

EACH BRAIN

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Abstract

Each Brain is a short 21-minute documentary film about two women, Melanie and Hana, their diagnosis of epilepsy and brain injury and the intersection of their unique but similar stories. Both women acquired epilepsy while pursuing visual arts in university, and in the film share their experiences of the neurological conditions that forever shaped and altered their lives. However negative one might assume these experiences to be, the two women reveal strength and perseverance despite misdiagnosis, and prevail despite medical challenges. Although they experience immense change, they seem, above all else, to maintain a positive outlook.

This documentary explores the subject matter through modes of poetic and alternative styles of filmmaking. The narrative is told through various recorded poems, letters and interviews set to stock footage and photography from the lives of the subjects, and the captured sounds of an epileptic seizure.

Though the film deals with the medical subject matter, it does not focus on the cause or symptoms of epilepsy. The story transcends diagnosis and highlights the often-difficult journey women experience on their way to acceptance through the challenges of acquired neurological disabilities. The title, *Each Brain*, echoes back to a poem by Jo Anna Davidson, who also experiences epilepsy, capturing the essence and uniqueness of the brain/body connection.

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Introduction

Each Brain is a film in the genre of alternative/abstract documentary that explores the stories of two women, Melanie Taddeo-Nxumalo and Hana Kujawa, who were both diagnosed with epilepsy early in their art school studies. Through their own distinct voices, we learn about their unique experiences and the ways in which they share understandings.

Due to the COVID-19 pandemic, I collaborated at a distance with both subjects throughout the process of making the film. Together, we prepared audio recordings of their stories and collected film, photographs, poems, and stock images where necessary to convey their stories in a genuine way.

The importance of accurate representation of persons with disabilities is a key component of this work. Integral to accurate representation is voice and input from individuals with lived experiences, and this ultimately affects the authenticity of the end result. As Lennard J. Davis questions:

It is not like we do not see a lot of people with disabilities in film. In some sense, disability is one of the sub-specialties of visual media. From Lon Chaney, Jr. playing the Hunchback of Notre Dame to Daniel Day Lewis' portrayal of Christie Brown in *My Left Foot* to Sam Worthington playing Jake Sully in *Avatar*, from the wheel-chair using dancer of *Glee* to the son with cerebral palsy on *Breaking Bad*, media loves disability. People with disabilities portrayed in media as present, in the sense of ubiquitous, are always marked as different, and yet rarely ever played by actors with disabilities. Why is that? (Davis 2017, 41)

Questions like these posed by Davis are central to new representative movements which aim to share space and accuracy within cinematic storytelling. Paramount to this pursuit is the access to tell one's story or to appear without hyperbolic tropes in storylines written about persons with

disabilities. Further, within the context of documentary film which aims to capture any element of life as a person with a disability, a collaborative approach for non-disabled directors is imperative to ensure accuracy and authenticity.

Prior to this film, I had not explored the genre of alternative documentary. However, as I dove into the less structured and more fluid depiction of the stories and themes explored throughout this work, I found more comfort in this space. While a more traditional documentary form, for example using talking heads, would have greatly simplified the overall process of editing and connected the pieces of both Hana's and Melanie's stories, the work undertaken with both women to create the visual "quilt" of *Each Brain* had a much greater impact.

The stories shared by Hana and Melanie in *Each Brain* are not a chronicle of their acquired disability but rather offer a shared experience in misdiagnosis, navigating the healthcare system as young women, and finally, as people who persevered in living within the context of their disabilities while striving not to be defined solely by their common medical diagnosis of epilepsy.

The making of this film posed two key questions:

1. Can a documentary be effectively produced without being physically present with the subjects despite the intimacy of their experiences?
2. How can documentaries be successfully created as an interabled collaboration with non-filmmaking subjects, focusing on the inclusion of disability-related experiences?

