended by the question, but Teodor told it with the air of, “Oh, those silly sighted people.” He found it odd that one woman, thinking that it was how blind people introduced themselves to new people, expected and asked for him to touch her face repeatedly. He felt obliged to handle strange requests politely if he thinks these changes will help a visitor better understand his life by the end of their tour. Mária told me that one person, not thinking their question through, asked her in the middle of a tour if she had a job, but that her fellow guides had heard much worse things. Ágnes told me one example of this: a small child exited the tour, looked up at her guide, and exclaimed with surprise that the guide looked like a normal person instead of a monster. These efforts to educate ignorant visitors are often present, despite the tour’s emphasis on more traditional forms of education about disability. Mária

shared several examples of the more typical questions asked: how long the guides have been blind, why they are blind, how they live on a daily basis, if they have families, and about their extracurricular activities. Teodor provided me with an extensive list of questions that addressed whether he used a cane or a guide dog, how he uses money, and how he cleans. He also referenced more unusual questions, typically from children. A recent visitor from a primary school had asked him about how he imagines flowers, and another young girl had asked him how he falls in love. He said he had received relationship questions from adults before but never from a child and found the experience odd while he tried to answer appropriately. These questions, in combination with the tour, are part of how the Invisible Exhibition understands its goal of education: people need to ask invasive questions, meet blind people, and experience blindness in order to truly understand.

Disability theory has acknowledged the conflicts between the medical and social models of disability, in which the individual experiences of disability can conflict with the idea that society is inaccessible and, seen through this lens, disability has entirely different roots. This conflict between individual and societal is often seen in the tour, as guides are expected to speak about both their personal experience and that of the blind community, but also tend to use anecdotes as a way to encourage visitors to be aware of the inaccessibility they face each day. One example of this came at the end of a tour, when a guide discussed how they encourage visitors to try and use coins to pay for a drink but they have difficulty identifying the different denominations of money. He added, sadly, that Hungarian forints are harder to use than euros since all of the bills are the same size. Earlier in the tour, when discussing what methods blind people use to cross the street, he asked me if cities in the United States used sound signals and textures to aid crosswalk safety and commented, “In Hungary, you can find it some places, mainly in those areas where you can find institutes that are dealing with the blind, but unfortunately not everywhere...” While finding small

opportunities to mention what governments and societies could do to improve their lives, guides are primarily expected to discuss their personal experiences: when they became blind (or if they were born without sight), if they have families and relationships, if they attended school or have other jobs, and how they feel about being disabled. The tension that disability theory has long acknowledged that is inherent in balancing individual and societal concerns is explicit in the narratives shared by guides.

Visitors in the Tour

Although I observed nearly a hundred visitors prior to entering the tour, I conducted all interviews after visitors returned from the tour and had re-acclimated to the reception area. In this section I will summarize how visitors described the tour, including the questions they asked the guide, and what they liked or disliked about the tour. In the following section, I will focus on the sensory experiences of being in the dark portion of the tour. My observations outside of the dark part of the tour were often brief, since groups stayed in the light for a maximum of fifteen minutes. I noticed several commonalities between new groups entering the reception area. Many were extremely shy and even if a guide was visibly in the room, visitors would slowly approach reception with their tickets and put their bags away before eventually the guide would call them over. If the group had time for the introduction to Braille and the tour, sometimes individuals would sit down while others floated around the back of the chairs. If the guide asked them direct questions, they would often hesitate or refuse to answer until continually pressed. Eventually, the lesson would begin and everyone would ease their way into talking with the guide. When they all stand up and gather by the entrance, and the guide begins to teach people how to hold their hands for safety, people become visibly uncomfortable and anxious about entering, and often enter the dark extremely slowly, in an individual trickle. When they exit, it is in a rush of everyone at once, with

people holding their hands over their eyes, faces in pain, and groaning. Over time they adapt to the bright lights and begin to laugh and talk with each other, often immediately discussing the tour. After some time, visitors drift back to the tables to try out different toys or games, or they leave the reception area.

