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Facades of Ingress

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FACADES OF INGRESS

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by

Kristopher Funk Berardi

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TABLE OF CONTENTS

LIST OF FIGURES

LIST OF APPENDICES

ABSTRACT
FACADES OF INGRESS
KRISTOPHER FUNK BERARDI

Facades of Ingress is an interactive puzzle-based experience revealing the monster that lies at the center of the institution. It holds the power to grant accommodations that make crip lives easier inside institutions. Instead, it is greedy. It creates complex systems of paperwork, deeply intrusive medical exams, and copious layers of bureaucracy to hold hostage the resources it hoards.

This paper looks at the theoretical concepts that helped shape *Facades of Ingress*. Using disability and monster theory, it examines the societal structures and systems that have failed crips, preventing them from gaining accommodations inside institutions. It looks at work by disability scholars and artists, such as Mimi Khúc's *Open in Emergency* and Johanna Hedva's "Sick Woman Theory." It also examines how disability is seen as monstrosity through an analysis of Matt Fraser's *Born Freak* and uses the social model of disability studies to prove that the real monster is the societal systems that affect disabled bodyminds' abilities to exist.

DEDICATION

To all bodyminds still waiting for their access needs to be met.
To my past self, who did not know I could survive.

ACKNOWLEDGEMENT

Thank you so much to my wonderful committee, whose support was invaluable. Thank you, Elizabeth Swensen, for listening to my crazy ideas and critiquing my games. Thank you, Michael Chemers, for introducing me to the world of Freaks and letting me borrow all of your books. Thank you, Cynthia Ling Lee, for your calming encouragement and for laughing at the absurdity of the world with me.

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WHY I AM TOO SICK TO BE IN GRADUATE SCHOOL

In early 2023, during my first year of graduate school, a professor told me that I didn't belong in the program. This was after I asked for a content warning before certain types of videos were played in class. You see, I am disabled. I am chronically ill. I have survived trauma and did not come out the other side whole. This means, among other things, that I get vertigo and motion sickness very easily. It is difficult for me to watch videos with constant motion and impossible for me to play 3D video games or experience anything in virtual reality. This professor could not comprehend how I was in a Digital Art and New Media program making games when I couldn't engage with some media. This led to months of intrusive emails about my health, harassment from other students, and ultimately, a meeting where, in front of the head of my department, I had to explain for the millionth time how I was sick and why I needed accommodations.

For months, I had to deal with the backlash of asking for a simple content warning that would have allowed me to go to class. All while I attended the class with the offending professor (who refused my request) and the student harassing me. And attended all my other classes. And worked as a teaching assistant. And attended doctor's appointments. It was a lot, and I almost didn't survive it. Then, over the summer, while I was preparing to start my second year, I suddenly lost access to one of the medications that allows me to function in the world. It was a month-long battle of calling doctors' offices, scheduling appointments, arguing with pharmacists, and praying I could get my medication before the new school year.

During this time, a monster started forming in my head. A giant gargoyle-esque beast that greedily hoarded the things that gave me access to the world. It would snarl and laugh as I cried on the phone to the doctor or begged the pharmacist. It smirked with every new harassing email. It snapped its jaws when I reached out for help from a system that was never designed to help me.

This monster does not only exist in my head. It is real, and many disabled bodyminds beg and plead to it every day for help. I needed to get this monster out into the real world because it was eating me alive. The journey to gaining accommodations is a lonely, never-ending road. I was so full of anger, frustration, and guilt. Thus, I created *Facades of Ingress,* a physical manifestation of the monster that lurks in every institution. I filled it with puzzles because puzzles are what I know best. After all, I have been pondering the unsolvable puzzles of my health for a long time. These puzzles are designed to be purposely obtuse and difficult, just like the bullshit bureaucratic hoops one must go through in order to gain accommodations.

Throughout this paper, you will see the use of the word “crip”. I use this word not as a derogatory slur, but as a phrase of power. Eli Clare discusses the power of words in his book *Exile and Pride*, “to stare down the bully calling *cripple*, the basher swinging the word *queer* like a baseball bat, to say ‘Yeah, you’re right. I’m queer, I’m crip. So what?’ undercuts the power of those who want us dead” (Clare 93). Queer is a word I have identified with for many years. It is pride, it is power, it is an embodiment of my identity. Crip, however, is somewhat new to me. Discovering it as a source of pride instead of a potential negative form of being was incredibly liberating on my disability journey. It also gives me a deeper sense of belonging than the word disabled can. Similar to how queer feels like a deeper embodiment of my sexuality than gay ever could. Crip goes beyond standard understanding of disability. As Margret Price puts it in her book *Crip Spacetime*:

> "[Crip] doesn't invoke individual bodyminds as insistently as *disability*; nor is it as abstract as *health*. It is itself a material-discursive concept, constantly in motion among language, flesh, environment, and object" (Price 12).

In this way, crip becomes a deeper embodiment of community and identity that connects more than individual concepts of health and disability. That is why when I speak of myself and of my disabled community, I use the word crip as a statement, not of hardship and lack of ability, but one full of potential and power.

This paper will explore the creation of *Facades of Ingress*. It takes a hard look at how society and the systems it has created have failed crips by using frameworks laid out by disability scholars such as Mimi Khúc's *Open in Emergency* and Johanna Hedva's "Sick Woman Theory." It examines theories of disability as monstrosity and uses the social model of disability to show that the true monster is the systems that prevent crips from gaining accommodations inside institutions.

IN MEMORY OF ALL MY SPOONS

Unlike most “healthy” people, I live my life by spoons. To those not in the know, it may sound like I am a big cereal or soup fan, but to those who understand, to the community of disabled bodyminds who must plan their every action like chess, it is a way of life. Writer Christine Miserandino developed spoon theory in a 2003 blog post on her website, *But You Don’t Look Sick?* The goal was to explain to her best friend what it feels like to be sick. Miserandino gave her friend a “bouquet of spoons” and told her each activity would cost one (Miseradino). They then played a game where her friend tried to explain an average day in her life while Miserandino took spoons from her hand for each task she completed. Her friend was shocked by how what she perceived as a simple task—getting up in the morning— was actually a long process for Miserandino. She broke it down for her friend,

> You don’t just get up. You have to crack open your eyes, and then realize you are late. You didn’t sleep well the night before. You have to crawl out of bed, and then you have to make yourself something to eat before you can do anything else, because if you don’t, you can’t take your medicine, and if you don’t take your medicine you might as well give up all your spoons for today and tomorrow too (Miserandino).

She emphasized each small task that encompasses the marathon of waking up. Her friend was horrified to discover that after "getting up," she was only left with six out of the twelve spoons originally in her hands.

Spoon theory plays a significant role in *Facades of Ingress,* as the piece doesn’t just explore the difficulties of gaining accommodations, but also the effort it takes to get and hold on to them. I wanted people to understand the bargaining and war strategizing that comes from planning your day around spoons. The unparalleled level of flexibility and compromise that most people won't understand. I need to go to this doctor's appointment this morning, which means I will not have the energy to attend the meeting this afternoon. I could go. I could grin through the aching pain so I don't miss another important meeting, but that means I'll have to borrow spoons from tomorrow, so I will most likely have to miss a different meeting. And which one is more important to attend? And am I using too many spoons stressing over missing one meeting that I won't be able to attend either? Miserandino explains that "the difference in being sick and being healthy is having to make choices or to consciously think about things when the rest of the world doesn’t have to" (Miserandino). Being a crip means calculating how each choice we make will affect us and how we choose to spend our finite amount of energy. And often, we do not have a choice on how to use those spoons.