As this paper and *Each Brain* will demonstrate, with sufficient planning, preparation, communication, and willingness to collaborate, a documentary can be effectively produced by a geographically dispersed team. From the beginning of production in 2020 to the finished film in 2022 the entirety of the team, including subjects and crew, was spread out across multiple provinces and countries. We prioritized strong communication over e-mail and Zoom to ensure the vision for the film was accurately reflected throughout the production, editing, sound mixing, captioning and colour correction processes. Through our commitment to and interest in the project, we were able to achieve an end goal which demonstrates that creating from a distance using modern tools of collaboration and connectivity is definitely possible.

This film involved an interabled collaboration, that is, a collaboration between myself, as a non-disabled filmmaker, and Melanie Taddeo-Nxumalo and Hana Kujawa, two artists with epilepsy. With respect to creating collaboratively to share stories of disability and inclusion, communication is a critical component. Further, Hana and Melanie were not filmmakers by trade, nor had they worked with video as an artistic vehicle. The success in meeting this challenge emerged from their overall willingness to explore and create, regardless of experience; in turn, I sought to remain open to creating what the film was meant to become. I would review content that they would craft and send through email or shared drive, and then Melanie and Hana and I would connect through email or phone call to establish how to fit the material into their story as they intended. Through this process, I would aim to first listen to their input on the content, view it, and then discuss whether the content would be integrated or might need to be revisited or reworked. The ongoing communication to evaluate the process and to produce content for the film was key to achieving a vision we all supported. I approached the film in

terms of presenting a shell, and together we collaborated on the way in which the categories and spaces would be filled to produce one single cohesive, inclusive piece.

Background on Key Themes

I have worked in disability support services in a variety of capacities throughout the last decade and created documentary and fiction projects on the subject matter of disabilities in various forms. Epilepsy became of specific interest to me through my one-to-one support work with two individuals with the diagnosis. I was interested in the ways epilepsy affected them and how it impacted their choices in life, and how vastly different their seizure experiences were given the unique way the brain can be affected in each individual case. Through this understanding, as well as additional research undertaken through the development of *Each Brain*, the key themes of collaboration and the uniqueness of disability, specifically epilepsy, emerged.

Collaboration

In the typical director-led documentary film, while the film may be *about* the subjects it is not collaboratively made *with* them. In contrast, given the topic of *Each Brain* and its subjects, I relied on themes within critical disability studies which “view[s] disability as both a lived reality in which the experiences of people with disabilities are central to interpreting their place in the world and as a social and political definition based on societal power relations” (Reaume 2014, 1248).

Additionally, the disability rights slogan “nothing about us without us” (Charlton 2000) highlights the importance of including the voices of those who are spoken about or impacted by disability-related content. This approach may seem obvious; however, in film and other media disability is still predominantly represented by non-disabled people (Davis 2017). Because of this, a main pillar of *Each Brain* was to heavily consider elements of collaboration within the

telling, imagery, discourse and follow-up to the end result. This approach also made this film possible in the context of the COVID-19 pandemic, which presented numerous limitations in filmmaking.

James I. Charlton's book, "*Nothing About Us Without Us: Disability Oppression and Empowerment*," explores the importance of ensuring that a person who has a disability is involved with the elements of representation and not merely a product of a perspective from a non-disabled maker. This is a continuation of a long history of advancing human rights. Charlton writes:

"Nothing About Us Without Us" resonates with the philosophy and history of the disability rights movement (DRM), a movement that has embarked on a belated mission parallel to other liberation movements. As Ed Roberts, one of the leading figures of the international DRM, has said, "if we learned one thing from the civil rights movement in the U.S., it's that when others speak for you, you lose." (Charlton 2000, 3)

In the context of *Each Brain*, I am a non-disabled person forging a relationship of collaboration with Melanie and Hana, where we were able to work closely together to develop and craft the resulting film. This interabled collaboration, input and the importance of the subject's experience drove the production as it evolved.