It is difficult to assess the expectations of visitors, although their ideas about what the tour would be like are often mentioned in their interviews or reviews. Nearly every visitor described the tour in an exceptionally positive way, often using the same vocabulary and ideas to illustrate how excited they were by the experience. Visitors described the tour as “eye-opening” and “unforgettable” and “phenomenal” and a positive experience overall. Most visitors also referenced that they thought it would be scary and although it initially was, although the fear slowly subsided and they became more curious and playful in the tour as their senses changed. They also described the tour as harder than they had expected and very challenging, particularly with the initial disorientation. In the guestbook and online, similar responses are abundant. The concept of a “once in a lifetime” experience is more present in written responses but many people refer to how amazing the tour was, as well as their increased understanding of and respect for blind people. One person wrote, “I have to say that the voyage you took us on was one of the most eye-opening experiences of my life.” Many coupled these explanations with an overall narrative of change, believing that their lives and senses had been altered by their brief experience in the tour. Overall, visitors are extremely positive about their tour and view it as a unique and life-changing experience.

It was exceptionally rare to find people who said negative things about the tour experience. A few people mentioned that they wished they had more time to ask questions or that the tour involved more parts of everyday life. One visitor explained several different things that she was displeased with, but she was the only person to speak in an expressly negative way. Because of the scheduling of several tours back to back, her part of the group

did not hear the introduction or receive a lesson in Braille. She mentioned wanting more of background information and a slower-paced, more complex tour, with specific examples of how the tour could be improved. She referred to a desire for more “interaction” that could involve learning tasks like eating or brushing teeth. Another visitor had said she wanted to try making her own drinks or even pouring them into glasses, just to understand daily tasks. For the first girl, she wanted more education about blind people, how they feel and go about their daily lives, and more information about vision impairments, as well as an extended tour where this information would be presented in an exhibit and combined with more activities. One of her specific complaints was the short time in the bar to ask questions and process the information from the tour: “We want to discuss now but we only have 3 minutes [in the bar] so it’s too short to realize, you have 45 minutes of experiences but it’s so many rooms... it’s like falling down and playing catch up.” Finally, she wanted concrete information about what to do if she meets a blind person on the street. Her interpretation of the educational aspect of the Invisible Education found it extremely lacking, although she was the only visitor I spoke with who didn’t feel as though she understood anything more now about disability. I did not question these desires but many of these questions could have been asked during the tour, not just in the bar, and there is information about types of vision impairments and other daily tasks throughout the reception area and prior to that space as well.

I asked several visitors specifically what they thought they had learned from the tour, if they understood what it is like to be blind, or if they will interact differently with blind people in the future. Guestbook reviewers believed they had a good understanding of what it is like to be blind and how blind people live every day, although they had also expected this level of education. One added, “very challenging for the mind... I have a greater understanding of what life must be like for a blind person but I still cannot imagine living like that every day. My appreciation of my vision, imperfect though it is, has grown a thousand-

fold.” References to an increased value of the visitor’s own eyesight were somewhat common, particularly in written reviews. In interviews, visitors expected, whether or not they had previous experience with blind people, that the tour would change how they interact with blind people in the future. One student admitted that in the tour she felt extremely isolated from the outside world and she believes that for blind people, this feeling of loneliness and disconnect is present in everyday life. All visitors who believed they understood what it means to be blind, or how to interact with blind people in the future, stated that the “first-hand experience” aspect of the tour is the most influential for them. Several visitors were also able to discuss that they had never realized how many or few disabled people they saw every day in their cities, but also that they were more aware of basic inaccessibilities: whether crosswalks were textured or their signals used sounds, how difficult their country’s money might be for a blind person, or how it might be hard to navigate their daily commute without help. This suggests that to some extent, the guides had been able to weave a discussion of inaccessibility and societal problems into their personal stories and slightly change the narrative of the Invisible Exhibition: not only did visitors think they understood what it means to be blind, but they were also more aware of the presence of disabled people in their cities and what societal barriers they face.

I also questioned visitors about what types of questions they had asked in the tour. Many people were extremely hesitant to answer, or provided vague answers to one question or nothing at all beyond, “I don’t remember.” Because the guides so frequently mention the questions that visitors ask, I am not sure if people are embarrassed to ask questions at all or if they are embarrassed to admit what questions they asked, outside of the comfort and safety of the dark. Some of the questions that people shared with me dealt with everyday life, such as how their guides navigated public transportation, paid for things, and if they use canes or not.

Other visitors focused on their relationships and friendships, often asking if the guides were friends with other blind people or sighted people, and questions about their family.