Korean American writer and artist Johanna Hedva’s essay “Sick Woman Theory” looks at how capitalism decides who is allowed to live and die. It holds us in its grasp and ensures that "the Sick Woman is who capitalism needs to perpetuate itself. Why? Because to stay alive, capitalism cannot be responsible for our care -- its logic of exploitation requires that some of us die" (Hedva 14). Society is making us sick. It holds us inside its systems so it can use our spoons, our labor, our bodies, then discard them after it has taken all it can.

Johanna Hedva's *Sick Witch* "is the performative id—the stand-up comedy routine—of ‘Sick Woman Theory.’ She retches, screams, needs to sit down, wobbles, regurgitates bullshit people have told her to do, takes off many wigs, and is wracked by ghosts" (Hedva). It is a horrifically accurate embodiment of how life feels when all of our spoons are being used inside systems that run on our unwellness.

Sporting a long black wig covering their face, a la the girl from *The Ring*, Hedva contorts their body. From their mouth comes deep, guttural moans of pain as they squat on the ground. They twist shaking arms behind them and grab their thighs for support. During their movement, Hedva speaks in a mocking voice, “If you reduce your stress, it would help a lot” (Hedva 1:38-1:44). They bend over, black hair completely covering their face, and retch towards the ground, “Aren’t you afraid the complaining will make you seem weak?” (2:04-2:12). They kneel on the ground, one arm in the air with a limp wrist as the rest of them bends over in pain. They spout nonsense, stilted as if each word is cutting their mouth, “But you’re too young… to be sick” (2:56-3:01). They grab the back of their neck, hugging their chest, head towards the ground as they sway back and forth. They stand up straight, clutching their dress in a fist so it cinches their waist and holding their hair in front of their face with the other hand, “ Side effects may include..." (4:29-4:32). They bend at the waist, as if they were using a cane, one arm a 90-degree angle behind them, the other hovering over their stomach, “CONFUSSSSIIIOOOOOONNNNNN, difficulty concentrating, short term memory loss, DRRRYYYYYYYY MMMMOOOUUUUTTTTTHHHH, constipation, diarrhea, NAUSEEEEEEAAAAA, INSOOOOMNIAAAA” (4:47- 5:24). They bend their knees outward, hair cascading towards the ground and hands on hips, “You MUST remember your doctor has chosen to PRESCRIBE you this medication because its benefits outweigh its SIDE EFFECTS!” (5:36-6:06)

Five years after releasing “Sick Woman Theory,” which became a staple of feminist and disability studies classrooms, Hedva reflected on how its success threw them further into the shackles of capitalism instead of pulling them out of it. Their inbox filled with requests about conferences, speaking engagements, and book deals that ignored their entire catalog of creative and scholarly work in favor of wanting Hedva to speak about “Sick Woman Theory” and become a spokesperson for the chronically ill. In their essay, “Why it's taking so long,” Hedva writes of how their identity was stripped down by society until only the Sick Woman remained,

> I knew that this was how ideologies of oppression work: they seep into you, get into your cells, hunker down and dig in and make a home out of you. I also knew that, no matter where it came from, the hurt was real, it sounded like my own voice, it lived in me now. But it was pain that had very little to do with my actual illness, and what fucked with my head the most was realizing that the internal condition of my illness—which felt vastly multiplicitous in

> what it made within me, all the worlds of experience it took me to—had been erased in favor of the external value placed upon it, which was carcerally narrow and confined to mean a set of things that I did not particularly agree with, nor consent to being (Hedva 2).

Societal ideologies took away Hedva’s experiences as a crip. All of the community, all of the learning and growing, everything that they were because of their experience with chronic illness was removed. In its place, was sickness. A disabled person fighting adversity. A token to parade as proof of allyship, but when push came to shove, the places that wanted Hedva to be a spokesperson for illness never wanted to do the work to make their spaces accessible.

Hedva's influx of potential engagements led to the creation of their "Disability Access Rider," a list of required accommodations they would need in order to work with institutions and make the events as accessible as possible for the audience (Hedva 7). This document, full of necessary accommodations – buildings must have elevators and ramps or live captioning for speaking engagements – was met with so much pushback that Hedva had to "grade on improvement" (Hedva 7). They would ask institutions to engage in conversation with Hedva about how they could work to make their spaces more accessible, but this led to Hedva spending more time in "email fights" than working on their actual work. Sound familiar? Trying to achieve accommodations in capitalist environments often puts more stress on the few overworked and underpaid individuals who care. Hedva points out that "most fucked-up conditions of capitalism exist because of ableism— because ableism demands that the staff work for ableism only, making the possibility of wear, depletion, fatigue, and illness, chronic or not, impossible under the relentless conditions of capitalism" (Hedva 10). It takes a community to dedicate themselves to the dismantling of capitalist structures that demand our bodyminds work past their limits. Alone, we are just a Sick Woman on our last spoon being looked upon by society as a fractured fragment of what it thinks we should be.

CRIP TIME IN COLLEGE

Being disabled means that I no longer live in the same time as most of my peers. Hours and minutes work differently for me. I do not live life in a linear fashion; instead, I tend to time travel. It is not as fun as they lead you to believe in the movies, for time still ticks at the same pace even as I skip through it. Part of being a crip means that sometimes I am stuck in bed for hours, days, or weeks, frozen in moments of pain, rest, and loneliness. During these bedridden days, I feel as though I exist in another dimension, one made up of pillows and blankets, fear and pain. The stuffing in my pillows is the only other voice I hear. For me, time has stopped because my world and my life have. I cannot go to work or hang out with friends. I cannot focus enough to read a book. The brain fog stealing memories of the last three hours as my pillow holds my tears and whatever video is playing on my laptop keeps me company. Once I finally make it back to the world, I often feel lost. The days in bed have left me out of the loop. I have time-traveled to next month. I missed a friend's birthday. I missed a deadline. I missed a major world event. I missed inside jokes and bonding with my cohort. Because for them, the world did not stop. It kept moving. They kept living their lives.

This is an example of crip time. As disability scholar Ellen Samuels explains, "Disability and illness have the power to extract us from linear, progressive time with its normative life stages and cast us into a wormhole of backward and forward acceleration, jerky stops and starts, tedious intervals and abrupt endings" (Samuels). Crip time is the way we move differently through the world. The way that I take the elevator while all my friends take the stairs. The way I have to leave study sessions early if I am able to attend at all. The way that our lives are not defined by society's schedules but by the shifting abilities of our bodyminds. It affects us all differently, but we all know the grief and anger that it can leave in its wake. Samuels describes crip time like being a vampire:

> It's the time of late nights and unconscious days, of life schedules lived out of sync with the waking, quotidian world. It means that sometimes the body confines us like a coffin, the boundary between life and death blurred with no end in sight. Like *Buffy*'s Angel and *True Blood*'s Bill, we live out of time, watching others' lives continue like clockwork while we lurk in the shadows. And like them, we can look deceptively, painfully young even while we age, weary to our bones (Samuels).

Two months before *Facades of Ingres*s was set to be exhibited, I had a bad flare-up. I was stuck in my bed, in the coffin of crip time, for a month. I wanted nothing more than to be in my studio working, but I could not. Instead, I laid against my pillows, laptop in my lap and sent emails of apology to professors for missing classes and cried over the loss of so much time. I wrote and rewrote my plans as I watched my timeline for *Facades of Ingress* drift further out of sync with the work I was able to complete. I removed features I really wanted to include, and I begged my body to let me start creating again. But crip time did not yield to my pleas.