The COVID-19 pandemic brought an additional lens to the process of filmmaking that further highlighted the importance of collaboration and representation. Melanie and Hana's reflections on their isolation following their medical diagnosis and lengthy recoveries after surgeries and further neurological events were similar to the isolation of the pandemic. This was a common correlation made by the disability community I worked with online, where I delivered media programs to adults with intellectual and physical disabilities. In other words, while the pandemic

introduced heightened feelings of isolation for most people, this was a long-familiar feeling for many people with disabilities. As Charlton explains,

People with disabilities are invisible and anonymous... there are three major reasons for this phenomenon: people with disabilities are often abandoned, hidden, and shunned by their own families and communities; segregation and inaccessibility have prevented people with disabilities from conducting fully public lives; extraordinary sociocultural stigmas have been brought to bear on those who have disabilities that are not readily apparent so that they tend to conceal these disabilities from others. (Charlton 2000, 84)

With this understanding, I recognized that despite the challenges of creating during the pandemic, it was most important to prioritize Melanie and Hana telling their stories how they wanted and needed them to be told.

When creating collaboratively, there is an undeniable element of relinquishing control (Coffman 2009, 72). Typically, control in filmmaking is helmed by the directors of the lead departments which have a hand in the overall outcome of the piece. Control in filmmaking, whether within the genres of alternative, fiction, documentary or any composite that exists, is a cornerstone of the typical filmmaker's relationship with their participants. It is largely what is taught and assumed by those who aim to become filmmakers. With this control comes the responsibility of blending words, imagery and sound into a final product that resonates with an audience. In *Each Brain*, however, to ensure that Melanie and Hana's voices were reflected, I traded the typical approach for a collaborative hybrid approach. This resulted in a process that required more connections with my collaborative partners and was more intensive and involved than in my previous experiences directing documentaries of different topics, lengths and aesthetics. Murray et. al. eloquently captures this feeling:

Working together involved various vibes. At times high in strife, at times immensely pleasurable, collaborating is a grab bag of messy contradictions. Collaboration means, if only temporarily, the implication in one another's lives, with all the entanglements that carries. The friendly therapeutic banter of sharing life experiences, and trying to understand what a fellow collaborator is going through, is an activity so inherent to the collaborative process that it remains a kind of social taken-for-granted, something that just happens when people get together, secondary to getting the actual collaborative work done. (Murray et al. 1996, 94)

In addition to creating together, the collaborative relationship between Hana, Melanie and myself continued once production was completed and the film was set to be delivered following colour correction. For example, I worked closely with Melanie, who experiences profound vision barriers, to add accessibility features to the film. This was a need based on my research and previous practice in the area of representation and accessibility in cinema, but also so the collaborators of this work could be included and experience the film as authentically as possible. In addition to working with a captioner to add closed captioning, Melanie and I worked together to develop audio description so that she could experience the film through the audio description. Audio description aims to add spoken word explanation about what is being seen on screen for those with low or no vision (Braun 2011). Practically, audio description is a common means of experiencing visual materials for people who are blind or partially sighted. However, a documentary with at times abstract imagery and often continuous speaking throughout the film creates challenges for adding a meaningful description. Our approach was for Melanie to listen to the film and then for me to describe, unencumbered by the timeline or wording, the imagery that was being linked to the audio in as much detail as possible. While I came to this work intimately familiar with the concepts of accessible media, providing a real-time audio description with Melanie present was an emotional experience. Her gratitude and feelings of enhanced viewing were an element I had not engaged with previously. As a result, my relationship with the themes explored, the subjects, and the overall direction of the film changed and deepened

dramatically. Although I had worked extensively teaching accessible media and providing support work for individuals with disabilities, I had not provided a service to an individual experiencing a barrier to sight. This profound connection allowed me to put what I had taught in the past into practice with someone with whom I also shared a friendship. This experience further informed the impact that universal design (or the “process of creating products that are accessible to people with a wide range of abilities, disabilities, and other characteristics”) and accessibility have on a person's interaction and engagement with media (University of Washington 2022).