5. “Trying On” Disability

Visitors’ Experience of the Tour

As explained by the Invisible Exhibition, the tour is ultimately a sensory experience. This is included in the description on the Invisible Exhibition’s website, where they write, “the participants obtain information exclusively through touch, hearing, scent and their sense of balance” and they “find [their] way only by touch, sounds and scent.” Because of the structural emphasis on visitors’ senses, I asked each person about how they felt in the tour and how they experienced the tour through their senses. Several visitors claimed that their senses worked differently in the dark once they adapted to the darkness. It was common for visitors to reference one sense more than others, although this varied by individuals. Many felt that they were feeling things with their hands and bodies more intensely than normal, and this enabled them to identify objects and people by touch alone. A group of students mentioned that they were “experiencing things much more than you would experience them if you see, because you feel it more, you listen more, it’s like everything is more intense.” This theme of strong sensory input was typical across most visitors, although some experienced it in a positive way and others were extremely stressed in the tour.

Those who benefitted from altered sensory input found that one sense worked better above all else, and used these changes to guide themselves. One visitor said that he was “more acutely aware of things” and used his legs and feet in addition to his hands to identify objects. Others cited their sense of smell and insisted that each scene had strong scents pumped into the environment: flowers in the forest, coffee in the house, or food smells in the street market, for example. The girlfriend of the “acutely aware” visitor said that as soon as she entered the street scene, “the bloody vegetables, they stank!” As previously mentioned, the Invisible Exhibition sources sounds and smells from one company and includes them in the tour, although it was not clear which scents are present in which rooms. A few visitors

prioritized their hearing above all other senses, and they told me that some of the rooms were so overwhelmingly loud that it made their other senses weaker. Another referenced her own method for dealing with this: “I just focused on my ears because I was hearing easier, I was like closing my eyes and just trying to listen and focus on the voices.” One person mentioned that the temperatures were different in each room, in conjunction with the scent: “In the garden, it was colder and the smell was different.” Many visitors also referenced feeling self-conscious about the noise they produced, claiming that their shoes had been so much louder than others’ or that they were touching people too much.

In contrast to people who felt that their senses were highly tuned to compensate for lack of sight, other visitors coped with feeling overwhelmed and lost. One person, a young student, responded that “a lot of the times you feel you are not in the same world, you are here, you are far away, you are not in a living room,” and described how her senses had become so confused in the darkness that she could not accurately place herself in space. The couple mentioned previously responded that they were so confused by the tour that they started visualizing things inaccurately or objects that were not in the room, as a source of comfort. The woman mentioned picturing what the furs looked like stretched on the cabin wall in order to identify them as animals, and she had “sensed where the wall was and how big it was” before realizing that in her panic, she was “imposing” her need for vision in order to “feel more secure in my mind” but occasionally believed she was hallucinating. Her boyfriend echoed this and mentioned his claustrophobia. He managed throughout the tour by inventing visual aids throughout the tour, and in the bar he imagined the exact set-up of a bar with the location of the tables, chairs, fridges, and everything in order to feel comfortable. More visitors referenced their anxiety over losing their sight and felt as though their eyes were constantly searching for things to see and had to close their eyes to manage. One such person was part of a group who engaged in a discussion about whether or not it was better to

close one's eyes to experience the tour, and how isolated they felt with a reliance on touch. Their senses served as a grounding technique when the experience became difficult, "I'm more with my mind somewhere else and then you have to be [focused] because you only have the listening and the feeling." This visitor was also able to connect their changed sensory and bodily experience with what they felt they had learned from the tour, and suggested that their perception of disabled people had changed after an hour.

Several visitors referenced the way they moved throughout the tour, beyond relying on their senses to locate themselves, describing instead the importance of their individual body in the tour. A few students felt that it was an unusual experience to "rely so much on your fingers and the noises of things" and began to describe their method of moving throughout the space, noting they had knocked on things and tested to feel the different textures, sending a foot or a hand out to explore before moving on. They were confused by different textures on the floor, which provoked fear over not being able to keep steady on the ground, but also described a hyper-focus that required them to be completely conscious and intentional with all movements. Another visitor, who did not have time for a full interview, approached me afterwards solely to tell me that he wished I could have seen him moving throughout the tour and demonstrated his movements: arms swinging and legs sweeping across the floor with his head bobbing, like a clumsy and unsure ballerina. More visitors tried to describe how their movements had changed but failed to find the words, so I settled for observing them as they exited. Often people would immediately huddle together after leaving the darkness, and would immediately begin to discuss the tour. It was rare to see groups like this who did not instantly begin to mimic their behavior in the tour: older individuals would demonstrate their hand movements and send out questioning hands that clasped at air, and younger visitors would use their entire bodies to show their hesitation and confusing. In interviews, people often tried to explain how their bodies worked in the tour but could only