The lack of crip time inside institutions can be detrimental to those within them. For instance, the lighting speed of academia weighs heavily on professors and students alike. *Open in Emergency* is Mimi Khúc's love letter to her community. It looks at and critiques ways in which the current mental health systems have failed the Asian American community through a box containing a series of items for intervention. In Khúc's own words, the box contains:

> … an editor's note from me in the form of a letter to my daughter; a hacked mock DSM: Asian American Edition exploring alternate modes of 'diagnosis'; an original deck of tarot cards, created from Asian American knowledge production to reveal the structural forces shaping our lives; handwritten daughter-to-mother letters tracing both intimacies and violences in our families; a redacted, re-written pamphlet on postpartum depression to intervene in medical knowledge dissemination; and a tapestry poster of

collective wounds gathered from across the Asian American community (Khúc 7).

Khúc and her collaborators wanted each piece inside the box to connect to different areas of mental health and use different forms to create diverse types of interventions. Each piece was chosen deliberately with care to address different issues and ways of thinking about Asian American mental health. At a glance, Tarot might seem like an interesting choice to include from an academic scholar such as Khúc, but she explains that Tarot is a "way of being vulnerable, making alternative sense of our lives, connecting to our colleagues beyond intellectual work and academic rank and professional development — to be more fully human" (Khúc 15). She also wanted to draw on Asian American practices of fortune-telling and divination as alternative practices of knowledge production. Khúc and her collaborators wanted to embrace the power of using a white-centric medieval deck of playing cards as a tool for Asian American divination. The 22 traditional major arcana were replaced with figures of Asian American life, written, drawn, and interpreted by Asian American scholars, artists, and writers (Khúc). Some of the new cards created by Khúc and her team include The Student, The Adoptee, The Crip, The Migrant, and The Model Minority.

Another important element Khúc wanted to include was essays, stories, and visual work, but they did not want it to be in a book or anthology because they felt that it "wouldn't do any theoretical or interventional work on the level of form" (Khúc 17). That is when they came up with the idea to create their own DSM. DSM stands for *Diagnostic and Statistical Manual of Mental Disorders*. It is supposed to include everything about mental illness, including all of the different types, how to evaluate and diagnose them, and how to treat them. However, the clinical and static nature of the DSM does not take into consideration all of the factors that can affect one's mental health, such as race, gender, sexuality, and disability. It does not acknowledge the nuances and cultures of these communities that lead to and affect their mental health. In Khúc's words, this is "not to say there aren't individual psychologists and psychiatrists and therapists who do the work of developing their individual practice in terms of understanding race — but as field and industry, psychology and psychiatry remain not only uninterested in but actually disdainful of the knowledge produced in the arts and humanities, which is where much of the most complex and important work on racialization happens" (Khúc 17). Creating a hacked version of the DSM created by Asian American scholars, writers, and artists allows them to disrupt the systems that ignore the complexity of mental illness in the Asian American community. In this way, their mock *DSM: Asian American edition* "takes back authority, places it in the hands of those not normally allowed to access it" (Khúc 17). This takes mental health out of the hands of gatekeeping professionals and allows the community to find new revolutionary ways of connecting to it.

Khúc's journey to creating *Open in Emergency* started in 2011. At a time when she "still believed in aspirational wellness, that we are supposed to strive toward something we're told is 'normal' and 'healthy,' and deviations from those are pathological, to be fixed" (Khúc 8). The birth of her daughter led to months of postpartum depression and feelings that her failure to correctly be a good mother mirrored that of her "daughterly failure" as a part of an Asian immigrant family (Khúc 9). She felt trapped in a cycle of endless failure with no way out, which made her realize "the game is rigged" (Khúc 9). Khúc then began examining the systems and structures that shaped well-being and the ways in which society told her how she needed to be.

I would like to note here that my experience as a white disabled transman is distinctly different from that of Asian American mental illness, but I feel certain connections in our experiences resonated with me. My journey to creating *Facades of Ingress* also began with questions about health and society. Not with questions about mental health (those would come much later), but with why it was so hard to exist in the "normal" world with my body. At 18, I left my parent's house and moved into a college dorm. Undergraduate was challenging for me; I did not understand why I was getting sick so often. I did not understand how my peers were going to classes and parties and jobs with ease while I had to lie on the ground in the middle of class just to make it through. I did not know that my pain was not ‘normal’. I started college, majoring in mechanical engineering, to follow in the footsteps of my father and grandfather. I quickly fell behind due to my lack of ability to attend classes regularly. When I reached out to my university's disability resource center, I was met with walls that I could not scale. They wanted doctors' notes and diagnoses, none of which I had, so they could not help me. In the end, my love of calculus could not save me from the brain fog and low attendance, so I was forced to switch majors.

As a professor of Asian American Studies, Khúc was faced with classrooms of Asian American students who faced the structural violence of "racialized and gendered conditions" inside institutions (Khúc 10). She saw the high suicide rates of Asian American college students in real-time. Khúc’s "idea for *Open in Emergency* was first conceived in [Khúc's] classrooms because [her] students were dying, and they needed us to see" (Khúc 11). Khúc, in collaboration with her community, began to dream and listen. They ask what they could do "to disrupt compulsory wellness — the need to pretend we are all okay and functioning and being productive — to stop being productive and to dwell in our unwellness. To take time to hurt" (Khúc 12).

As a teaching assistant in graduate school, I have noticed the violence of unwellness built into academic institutions. Not only have I felt it myself, but I see the dark circles under students' eyes, and the panic in their voices when they tell me they could not finish an assignment on time or attend class. And it hurts. I can trace the same circles on my skin and know the panic in their throats because I have been there. I do not know their exact struggles, but I recognize the ways in which the system is harming them. I see how academic institutions never gave them time to hurt and sit in their unwellness. Whether they are a crip like me or dealing with struggles I can never fully understand, such as those of Khúc, how we as a society treat unwellness is harming ourselves and the generations after us.

WHO’S THE REAL MONSTER?

Monsters are cultural bodies. They are created and popularized "as an embodiment of a certain cultural moment" to represent a society's "fear, desire, anxiety, and fantasy" (Cohen 38). Disability is a huge societal fear. It is inevitable! At some point in their lives, every single human will become disabled. Disability scholar Rosemary Garland Thomson explains that: "not only can anyone become disabled at any time, but the pain, bodily damage, or impairment sometimes associated with disability make it seem an uncontained threat to those who consider themselves normal" (Thomson 37). Whether from birth, aging, or unexpected trauma, health (and, by extension, normality) is temporary, and that can be a terrifying realization.

Monsters also exist outside of the ‘normal’ (cisgender, white, male, and able-bodied). They do not follow societal systems of classification, making them a danger to the "order" that these systems create. As monster scholar Jeffery Jerome Cohen puts it in his essay "Monster Culture (Seven Theses)," "[monsters] are disturbing hybrids whose externally incoherent bodies resist attempts to include them in any systematic structuration" (Cohen 40). The disabled bodymind is not a “normal” bodymind. It can not do things the same way that a nondisabled person could. While a nondisabled individual can simply take the stairs, many disabled bodies cannot. Some nondisabled folks can watch a movie or attend a speech, while a disabled bodymind might need an interpreter or ear protection. A nondisabled individual can work in ways that contribute to capitalist society, whereas a disabled bodymind works at a different pace, or not at all. This makes them a threat to the order that society provides.

The fear and anxiety of losing one's health combined with it pushing them outside of what society deems as normal twists the disabled from a metaphorical monster to a physical one. You are disabled; therefore, you have become what I fear and must be a monster. Yet, this great fear is also fascinating to a nondisabled audience. To have the power to look at what you fear from a safe distance and reassure yourself that you are not like that does wonders for soothing normality's anxieties. Thus, the freak show was born, a place where ‘normal’ nondisabled individuals can openly gawk at the abnormality of disability.