Unique Nature of Disability and Epilepsy

Traditionally, epilepsy is often a disability that is in the shadows. This explanation of epilepsy was first described to me at a workshop I attended through the organization Epilepsy Toronto. Often those who have epilepsy do not have visible disabilities and thus, it is not uncommon for people who have this diagnosis to keep it from their friends and colleagues (Matthews and Harrington 2000). Along with this secrecy can come shame and misinformation. For example, many people believe that individuals should have a spoon or wallet placed in their mouths during an epileptic episode so as not to swallow their tongues. This is not factually correct and is harmful to the individual who may become incapacitated while experiencing seizures. Further, there is a degree of mysticism about epilepsy that is still present today in all areas of the globe. Often religion plays a key role, with the common misconception amongst a variety of cultures globally that epilepsy is related to demons, or dark forces (Devinsky and Lai 2008). This is also reflected in media representations of epilepsy. For example, in a recent study of 21 films made between 2000 and 2014 that feature a character with epilepsy or a significant scene with a

seizure, 24% of films reviewed “contained some reference to supernatural phenomena in relation to epilepsy or seizures they portrayed” (Baxendale 2016, 271)

While working in creative arts programming, respite care work, curriculum planning and in general interacting with individuals who had a diagnosis of epilepsy, I observed the profound uniqueness of each person’s seizure experience. The ability to have one’s experience of epilepsy understood and respected can have a significant impact on quality of life (Tuitaité and Šedienė 2018).

The importance of recognizing and navigating this uniqueness of the experience is amplified as we learn that for both Melanie and Hana, the seriousness and complexity of their conditions were not initially recognized by medical professionals. This builds upon growing literature regarding misdiagnosis and bias in treatment, especially given the intersectionality of the subjects as female-bodied and disabled:

A quintessential example of this bias is the minimization of pain and other symptoms reported by women. Studies, news reports, and patient narratives all suggest that compared to men, women are less likely to receive and wait longer for pain medication, feel dismissed as ‘hysterical’ or ‘hypochondriacal’ when they describe their symptoms, and receive wrong, and delayed diagnoses as a result. (Cho 2019, 37)

In addition to features such as gender and disability (as featured in *Each Brain*), other factors including race, age, and language can all impact access to comprehensive medical care (Cho 2019). Symptoms can present differently than explained in a medical textbook, and may not align with the perceptions and perspectives of the medical community. This can have real consequences for individuals who may be discounted, misdiagnosed and delayed in receiving an accurate diagnosis. *Each Brain*, in highlighting the individuality of two women with the same

diagnosis of epilepsy, aims to dismantle and challenge the framework of uniformity that still pervades the medical system and society more broadly.

Alternative/Abstract Documentary

I chose the alternative/abstract form to tell the stories in *Each Brain* for two primary reasons.

Firstly, I was eager to explore new modes of delivering stories through filmmaking. I wanted to depart from observational and expository approaches featuring the talking head documentary intercut with additional contextual scenes related directly to what the subject was saying. I hoped to create a more poetic, dream-like visual exploration to convey a person's story, where the imagery was not necessarily directly linked to what was being said in a literal way. The exploration of the alternative/abstract documentary style meant more freedom to explore visual textures and metaphors in portraying what Melanie and Hana were sharing.

Secondly, the way in which this film had to be created, due to restrictions with the COVID-19 pandemic, lent itself to interpretive and abstract/alternative style. The ability to meet consistently in person and or to capture video content while collaborating in the same space made this form a more realistic and overall more flexible genre to apply to this work. Moreover, this form lends itself to collaboration where multiple content types and aesthetics can be contributed; ultimately the narrative was supported by the disconnected and imperfect imagery, which amplifies the nature of epilepsy and its unpredictability.

The importance of an accurate representation of Melanie's experience as a person who is blind was a central concern when creating, compiling and engaging in the montage that accompanied her recorded story. This discourse and possible approach were explored by Helen Hughes in her writing on Andrew Kötting's experimental documentary film *Mapping Perception*. In the film, the visualization of visual impairment is explored through collaborative art/science projects.

Hughes writes, “It is understood that documentary images, like the images of fiction films, are in some sense detached from the life they depict, but it is also the case that the ‘truth of cinema’, or cinema verite, also feeds back into every day, particularly when it participates in the politics of representation” (Hughes 2017, 284).