describe how often they touched each other or who ran into who and which person fell on the ground. This often resulted in references to the way that people held hands or formed a chain during the tour to maintain connections, and some online reviews or guestbook reviews mention the physical connections between individuals as well as their “bonding” while struggling to navigate.

“We don’t let them in”: Who Can Perform Disability?

Although it is fairly common for disability simulations to be designed, managed, and run by people who are not disabled (this will be discussed more in the following section), something particular to the case of the Invisible Exhibition is the active exclusion of disabled people as participants. From our first meeting, Ágnes told me that disabled people were not allowed to visit the Invisible Exhibition or participate in the tours. It took several visits until I found the accessible entrance to the location, which involved entering through another building. It was a strange idea to me that disabled people could not share the same experience with non-disabled people, so I asked questions about this when interviewing guides, to see if they had ever met a disabled visitor, and what their experiences were like. Their responses ranged from neutral to explicitly negative, and it was clear that while blind people are the exception to the “no disabled people allowed” rule, blind outsiders were still unwelcome. I have mentioned the official reasons given by the Invisible Exhibition and Ágnes, but it is also worth mentioning the reaction I got from the guides. The most neutral on the subject, Teodor described only the confusion about how to interact with blind visitors, summarizing the awkwardness as, “it’s an interesting question what to tell them.” The authority of being the only blind person is lost, and occasionally blind visitors disagree with the Invisible Exhibition’s methods. One blind visitor filled out his guest survey with suggestions on how to improve the sound system and others identified further issues with the tour. Some guides

were more explicit in their distancing from other blind people; one guide mentioned that he does not have blind friends or family members and prefers to live and work in integrated environments, another stated that she “[doesn’t] like to guide other blind” because they are “harder to control... they are always arguing.” Although many of the guides participate in blind-centric sports, for example, and there is a good relationship between a Hungarian blind organization and the Invisible Exhibition, there is a clear separation between the guides and the larger blind community, both in Budapest and internationally.

In addition, the exclusion of otherwise disabled visitors suggests a lack of intersectional awareness or visibility. Presumably a blind visitor who uses a wheelchair or is developmental disabled would not be permitted to participate, although it is common for disabled people to have more than one disability. This raises further questions about who can perform disability, or blindness in particular. In the literature on disability simulations, whether from scholars or activists, the exclusion of disabled people from the planning process is frequently highlighted, but I have not read anything that addressed the exclusive nature of most disability simulations: that they are not accessible to people with disabilities other than vision impairments. Although disabled people are regularly expected to perform their own disability in particular ways (for two examples: wheelchair users are questioned if they do not constantly use their wheelchair, and those with invisible disabilities are regularly told that they do not “seem” or “look” disabled), Siebers acknowledges that this focus on bodies privileges “performativity over corporeality” (2008, 57). Siebers compares able-bodied individuals “playing” disabled (whether they are Hollywood actors or simulation participants) as a form of drag that allows exaggeration and open consideration of stigma (Ibid., 115). The sole example of a disabled person pretending to be disabled in a secondary way (that I know of) is Titchkosky’s experiment where she acted in a way that caused others to perceive her as blind: using a guide dog and wearing sunglasses. For Titchkosky, this

experiment allowed her to “disrupt conventional notions of disability and theorize the tie between oppressive cultural assumptions and the meaning of embodiment” (2005, 219). When disabled people are expected to constantly perform their own disability, but able-bodied individuals are the only ones who may mimic disabilities that are not their own, the potential for this disruption of boundaries is lost and only nondisabled people who can experience the life-altering changed promoted by the Invisible Exhibition.