Mat Fraser’s *Born Freak* begins with a question, “As a disabled actor, will I ever be seen as just an actor? Or will I only ever be seen as a freak who acts?”(Fraser, 00:11-00:47) Fraser is a drummer, actor, writer, and performance artist. This question is followed by a scene in which Fraser plays a secret agent saving a damsel in distress from two goons. A conventionally beautiful woman sits in a chair with her arms tied behind her back. She cries out in fear, asking for help as two bulky men loom over her. Suddenly, Fraser kicks in the door, striding in with all of the confidence of *James Bond*. There is a tense moment as the goons turn toward him, fists raised in preparation for a fight. Fraser stands ready for an attack, but instead of coming at him, the goons burst out laughing. All the fear leaves the woman's face as she, too, begins to laugh at her rescuer. This scene and the rest of *Born Freak*, examines the ways in which the disabled actor is treated as human and freak. Fraser struggles with the complexities of his disabled identity and his desire to be taken seriously as an actor, fearing that his disability will stop him from being anything more than a freak onstage. Thus, he begins his exploration into the world of Freakshows.

Fraser dives into the world of freaks by going to *Coney Island USA Sideshows by the Seashore* to reprive the role of Sealo the Seal Boy previously held by Stanley Bernet. Fraser felt a kinship to Bernet due to sharing the same condition, phocomelia, causing them to have stunted arms. Bernet's career as Sealo spanned 60 years, during which he performed all over the country in his act of shaving his face and exhibiting other everyday tasks. Fraser's performance as Sealo the Seal Boy furthers his curiosity. He does a similar act to the original Sealo involving shaving his face and cutting a piece of wood with a saw. Fraser loved his time at *Coney Island USA Sideshows by the Seashore.* He found power in using his role as freak to subvert the meaning of the word and be seen as a performer rather than a spectacle.

His enjoyment of acting as Sealo is dulled, however, by how much he hates the bally platform, where performers stand to be gawked at in order to drive audiences inside for the actual show. There is a stark power dynamic as beachgoers on the boardwalk openly stare at Fraser. In his book *Exile and Pride*, Eli Clare argues that "the Freakshow… carefully [constructed] an exaggerated divide between 'normal' and Other, sustained in turn by [audiences] willing to pay good money to stare" (Clare 87). The entire point of the bally platform is the staring. It accentuates the differences between the spectator and the performer. The social stigmas that surround disability force Fraser to be on display only seen for his 'deformity' in order to pique public interest in seeing the show. They get to gawk openly at Fraser, easing their anxieties that they are not like him. The power held by the audience outside of the Freakshow completely shifts once it is moved to the stage. It draws in a crowd based on their voyeuristic desires, causing them to drop their guard. Then, once inside, the show can challenge their views through performance.

Fraser's *Born Freak* inspired me to explore my own disability through the Freakshow. While my chronic illnesses are invisible, offering no outward signaling of my disability, I use a cane as a mobility aid. Using my cane in public means that I often become the spectacle of stares. In the spring of 2023, I workshopped an interactive performance piece that explored myself as a freak. I used radio transmitters and a dial radio to let the audience change the performance based on what station/sound was playing. I switched between performing with a pair of Luna Stix and dancing with my cane. The Luna Stix showed a conventional circus type of performance that gave no reference to my hidden disabilities. When dancing with my cane, focused on my use of it for balance during bouts of vertigo, I would sway back and forth, falling in all directions, catching myself at the last minute with my cane. I would spin in circles using my cane as a center point to turn around and stumble across the stage. I did not end up pursuing the performance beyond the workshop, but it was my first dip into the world of freaks that led me down the road to creating *Facades of Ingress*.

Unfortunately, unlike myself and Fraser, there were many performers who did not have control or power while on the stage. There is a long history of enslavement and exploitation that helped create the Freakshow's legacy. Many Black people and other people of color who were sold into slavery ended up in the freak business. This was the case of Saartjie Baartman, who was displayed for European audiences from 1810-1815 as the Hottentot Venus due to having a large buttock. She was enslaved and exploited, forced to show her body to the public and various members of the medical community to study her "excessive sexuality" (Fusco, 146-152). Her genitals were dissected and preserved on display at the Museum of Man in Paris until 1974. It was not until 2002 that her remains were repatriated and buried (Parkinson). Baartman was exploited against her will for her whole life, not gaining her freedom even after death. She is just one example of the racist atrocities connected to the abuse of power hidden in the Freakshow lineage.

Literary and social critic Leslie Fielder argues that society's fascination with the disabled over time turned from fear into pity (Fielder 40-43). The time spent gawking and thanking the gods that they are able-bodied makes way for feelings of guilt as they look upon what they perceive as tragedy. How could society let these poor souls suffer on the outside for so long? The freak shows were abandoned as heartfelt hospitals and doctors pledged to fix them. Stages and audiences were replaced with blue curtains and nurses. This, unfortunately, did not end the monsterization of the disabled, but merely moved it to what was deemed a more appropriate place: one that moves disability out of the public eye so the deviance can not spread through society. As Fielder points out, this is a place where “doctors (still predominantly White and male) continue to be regarded as defenders of a dying status quo: racist and sexist almost by definition” (Fiedler 115). Anyone who lived outside of the ‘normal’ was contained in the shadows of medical institutions. This was known as the medical model of disability. As Thomson put it, this model pathologized disability, rescuing it from its perceived evil, only for it to be assumed as something that needed to be cured (Thomson 37). Disability was seen not as folks with different ability levels, but instead as something that must be fixed and made to match the ‘normal’.

Hospitals, while for the ‘normal’ are considered a place of healing, are often the sites of trauma and harm for disabled bodyminds. Doctors make a living off of maintaining that disability is monstrosity. Disabled bodyminds, or as Thomson refers to them in her book, "Extraordinary bodies are seen as deviations to be standardized, rather than as unique, even enriching aspects of individuals that might be accepted" (Thomson 79). Their goal is not to improve our quality of life but to instead make us appear ‘normal’. Fielder reflects on this saying, “the humor is compounded by our realization that finally the joke is on us, the patients; since in our time – as always– physicians and surgeons make a good living by failing to heal us” (Fiedler 110). Thus the real monster reveals itself: not the crip trapped inside a system created to hide and hinder them, but the system itself, which focuses not on the actual needs of their patients but on getting the patient to a perceived level of ‘normal’.

FACADES OF INGRESS

Facades of Ingress is a puzzle-based interactive experience centering on a large looming sculpture of a monster. It sits behind a curtain of stringed golden spoons and hoards – necessary medications – and accommodations that one needs to function in society. Along its arms and back protrude sharp pill bottle orange crystals. There is a hole in the monster's chest where a heart could fit. Its mouth is large, and when open, rows of shark-like teeth part in the middle, making a slot wide enough to fit a prescription slip. A crown made of pill bottle shards sits on its head. Its skinny, long arms extend out over the pedestal, one on the ground digging its claws into the floor, while the other extends high over its head, claws poised for attack. Nearby, a table holds the broken pieces of the monster's heart

FIG 1: Facades of Ingress, 2024

and a series of prescription slips, all of which are actual medications that I have been, or am currently, on.

This experience was exhibited at UCSC's Digital Arts and New Media MFA Exhibition entitled "Embodiments." It was shown alongside Elliot Rex White's *A Night for Flesh and Roses*. The public could sign up for a time to participate in the experience in hour-long time slots. Each time slot allowed up to 4 people.