The collaborative approach taken to create *Each Brain* allowed for representation to be a centralized concern. Working actively with Melanie in ways she is comfortable meant that she could contribute creatively to the content and provide feedback throughout, which was enabled by the fluidity of the form. Hana, on the other hand, was able to produce content to represent her story guided by her own creative compass.

While creating *Each Brain* as mentioned in detail above through a pandemic, the film relies heavily on stock imagery obtained through artgrid.io. This library of still and moving images provides a body of work captured applying a specific aesthetic so filmmakers may use multiple files with similar treatment and overall style. This was an integral piece to the making of this film as there were not the typical opportunities to create in real time. Medical imagery is heavily used throughout the film in overlays with archival footage and still imagery provided by collaborators, Hana, and Melanie. These images bring further context to the intersectionality of life before and after acquired disability. Josef Parvizi and Chris Chafe’s work to audibly capture and visualize the sound of a person’s seizure experience were equally as integral to the work. The animation provided by Parvizi and Chafe where the viewer sees the pulsating rendition of a brain’s colorful pathways moving to the disturbance of a seizure provided inspiration to further include medicalized imagery. My choices to include both stock imagery in addition to Parvizi and Chafe’s capturing of the sound and visuals of a seizure were firstly influenced by the

challenge creating this work without accessing the subjects directly. Secondly, specific to the subject matter I felt it was important to visually contextualize the memory and impact of both Hana and Melanie's medical experiences.

Significant Influences

Significant film influences for *Each Brain* include *Montage of Heck*, *Crip Camp*, and *Alter Ego*.

I was also inspired by poetry, science and visual art. These works were integral to informing my thought process, and discourse throughout the journey of making *Each Brain*.

Kurt Cobain: Montage of Heck

There have been dozens of books, articles, biographies and films made about Kurt Cobain, the lead singer of Nirvana, and his life and untimely and suspicious demise. This film worked with his journal entries and furthermore collaborated directly with his daughter Frances Bean to develop the film. Ultimately, the style of chaotic and abstract animation was what I had similarly envisioned for much of *Each Brain*. Despite *Each Brain* not continuing in the style of an animated documentary, the overall departure from a clean-cut presentation of events and storytelling was strongly influential. Furthermore, the involvement of Cobain's daughter, Frances Bean, in the telling of Cobain's story spoke to the collaborative effort I aimed to apply to *Each Brain* in the interest of authenticity and accurate representation. Additionally, the use of archival footage, images and edited overlays when applying these visual materials impacted the way in which I approached integrating like content provided by Melanie and Hana.

Crip Camp

The Netflix documentary *Crip Camp* was influential in the development of *Each Brain*. *Crip Camp* highlights the revolutionary nature of the disability rights movements in the 1970s. In particular, this film informed my approach to filmmaking when featuring an individual with a disability where the subject's voice, representation and experience are integral to the piece. The

film features a variety of archival footage and present-day interviews covering the profound impact of the disability rights movement. The film also explores the ingenuity, perseverance and isolation of the camper's disabilities, themes which were reflected in *Each Brain*. As Sara Luterman's review of *Crip Camp* states:

Crip Camp ... offers a new glimpse into Heumann and the history of the disability rights movement that is raucous, joyous, and even sometimes shocking. "Crip Camp" serves not only as an excellent introduction to disability history for those who are unfamiliar but as a humanizing glimpse into the lives of civil rights leaders I thought I already knew. If you want to marvel at human ingenuity, perseverance and triumph ... "Crip Camp" has you covered, whether you have a disability or not. (Luterman 2020)

Further to the historical importance of the disability rights movement explored throughout, the activists in *Crip Camp* are not infantilized, they are adults who have strong opinions on their place in society. They swear, talk about sex and drugs, and simply are adolescents in the 1970s. Similarly, ensuring a holistic representation of the subjects of *Each Brain* was critical to the effectiveness of the film.

Alter Egos

I was introduced to the National Film Board film *Alter Egos* by director Laurence Green in the third year of my undergraduate studies, but it stayed with me for many years. The documentary uses a unique animation style by animator Ryan Larkin, to explore the nuance of mental health and addiction. I was inspired by the cross-section effect the animation gave where the viewer could see intricate parts of the main character Ryan Larkin's body. There was humour and a distinct loneliness that appeared throughout the film. Key insights from *Alter Egos* that I brought into *Each Brain* included the unique visual presentation, as well as the manner in which delicate health issues were explored.