Performing Ability: The Emotional Labor of the Researcher

When I began writing my thesis, I became more aware that I could not discuss the emotional labor enacted by the guides without discussing my own emotional labor. While the guides were expected to perform their disabilities and open themselves up to questions and connections with several dozen people each day, I was trying to perform ability against my own identity. Given that the majority of people managing, working at, and visiting the Invisible Exhibition had limited to no experience with disabled non-blind people, and the anxiety exhibited by Ágnes when I expressed interest in studying the tour, I was under pressure to build these relationships by positioning myself as an outsider and non-disabled researcher. This was at the risk of being unable to develop better relationships with the guides or mention my own experiences in the disabled community in interviews, but it was absolutely necessary to pass and normalize myself in order to foster trust and respect from the organization itself.

As stated by Ágnes and the guides, disabled people (except for the occasional blind visitor) were unwelcome at the Invisible Exhibition in any capacity, and I was under constant self-surveillance to make sure that I was not outed as a disabled person. I prepared for interviews by practicing how I could respond to comments about disabled people. A significant part of this was the ban on non-blind disabled visitors, which came up in my

interviews with Ágnes. In my first interview with her, it was a surprise to me that I tried to manage as best as possible, and then bring up in subsequent interviews:

I asked again about why they don't allow disabled visitors, and got the same answer about safety, except when pushed a little more, she made a comment about how the guides already have to deal with one disability and they shouldn't be given more than that to handle. She also said it's not just people in wheelchairs who aren't allowed but anyone with a mental disability. I always feel so uncomfortable when this comes up, like I would never be able to disclose in this environment as a researcher or a visitor, since I'm being explicitly excluded from the experience. I have obviously been clear about my role as a researcher but I wonder how often this comes up for researchers who are members of similarly marginalized groups, especially when researching their own community.

This question continued to make me deeply uncomfortable, to the point I was regularly asking guides about their experience with disabled guests to try and understand why this experience was limited to people with a particular bodily experience. As mentioned, I had to prepare myself to inevitably be told on a daily basis that disabled people were dangerous burdens and not permitted to visit the Invisible Exhibition.

As quoted from my field journal above, this anxiety over performing ability extended to my comportment and I lived in heightened paranoia that I would become too tired or stressed to control my body and my performance would lapse. I wrote regular reflections throughout the research process, in part because it took place over 4 months and I was worried about forgetting details, but also because it helped me track my response to fieldwork. These themes of fear and anxiety were frequent in my field journal, where I could tell that pretending I was not disabled was taking a toll:

[I was so] uncomfortable and I felt like I was having a hard time with self-presentation and trying to seem like a normal and authoritative person (or, it was harder than normal). I kept playing with my hair and trying really hard to keep my stims limited but the more anxious I got, the harder it was. I can't tell how anyone there sees me, but that might just be paranoia and stress.

This fear was based in prior experiences where (typically after a long day of work or school and in a setting of heightened emotion or pressure) I would be unable to perform ability and

someone would begin asking questions. By the end of the research process, I was taking several days off in between a day of interviews and observations, simply because I was unable to perform ability for several hours a day throughout the week.

A key part of the emotional labor performed by guides is the expectation that they would represent the blind and disabled communities, serving as the entry point for visitors with no prior experience. They are also asked invasive and rude questions by guests who believed, as supported by the official narrative of the Invisible Exhibition. One of the most common threads, behind how sick I felt after each tour, was that I was finding it increasingly difficult to perform ableness or “pass” in the field. In my second tour, I tried to ask the guide questions about the importance of community and finding people with the same identity versus the strong narrative of inclusion that the Invisible Exhibition pushes. In preparing questions and responses, I sought to avoid any hint that I had prior experience with disability. It was difficult, however, to try and avoid the sense of community that most disabled people feel with each other, and I was not able to build the connections with the guides that I normally would whenever meeting a fellow disabled person (particularly with the guides who were also students). I tried to find examples unrelated to my own life and could only find one, nor could I explain why I felt so strongly about the issue. I was aware of trying to perform both the role of an anthropologist (while also fighting the stereotypes associated with being a young, female student) and able person. Because of this, and in part because of the intense emotional labor performed by the guides, they treated me like any other ignorant visitor or even a journalist. This is a different type of emotional labor: management in order to maintain the relationship between myself and the Invisible Exhibition, and to control self-presentation and pass to minimize others’ anxieties about disability.