Before entering the installation, participants are given a number of golden spoons (ranging from zero to four). While playing, a spoon can be given to the experience facilitator in exchange for help with a puzzle, the answer to a question, or a hint of how to proceed. Any interaction participants would like to have with the experience facilitator must be preceded by them giving the facilitator a spoon. If participants run out of spoons, then the facilitator will no longer provide help. However, through two windows into the neighboring exhibit, participants can ask folks not playing the game for more spoons hidden around the exhibition.

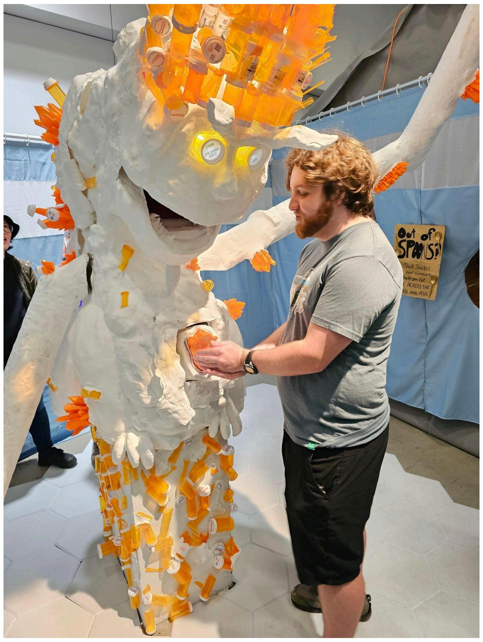

FIG 2: Participant placing heart, 2024
Participant places the completed heart in the monster's chest

Once participants make their way through the spoon curtain, the monster looms in front of them. They must assemble its heart and place it in its chest to bring the monster to life, a symbol that it would not exist without us constantly feeding it, but also that we need to feed it to progress at all, a bitter cycle. This causes the monster's pill bottle eyes to glow with life as it roars with pleasure. Then, four of the crystals on its back begin to light up and chime. Participants must make their way to the back of the monster. There, they find that the glowing crystals are all topped with different pill bottle lids from various pharmacies. Each one matches one of the pill bottle lid buttons at the base of the monster's back. Participants must complete a memory game (akin to Hasbro's game *Simon*) in which they push the buttons in a sequence corresponding to how the crystals light up and chime. The sequence gets harder every time as it changes and another crystal is added to memorize. If participants fail, they must start the puzzle from the beginning; if they succeed, the monster will roar its approval and open its mouth. Participants will then have to look at the prescription slips and decide which one to feed the monster. They have three chances to feed it a prescription slip that it likes. If they are wrong three times in a row, the monster will let out an angry roar and throw its heart out of its chest, starting the game from the beginning.

FIG 3: Participant pushes button, 2024, photo Participant pushes one of the buttons on the monster's back trying to solve the Simon Says puzzle

But there is a secret. *Facades of Ingress* has no end. The final puzzle has no solution. None of the prescription slips will make the monster happy. It will always reject its heart and restart the game. It continues in this cycle forever; just as those seeking accommodations must continuously work to keep and update them, participants become stuck in what Margaret Price calls “the accommodations loop” (Price 82). This loop represents the infinite cycle of gaining and keeping accommodations. It consists of four steps on a figure eight: slow system, time-sensitive needs, employee uses own resources, and emotional cost (Price 82). Each one is a potential step in the journey for accommodations.

For example, I need a content warning for 3D videos with excessive camera motion. This is a time-sensitive need because this type of video triggers my vertigo, and a video featuring excessive camera movements is being shown in class. So, I reach out to my professor and ask for this accommodation. Unfortunately, this professor will only accommodate me if I go through the Disability Resource Center (or DRC for short). I already have accommodations filed with the DRC, but I did not anticipate needing this specific accommodation until I showed up for class because this part of my illness has never impeded my ability to function in class before. Because this is not one of my official DRC-sanctioned accommodations, a long email thread about possibly getting this content warning occurs. This email thread becomes a months-long endeavor as I spend physical and emotional labor repeating what I am asking for and why. It has now been months since the accommodation was needed. I have used my own resources to solve the problem (trying to anticipate what the content of a video will be before it plays, enlisting my colleagues to quietly describe a video in real-time while I put my head down on my desk to avoid seeing it, spending long bathroom breaks crouched on the floor and breathing deeply to try to mitigate the symptoms). The slow system failed to help me when I needed it, and the emotional cost of trying to go through the proper channels has left me barely able to attend class and complete my work.

Facades of Ingress mirrors this cycle through the puzzles. Participants must repeat the tedious puzzles continuously if they want to keep playing the game. There is another secret, however, as each puzzle is designed imperfectly. For instance, the hole in the monster's chest is not a perfect fit for the heart, so participants must repeatedly pull it out and replace it until they can get the sensors that detect when it is in place to trigger. The crystal Simon game will sometimes restart even if the correct sequence is input. The prescription slips must be a certain orientation in the monster's mouth for the monster to recognize it. Even if you do everything right, you do not always get your accommodations.

This project was the most physically and conceptually complex thing I have designed. The scale of the monster and my plan to make it fully automated were the two most challenging elements.

The six-foot-tall monster has a sturdy wood and cardboard skeleton coated in spray foam that was carved to create the details of his body. A thin layer of foam clay was put on top of the spray foam to create the monster's smooth skin. It is hollow on

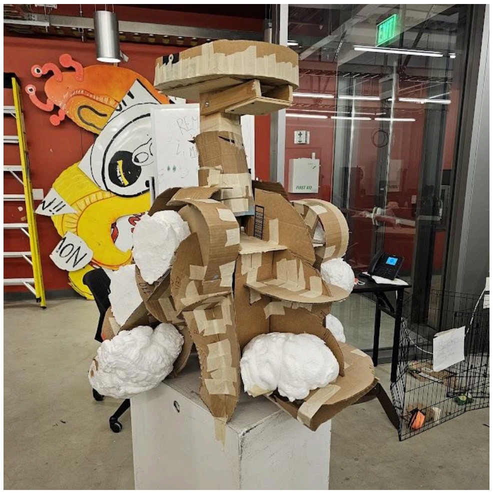

FIG 4: Monster skeleton, 2024, photo
The monster's skeleton made up of a wood inside for strength and cardboard to help sculpt the body

the inside to easily store all the electronics. The large crystals and the 3D heart jigsaw puzzle were 3D printed with a transparent orange filament resembling the color of an orange pill bottle. It was also really important to me to include objects from my community. All of the pill bottles on the monster are sourced from friends, family, and colleagues. Small as a pill bottle may be, the amount of support I received from folks willing to share theirs was a huge reminder that while the institution rejects my accommodations, I still have my community supporting me.

There are four Arduinos inside the monster that make all the electronics function: one for each puzzle and one that acts as a server to facilitate communication. At first, I planned to use Arduino Uno R3s because those are the circuit boards I am most familiar with; however, Uno R3s can only communicate with one other board through a hardwire connection. So, I switched to using Arduino Uno R4 WIFIs. These boards could communicate to

FIG 5: 3D printed crystal, 2024, photo
Transparent orange 3D printed crystal with pill bottle caps

multiple others over WIFI instead of the hard connections. The switch to Arduino Uno R4 WIFIs was a huge innovation in the construction of the work. Without the capability of the boards to communicate quickly and wirelessly, I would not have been able to make the flow of the game smooth or automate it completely.

There was so much tension in creating this piece. It is a monster. It is purposely inaccessible at its core, but it is also a piece about accommodations. I wanted it to be accessible. There are so many art and game pieces that I cannot participate in. I know the woes of skipping a section of an exhibit or not being part of an experience. I wanted to combat that as much as possible while creating something that held the frustrations of surviving in an inaccessible system.