Poetry of Jo Anna Davidson

Toronto-based poet Jo Anna Davidson contributed two original pieces on the subject of her own epilepsy experiences to include in *Each Brain*. These poems captured the experience of a seizure and the medical intervention she received. In the poem “each brain”, Davidson writes about the unique nature of the brain, likening it to a fingerprint. This description of the abstract yet universal nature of our brains felt like a fitting analogy for *Each Brain*, which largely deals with epilepsy as an invisible shadow that momentarily transfixes the brain into a series of repeated electrical pulses stopping and starting again. While similar in definition, the manifestation of epilepsy presents uniquely in all those with this diagnosis.

Researchers Josef Parvizi, MD, PhD and Chris Chafe, MA, DMA

The work of Professors Josef Parvizi and Chris Chafe from Stanford University was inspirational. Their research capturing the sound of a seizure and actively sonifying it into audible tracks changed the trajectory of the film (Parvizi et al. 2018). This research was not the initial figurative pulse of *Each Brain*, though while in the process of recording interviews with Hana and Melanie, I found myself wondering how to articulate any piece of what they might experience or feel inside during an epileptic experience. That led me to consider creating music from the data captured during an MRI or perhaps through brain mapping during a seizure. This was difficult for a variety of reasons given the timing and the obvious ethical issues around inducing seizure to capture the needed data. Luckily I discovered the work of Professors Parvizi and Chafe, and the recordings that were collected as part of their research gave a new lens to *Each Brain*. This audio gave context and voice to the internal storm that occurred when someone experiences a seizure.

My Experience

As a maker of cinema, I have been interested and worked in both fiction and documentary genres. Documentary filmmaking came naturally to me, having started documenting voices, songs and stories with a cassette recorder as early as I can recall. At York University as an undergrad, I directed documentaries exclusively. *Welcome to Holland* (2009) was my first foray into a classical format of documentary filmmaking. In that film, I sought to capture my subject's unique and extremely sensitive stories related to his diagnosis of a rare chromosomal disorder called Pallister Killian Syndrome. I appreciated the rigid structure of the typical form of documentary because my experience in structure was limited. Following this form was the right choice. While I grew as a filmmaker through my undergraduate degree, I still followed this traditional process in subsequent documentaries. After my undergrad, I directed several fiction films funded through grants. However, I found the process to be significantly more stressful and taxing than the fluid pursuit of documentaries. Through my career, I have come to understand that for me, the documentary form provides the freedom to explore experience and truth in an emergent creative practice, without the limitations of being married to a script or even an overall theme or goal. It is this flexibility that I appreciate most about the documentary form, and why I have returned to it in my Master's work.

For my Master's thesis, I wanted to depart from a talking head style documentary, and challenge myself to try and create more closely what I envisioned in my mind-eye. Before *Each Brain*, I explored this possibility in a graduate seminar for which I made a highly personal film called *Eulogizing My Mother*. I worked from the context of a thought, a fear, and a longing to capture the essence of the grief I was experiencing. I did not have inspiration from an external source to

go on while writing, filming, recording voiceover and editing what I recorded. I had instead allowed for abstract concepts and imagery to accompany the very personal love letter to my ill mother. I relinquished power and the feeling of being bound to a formal idea, and in doing so, found a place of deeper creativity. From this project, I fell in sync with my instinct to create with less form and more feeling. This concept and discourse would be amplified as I worked on *Each Brain* throughout the COVID-19 pandemic that restricted access to even filming basic footage of Melanie and Hana. Without access to traditional tools of documentary and film, I was able to fully embrace the collaborative effort to weave the audio and visual fabric of *Each Brain*.