My performance cracked occasionally, however, particularly in the second tour when I was tired of the assumption that I had never met a disabled person before and had no idea

how they functioned in society. In response to obvious questions about how blind people use computers, or what sports disabled people play, or the different ways a blind person could cross the street, I let loose with lengthy answers about text-to-speech programs and Braille, the array of adaptive sports and disabled athletes I was familiar with, and how to use several senses and the assistance of a friend to avoid an accident. When I listen to the recordings, it becomes clear that the guide had no idea how to respond to this and settled for the assumption that I had dated someone blind or otherwise disabled, which could explain why I knew so much. He became increasingly flirtatious and mentioned that, like many of his peers in the blind community in Budapest, he too dated sighted girls. He was not the first guide to flirt with me, as did many of the visitors and other people I met during research, since no one thought that I was disabled or had any real knowledge coming into the tour. Because guides did not read me as disabled, any knowledge about disability was assumed to be something I had learned during my research: if I was able to respond correctly or with any sense that I knew what I was doing, the expectation was that I had heard this in a tour. Ágnes was shocked after an interview when I seemed more respectful and knowledgeable than typical visitors and pulled me aside to mention this:

...just one mark, it's really nice actually when someone is talking to a blind person and someone has to translate or with the doctor, usually it happens that the one [the doctor or other person speaking] doesn't talk to the blind but to the person next to him or her but you never did this! So it's good.

Even these small moments where it was more evident that I actually had some experience with disabled people, I was contrasted with other able researchers or visitors, rather than assumed that I had disabled friends or that I could be disabled myself. This emotional labor, of mediating how much I could show that I knew or what my own experiences were, and managing each interaction, was exhausting, but still necessary in order to try to understand how visitors experienced their tours.

The Emotional Labor of Guides

As stated, I conducted very few interviews with the guides, and those that I was able to speak with were distrustful and answered questions vaguely or simply. Reflecting on this process, I find it relevant here to discuss the concept of emotional labor, as I believe it provides some insight into my experience with the guides. Literature on emotional labor typically focuses on service industry workers, teachers, and other positions (most often held by women and other marginalized individuals), but in discussions of disability, the focus of emotional labor discourse tends to focus on caregivers, family members, or service-providers. Although managing all social interactions is a form of labor, the guides at the Invisible Exhibition are consistently asked to let people into their lives, to serve as educators and ambassadors for all blind people across the world, and to do so with warmth and joy, therefore performing emotional labor.

In my interview with Teodor, the stress of this work was most evident. He was clearly upset by the revolving door of visitors he was expected to make instant connections with, spend time with, and then say goodbye (sometimes after just an hour) to potentially dozens of people per day. When it came time to speak with me, whether our interview took place in the tour or not, the guides treated the interview as part of their job. While disabled people are often expected to perform their identity (or to pass), this is often weighted by significant risks: losing a job (as in the case of the Invisible Exhibition), losing relationships, losing respect, etc. Just as sighted visitors are expected to perform blindness in the simulation and learn from the experience, the blind guide are also asked to perform their own disability, for the benefit of others, and this was evident in interviews, observations, and tours. It is noteworthy here to reiterate that in the middle of giving a tour and fielding questions, a visitor asked Mária if she had a job – not recognizing the intense work that she does as a guide and the additional emotional labor.

A subject of particular importance for Teodor was his relationship with the visitors during the tour and after they left. He describes himself as extremely attached to the people he takes on tours and says that it is hard to let them go because “they’re still in my mind sometimes.” As he wrung his hands, he told me that by the end of the day he is completely exhausted from the social demands of forming bonds with so many people and then letting them leave. In our interview, he was highly critical of his abilities as a guide and said that he is constantly trying to improve, reading reviews online, and asking for feedback. He is aware of his difficulty maintaining boundaries and a distance between himself and the visitors. When he told me about two girls from New York who were so interesting that he wanted to be their friend, he recognized that this was not appropriate and chose not to ask for their contact information. Instead, he has a song on his iTunes about girls from New York City that he likes to play. When asked more about how it is difficult to let people exit the Invisible Exhibition and never see them again, Teodor said that it could be hard for him, he’s too “naughty” and cares too much. He acknowledged “Sometimes I get so close to people... but I know I should let them go because others are coming. It’s important to learn in life that you let them go, things and people, to make space for the new ones, that’s what I’m learning here.”