This thinking deeply informed my puzzle-designing process. The goal was to make the puzzles feel tedious, obtuse, and/or difficult while also making them as accessible as possible. Some of this was done during the actual puzzle design and creation, while others I implemented during the experience.

Puzzle design and creation was not a straightforward process, and all of my puzzles went through several iterations before I landed on the final product. The heart puzzle, for instance, began as a flat paper puzzle, then a large sculptural iteration before I finally settled on a 3D jigsaw puzzle. Originally, participants had a series of prescription slips with pieces of drawings on them. They had to layer the slips on top of each other to form a picture. This iteration had many problems as participants had difficulty maneuvering the paper slips and seeing the image once it was complete.

The switch to a larger sculptural puzzle was inspired by Georgina Kleege's “The Art of Touch.” Within her article, Kleege discusses the value of tactile elements for blind and visually impaired folks as well as sighted ones. There is so much to be learned from a piece of art through touch because you can feel "traces of the workmanship" (Kleeges 17) under your fingers. Kleege created three categories for sculptural work based on different tactile sensations and aesthetics: Works receptive to touch (fabric, fuzzy, soft, smooth), works indifferent to touch (systemic, scientific, idealized), and works that are hostile to touch (rough, sharp, grainy). These descriptions not only had me thinking deeper about how the tactile elements of my work inform participants about their meaning but also, how I felt all these sensations in my body. If I were the sculpture, what parts of me would be receptive, indifferent, or hostile to tactile sensation? When my joints are inflamed or my nerves on edge how does it feel to hold, carry, pick up, touch?

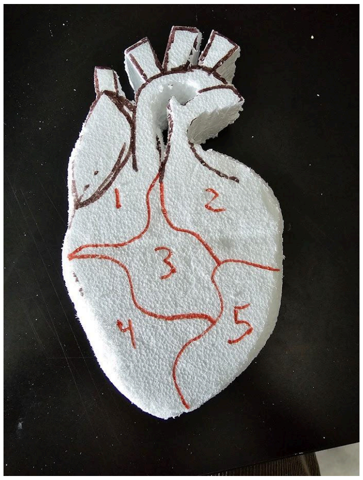

FIG 6: WIP of heart puzzle prototype, 2024, photo

This second sculptural iteration was made by creating a 3D styrofoam anatomical heart, slicing it into pieces, and coating the outside edges in a moldable plastic. It was smooth but lumpy. Some pieces were heavy with plastic, while others were lighter. It was flimsy, held together by Velcro strips along the inner seams. These elements made it awkward and bulky. It was certainly an obtuse sculptural element, but overall lacked the structure and

FIG 7: Heart prototype, 2024, photo

strength it needed. Ultimately, I went with a 3D-printed anatomical heart jigsaw puzzle that provided participants with a smooth and clean puzzle experience. The outside of the heart had more detail than its previous iteration, including small veins that ran over its surface. It was no longer an obtuse and difficult-to-maneuver object. Instead, 3D printing the heart allowed for a more intricate design, which made it harder to solve. During the experience, participants spent the longest time solving the puzzle and needed the most help finding the solution.

The monster also played with tactility. While its flesh was made of light foam and smooth clay, it was also covered in sharp, spiky plastic crystals and pill bottle shards. Upon touching its flesh, many participants described it as feeling like smooth, soft plaster, giving it a friendly feel until a finger or arm scratches against a crystal. This distinction between soft and hard embodies the invisible torment caused by the monster. Similar to Hedva in *Sick Witch*, I wanted there to be a little humor in the physicality of the monster. *Sick Witch* was a comedy routine of exaggerated movement that was used to make the subject matter of the performance more palatable for the audience. The monster in *Facades of Ingress* purposely has a very cartoonish appearance in order to appear more approachable and game-like. It eases participants into the experience with its soft and silly pose before revealing the sharp reality that lies inside the puzzles.

Facades of Ingress was shown together with Elliot Rex White's piece *A Night for Flesh and Rose*. Both pieces explored themes of embodiment and monstrosity, though in very different ways. White's installation created a speculative future where one's physical form is ever-fluid, allowing players to construct their idea of what a body can be. The main feature of their exhibit was a gothic visual novel. Through the use of collage and texture, White explores being transgender, body modification, and transhumanism.

The main interaction between the installations occurred through a pair of windows placed in the dividing wall that separated them. These windows were little

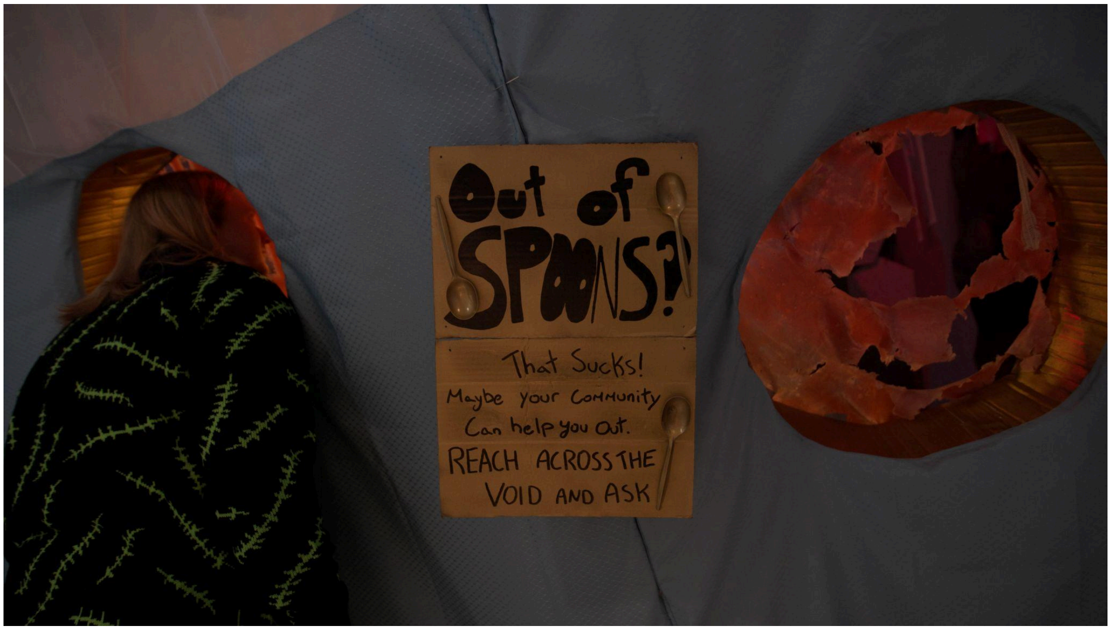

FIG 8: Windows between installations, Swandive Media, 2024, photo
Two windows between Facades of Ingress and A Night for Flesh and Roses. In between the windows is a sign that reads, "Out of spoons? That sucks! Maybe your community can help you out . REACH ACROSS THE VOID AND ASK"

tunnels into other worlds. Participants playing *Facades of Ingress* could look through the windows at this possible future while they struggled in the present, while those enjoying *A Night for Flesh and Roses* got a peek into the struggles of the crip world.

We used these windows to build a bridge between the communities that existed between our pieces. This community became a helpful resource for participants in *Facades of Ingress*. When they were stuck on a puzzle or had a question but were out of spoons, they could peek through the window and ask folks inside the other exhibit for some. Then, those inside *A Night for Flesh and Roses* could find one of the golden spoons hidden around White's space and offer it to their struggling friends. This use of community as a resource was inspired by Khúc's *Open in Emergency*. Khúc reached out to her Asian American community to create something to help struggling members. This reminded me of the community within the space that White and I made.