It is also challenging to him to not know what impact he has had on people, he mentioned that he wants people to learn things and experience something but he does not know what people “bring home” with them, so he tries to offer a time to ask questions and decompress from the tour. From our conversation, and by watching him regularly interact with visitors, it is clear that he is highly invested in meeting people and introducing them to being blind, even as difficult as this can be. Ágnes mentioned similar themes in my interviews with her, largely that there is a significant impact on the guides from working at the Invisible Exhibition. She regularly mentioned the impact of the tour on the guides, that

they were interacting more with sighted people than they would in everyday life and getting to form these connections, as well as providing them with a good job and a sense of importance. In an email to me, she restated the tour's commitment to integration and encouraging blind and sighted people to interact, telling me, "it [is] important to live and 'breathe' together with sighted people – this is the way how we can make it natural." Teodor reflected these ideas, although not by other guides, but he clearly believes that the experience of visitors in the tour is equally an experience for him, despite the emotional labor involved.

Guides therefore perform intense and difficult emotional labor when asked to perform their disability in order to support the goals of the Invisible Exhibition: education and social integration. Their job requires this labor, and their ability to let people in and answer questions honestly and openly determines whether they are "good" at being a guide. As stated by Teodor, interacting with dozens of individuals in a day, and being expected to form a lasting and impressive bond with each visitor (so that they may leave the exhibition and produce social change) is challenging and often unrewarding when their departure cuts the relationship. In addition, the guides' formal work as a guide is often not recognized as such, which leaves their emotional labor burden invisible. This demand that the guides "manage or manipulate the presentation of their impairment to others, and their own and others' emotional responses" has also been addressed by Jackie Leach Scully, who identified a category of interaction management as such: "some disabled people feel a responsibility to inform others about the nature of their impairment, what it entails, and what sorts of accommodations are needed, so that future others will benefit from a more informed nondisabled population" (2010, 25 & 30-31).

Phenomenology, Performativity, and the Invisible Exhibition

One of my primary theoretical frameworks for my research is the field of phenomenology, which suggests that perception is how humans understand the world around them. This often occurs in highly individualized ways, and Merleau-Ponty includes a brief discussion of how blind people engage with the world. He references the importance of touch, whether with hands or the use of a tool (such as a cane) that can act as a “parallel to sight” (2012, 144). Another prominent phenomenologist, Schutz, discusses how differences in individual experiences provide people with their own particular way of living. It is understood, therefore, that people with sensory differences or disabilities experience the world in completely different ways than their non-disabled counterparts (1967). This is essentially the foundation and reasoning behind the Invisible Exhibition: people live in different worlds and it is important to try and understand each other’s perspective. Given phenomenology’s emphasis on embodiment and the role of the senses, it is understandable why a simulation that prevents people from using their vision would be understood as comparable to being blind.

Understandings of performing identities and phenomenological empathy are frequently found in literature discussing simulations. Non-disability simulations are common across the world, designed to help participants understand other types of oppression or marginalization (such as issues around race and class) and to build empathy.

Phenomenologists have frequently discussed performances, such as simulations, as a site of identity construction. From my interviews at the Invisible Exhibition, the idea of understanding disability through phenomenology was suggested both explicitly (by the site manager and guides) and implicitly (by many visitors). When speaking with Ágnes, often in the context of the design and purpose of the Invisible Exhibition, phrases like “step into other’s shoes” were often used to describe how people “tried” disability. The importance of a

first-hand experience was mentioned, Ágnes referred to the “100% experience” or “see things from the other side,” and argued that body-centric learning has a deeper impact. The descriptions from the guides changed based on the individual: most used similar language to describe how visitors were experiencing disability first-hand, “showing [them] a part of our life,” and the importance of this individual experience. The exception to this narrative came from Teodor, who said that while guests are “wondering how to be blind,” he believes it impossible for them to entirely understand what it means to be blind, and that even one blind guide cannot entirely represent that world.

However, nearly everyone explicitly stated that they understood what it is like to be blind after going through the tour, and other visitors were able to extrapolate how blind people must feel in different situations based on how they felt: generally these involved feeling isolated or uncomfortable or worried, particularly when encountering a new environment. Most visitors admitted that they were scared when entering the tour, but did not connect any sense of fear to being blind. Rather, they focused on the separation between their own experience and that of the guide, whose ability to move confidently through spaces and identify anything was something described with either confusion or jealousy. A few visitors were able to connect their feelings of being lost or adrift with how they presumed blind people felt out “in the real world,” and thought therefore that they understood “the blind experience” as such.