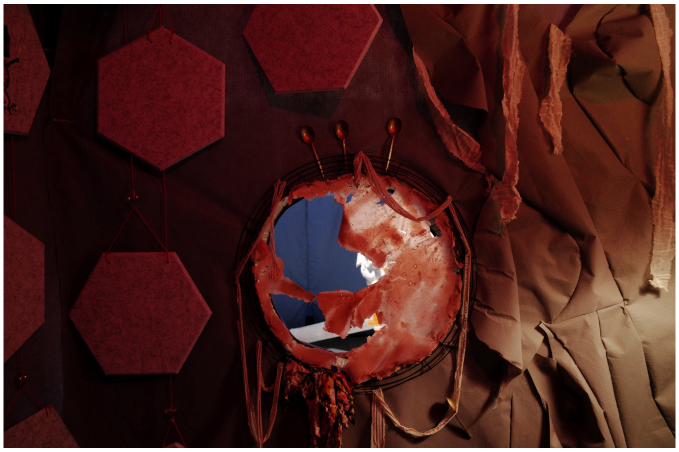

FIG 9: Portal from A Night for Flesh and Roses, 2024, photo
On the side of A Night for Flesh and Roses, the windows were covered a fleshy silicon. Golden spoons were hidden around the outside of the windows and throughout the exhibition.

I will admit that my system for determining the number of spoons was biased. I did not have a system to decide the number at random. Instead, I looked at the people in front of me, and based on what I saw, I decided how many spoons to give them. I determined the number of spoons based on how likely I thought they would understand the experience.

If someone had a knowing glint in their eye, made a knowing comment about spoons, or gave me the impression that they understood the struggle, I would give them more spoons. These are the people that I assume already understand the system, so I chose to provide them with more spoons to make the experience easier for them. *Facades of Ingress* aims not to retraumatize those the system has already failed. On the other hand, if participants came ready to win what they thought was more akin to a winnable game, I would give them fewer spoons to start. I wanted them to know what playing the system's unwinnable game felt like.

FIG 10: Kris helping participants, Swandive Media, 2024, photo Kris holds a golden spoon in his hand as he helps participants with the Simon Crystal Puzzle.

There was an interesting correlation between the two groups. Those who entered with the understanding that this experience was designed to mimic the cruel ways in which the system works were more likely to ask for help. They would use their spoons liberally, understanding that this was not a game meant to be played alone. They had a community through the void that was ready to help and did not hesitate to ask for it. This was heavily contrasted by the participants who wanted to win. The egos of people used to ‘winning’ games often made them want to figure it out alone without help. This type of participant spent more time in the game, completed more loops, and used fewer spoons. They were more frustrated with every failure and often were upset with me upon finding out there was no winning. I think there was an element of pride and stubbornness that would not let them ask for help, mixed with a nondisabled understanding of the systems the game mimicked. In their minds, the game had to have a solution because their experience with illness usually leads to a cure for whatever ails them.

Of course, my judgment in who received spoons was clouded by my own biases as a white disabled transman and how I perceived sickness and allyship to look. It also changed throughout the exhibition as my perception shifted. I sometimes felt the power that being one with the system gave me. No longer was I begging the monster for help, but instead, I became an agent of the monster as participants struggled and asked for help. It was a really conflicting experience because I knew what the participants felt and wanted to help them. Still, a part of me also liked watching people struggle as they finally understood what it can be like.

I hope to have the ability to share *Facades of Ingress* with more folks in the future. There are plans to improve the experience by implementing features that I had to exclude due to time restraints. The original concept for this piece included a heart rate monitor that players would wear on their wrist to activate the experience. There are also a couple of sound elements that were not able to be completed on time. Spoons allowing, these components will be added over the next few months so that future participants can experience them.

Disability can be a lonely journey. Navigating institutional systems and battling with the medical industrial complex about something as personal as your bodymind often feels like an individual war. It's hard to remember that others are fighting alongside me, who, while not dealing with the same struggles as me, are dealing with the bullshit of the same system. Watching participants play the experience and hearing their stories and struggles that were so similar to mine was amazing. I didn't build *Facades of Ingress* thinking about the community that you need behind you to keep fighting, but it is still ingrained within it. *Facades of Ingress* is not a solo experience. No one going in had to work alone. There was always someone with you to commiserate about the difficulty of solving the heart jigsaw or laugh with when the crystal Simon game failed you for a fifth time in a row. The windows between installations created a space for mutual aid, where those exploring White's installation could reach out to and help participants inside *Facades of Ingress* by providing them with extra spoons.

Even though I set up these interactions when creating the installation, I was unprepared for the tender moments of access intimacy. These moments, where I connected with those playing *Facades of Ingress*, left a freeing light in my heart. Even as I made this piece based on the trauma I experienced inside an ableist system, there was a deep sense of kinship as I held space for others to share their own experiences of trauma. Mia Mingus said it best:

> Access intimacy is not charity, resentfulness enacted, intimidation, a humiliating trade for survival or an ego boost. In fact, all of this threatens and kills access intimacy. There is a good feeling after and while you are experiencing access intimacy. It is a freeing, light, loving feeling. It brings the people who are a part of it closer; it builds and deepens connection. Sometimes, access intimacy doesn't even mean that everything is 100% accessible. Sometimes, it looks like both of you trying to create access as hard as you can with no avail in an ableist world. Sometimes it is someone just sitting and holding your hand while you both stare back at an inaccessible world (Mingus).

Thank you to those kind souls who experienced *Facades of Ingress* and held my hand as we watched the inaccessible world around us. This project was for you.