Just as guests believed they understood what it meant to be blind, centered largely on how it must “feel,” they were also convinced that they had used their bodies in the same way as someone blind. In interviews and when I observed groups leaving the tour, visitors demonstrated how they had pretended to be blind – often using their bodies and facial expressions to act out how they had “been” blind. One visitor went as far as to approach me as he was leaving, just to show me how he had been holding his hands in front of him and the

way he walked. This expectation of body language, although not ever acted or mimicking the way the guides used their bodies, was seen as an important aspect of the tour experience.

Visitors were convinced that their senses, beyond impaired vision, had functioned differently in the tour and that this must be like what blind people experience on a daily basis.

Phenomenology and performativity have rarely directly touched upon disability as an embodied knowledge or identity, but disability theorists have made these connections within their own field, as previously described in my theoretical discussion. Siebers, among others, has written that “situated knowledge does not rely only on changing perspectives.” While phenomenology and performativity have suggested that “trying on” different identities can convey their particular knowledge, disability theorists find fault with this argument. Siebers continues with this argument, stating, “the disposition of the body determines perspectives, but it also spices these perspectives with phenomenological knowledge that affects the interpretation of perspective.” There are particular representations of disability in society, and theoretically non-disabled people could come to understand these representations (and even gain perceptive ability through changed perspective) but this ultimately focuses on “the phenomenology of the individual body,” as Siebers puts it. He finds fault with disability simulations on multiple levels, which I will address later, but he ultimately disagrees that phenomenology or performativity can be life-altering experiences when it comes to disability.

For disability simulations, however, what these fields can do is explain their creation and lasting popularity. People do legitimately believe that they will understand disability, and its connected identity and knowledge, by “trying on” or performing disability. Butler is one of the sole theorists to acknowledge the difference between performing a marginalized identity in the context of theatre, for example, and how people react to someone with that

identity in everyday settings. There is a clear disjuncture between what theorists believe is possible in embodiment and what disabled people understand.

Conclusion

It is clear that visitors believe performing blindness in the context of the Invisible Exhibition as exactly the same as being blind. They do, however, perceive their own role outside of the tour differently, and will often rely on the distinction between recognizing that a simulation is an act and that on the street, these acts are no longer clearly demarcated. While fields like phenomenology argue that individual experiences shape knowledge and worldview, this is a simplistic and idealistic understanding of perception. This rationalizes the approach of simulations: providing a temporary change in perception allows the participant to gain the associated knowledge and embodied identity. However, while theorists and the Invisible Exhibition argue for an experience-based change, disabled scholars and activists actively disagree with this narrative. I identify with the community of disabled scholars and activists, and do not believe that simulations can be improved enough to increase the visibility of and support for disabled people in a respectful and inclusive way.

I drew phenomenology, performativity, and ethnomethodology together with disability studies because they contradict each other and similarly conflicting ideas are also present at the Invisible Exhibition. There are competing narratives, much as the medical and social models of disability are debated in disability studies; each takes a different stance on the prioritization of individual and society. This is why I use these theories in conversation, it is important to understand their debates and tensions in a case where conflicting perspectives and understandings of disabled embodiment are key. I agree with disability theorists, however, that it can be difficult to draw from other disciplines who never address disability outright, and therefore their theories do not leave room for non-normative bodies, minds identities, knowledges, or experiences. Theories like phenomenology and performativity

were not designed to discuss how disabled people perceive the world or perform their identities, and emotional labor and autoethnography were similarly not developed with an awareness that they were essential concepts for describing the disabled experience. There is extremely limited research on sensory ethnography and ethnomethodology conducted by disabled researchers, despite the frequency that disabled scholars refer to their own experience and its influence on their research process. Because these theories were not created by or for disabled individuals and their lives, it is important to adapt each and put them in dialogue with each other and disability studies. This will provide a more expansive and inclusive approach to research, and improve the potential for self-representation in academia. I believe that my research contributes to each of these fields individually as well as collectively, and that there is great potential for further cross-discipline research. My research, using the Invisible Exhibition as an example, substantiates the need for further cross-discipline research.

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