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APP 1: MAKING MY MONSTER

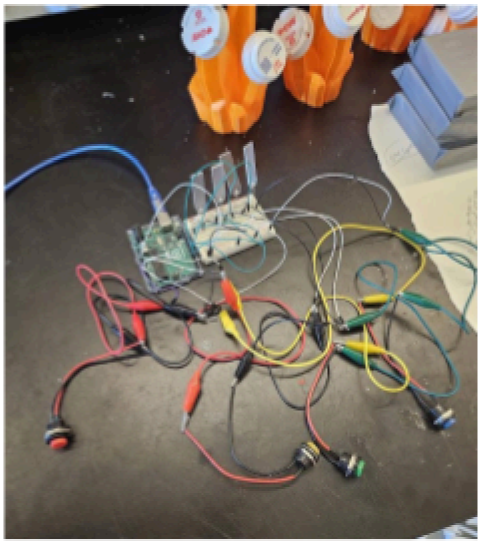


FIG 11: Prototype of the Simon Crystal Puzzle, 2024

FIG 12: Prototype of mechanical jaw, 2024

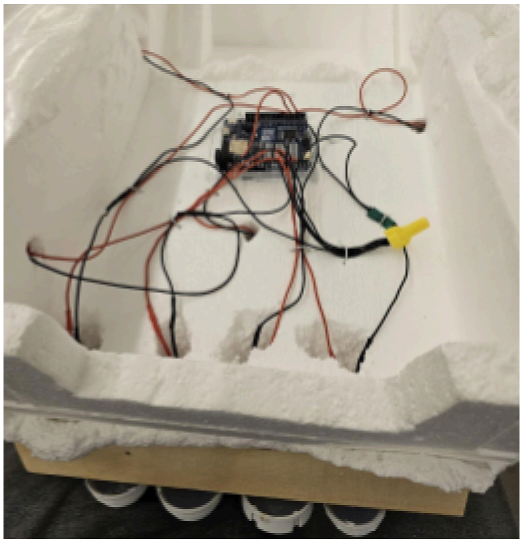


FIG 13: Wiring for Simon Crystal Puzzle hidden inside the monster's back, 2024

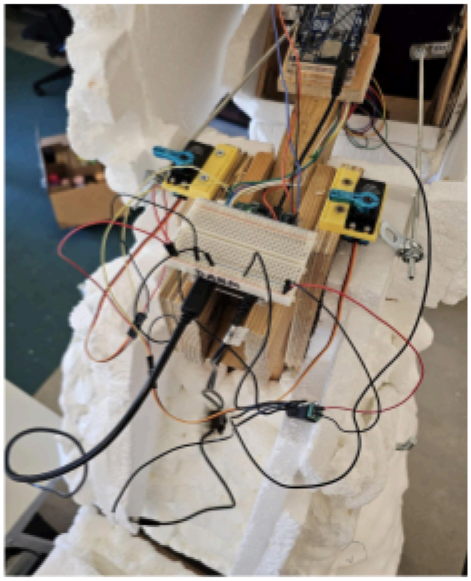
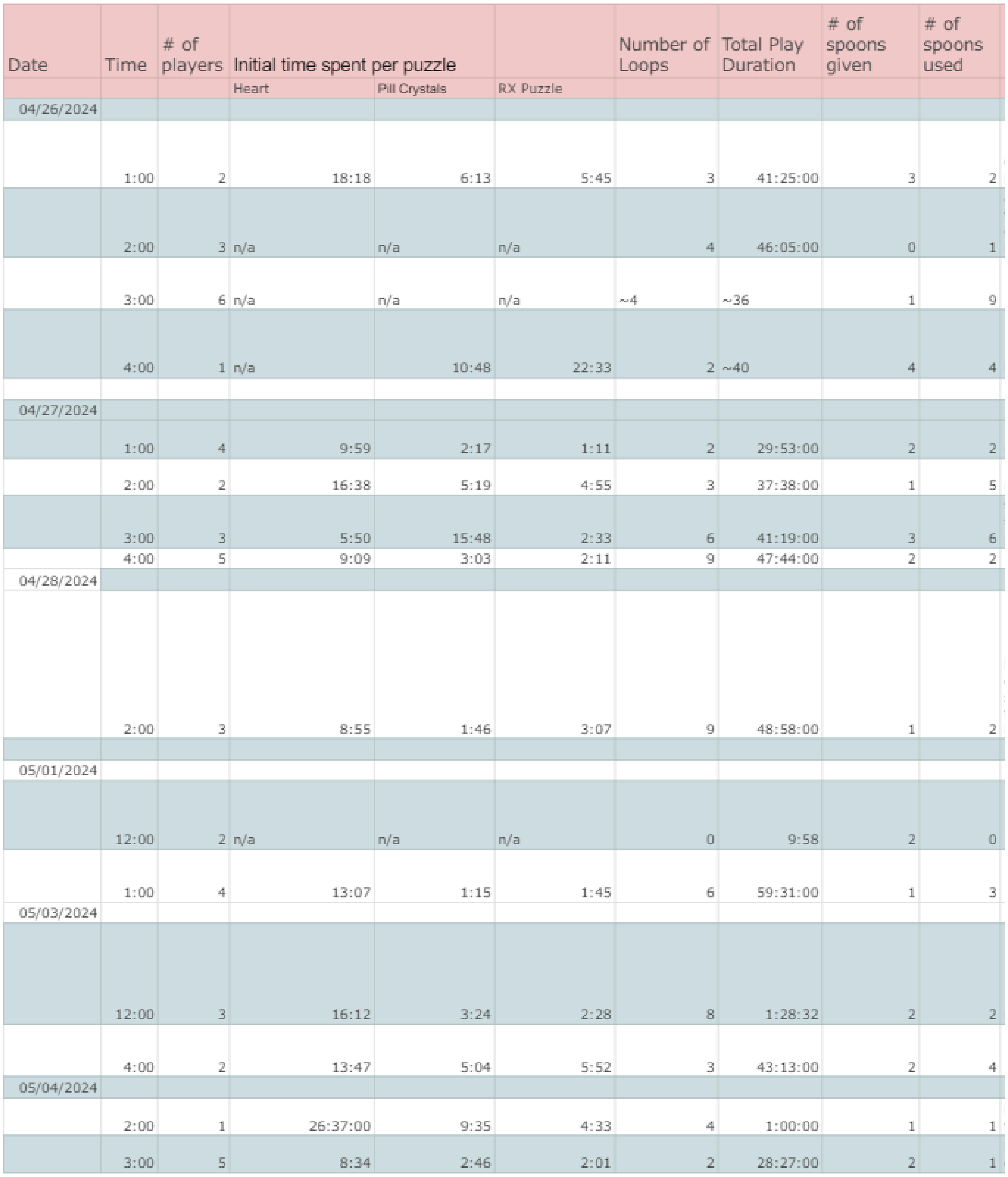


FIG 14: Second iteration of mechanical jaw prototype, 2024

APP 2: EXHIBITION STATISTICS

Below is a spreadsheet used to track different statistics during the experience. This includes the date, time, and number of participants playing. It also includes how long each puzzle took to complete the first time they solved that puzzle. The “Number of Loops” indicates how many rounds of completing all three puzzles a group completed before deciding to leave the experience. “#of spoons given” represents how many each group received before entering the experience. “# of spoons used” indicates how many spoons they used to get help throughout the experience.



Date	Time	# of players	Initial time spent per puzzle			Number of Loops	Total Play Duration	# of spoons given	# of spoons used
			Heart	Pill Crystals	RX Puzzle				
04/26/2024									
	1:00	2	18:18	6:13	5:45	3	41:25:00	3	2
	2:00	3	n/a	n/a	n/a	4	46:05:00	0	1
	3:00	6	n/a	n/a	n/a	~4	~36	1	9
	4:00	1	n/a	10:48	22:33	2	~40	4	4
04/27/2024									
	1:00	4	9:59	2:17	1:11	2	29:53:00	2	2
	2:00	2	16:38	5:19	4:55	3	37:38:00	1	5
	3:00	3	5:50	15:48	2:33	6	41:19:00	3	6
	4:00	5	9:09	3:03	2:11	9	47:44:00	2	2
04/28/2024									
	2:00	3	8:55	1:46	3:07	9	48:58:00	1	2
05/01/2024									
	12:00	2	n/a	n/a	n/a	0	9:58	2	0
	1:00	4	13:07	1:15	1:45	6	59:31:00	1	3
05/03/2024									
	12:00	3	16:12	3:24	2:28	8	1:28:32	2	2
	4:00	2	13:47	5:04	5:52	3	43:13:00	2	4
05/04/2024									
	2:00	1	26:37:00	9:35	4:33	4	1:00:00	1	1
	3:00	5	8:34	2:46	2:01	2	28:27:00	2	1

APP 3: THE EXHIBITION

FIG 15: Monster's Heart, Swandive Media, 2024, photo
Participant places the heart inside the monster's chest.

FIG 16: Monster's Heart 2, Swandive Media, 2024, photo
Participant looks up in awe as the monster's eyes light up once the heart is placed.

FIG 17: Kris explaining the Heart, Swandive Media, 2024, photo
Kris explains how to solve the heart to a participant.

FIG 18: Simon Crystal Buttons, Swandive Media, 2024, photo
Close up of the buttons for the Simon Crystal Puzzle

FIG 19: The Monster, Swandive Media, 2024, photo
Participants watching the monster

FIG 20: The Monster 2, Swandive Media, 2024, photo
Two figures stand looking at the monster which glares down at them with glowing eyes.