Preparation, Production and Post-production

Shifting Vision

The original vision for this film was to explore many artists' experiences with epilepsy, told through a variety of animation styles and artistic mediums befitting the experience. Each person featured in the film with an experience with epilepsy would be connected with an artist they would collaborate with to create the accompanying visuals to their stories. The idea is that this approach would capture the unique nature of this diagnosis.

Each Brain had been a film I had wanted to make for a long time, and I had thought a lot about who I could include in the process, how I would visually present this film, and which organizations I could explore partnering with for possible funding. From the outset, however, I was faced with more practical questions about how to execute this idea. Early on, I had hoped to work with three to four individuals who had lived experiences with epilepsy. Further to these collaborators, I intended on connecting with a variety of visual artists who might be able to match their style of art to the collaborator's story in how it was going to be presented. After budgeting the cost of animation, however, it was clear that the film I was endeavouring to make was much more expensive than I was anticipating. Recognizing this, I began to look to other ways of presenting this idea.

Research and Planning

Field research was largely conducted virtually given the context of the pandemic. I attended virtual art shows and online galleries, and attended free programs delivered by artists with disabilities through DramaWay, a creative arts agency, throughout the initial lockdowns. Due to the vulnerable communities engaging with DramaWay, the participants, families and facilitators opted to conduct all classes and productions online. Additionally, I connected with Epilepsy Toronto to speak with their administration and to discuss their work in the community directly. The organization was first brought to my attention 13 years ago when I first received epilepsy knowledge and safety training when I was preparing to assist clients who had a diagnosis of epilepsy. Through Epilepsy Toronto, I was able to speak to many people who had specific experiences with epilepsy, which helped me develop the foundations of the film as an effort to highlight the uniqueness of each person's experience vs. diagnosis. Although this was a good connection to develop the context of the film, it was not where I eventually found my collaborators.

Finding Collaborators

As discussed, at times, the process of making a documentary is fluid and emergent, and this was the case with identifying the subjects and collaborators of *Each Brain*, Melanie and Hana. After becoming open to other ways of making the film given budget limitations, it was extremely fortuitous to connect with two women, both diagnosed with epilepsy and both artists in their own right. It quickly became clear that they were best positioned to represent their own experiences as we co-created the film.

Melanie Taddeo-Nxumalo is the director of a charity which assists people with disabilities in accessing training in radio and broadcast. With Melanie's loss of sight after her stroke at age 21, she looked to redefine her impact on art and the disability community by offering an audio-based program. We met when her organization moved into our shared workspace when I was working in social services delivering film and media workshops to professional adults seeking employment. We became fast friends and were able to connect on many levels.

Melanie's interest in my concept for this abstract documentary was instant. She suggested that she could be involved and I was elated. We spoke at length about her background and her experiences before we sat down to record her story. Fortunately, we recorded this initial component of the film prior to the onset of the pandemic. For her health and safety as advised by her medical team, during the pandemic, Melanie was in consistent isolation with her husband. Despite this, Melanie and I stayed connected throughout the pandemic and worked closely as we experimented with writing her story to emphasize different aspects.

I was introduced to Hana Kujawa through a colleague in the Master of Fine Arts program. I was giving my update presentation during the Graduate Symposium, and my explanation of the kinds of collaborators I was looking to be connected with drew the attention of a student who had worked with Hana in the past. Hana is a photographer from Alberta and has produced pieces of work around her experiences with acquired disability and epilepsy. Hana and I met online in late 2019 and instantly connected on the discourse and vision of the film. She and I exchanged frequent emails on our respective artistic endeavours, including *Each Brain*. I knew Hana fit into the collaborative relationship I was looking to obtain through this process instantly, and we

worked to collect audio of her story. Hana had extensive artistic material and let me into her world and experience with ease. I also introduced Hana and Melanie as part of the storytelling process, and Hana's recorded correspondence formed part of the audio of the film.

Crafting the Visual Fabric

The dynamic approach and meaningful collaboration in developing *Each Brain* were further present in the decisions regarding visuals for each subject's story, as was the need to be flexible because of the limitations of the COVID-19 pandemic. After getting to know Melanie and Hana, our early collaboration focused on the story and audio components of the film. I still had not arrived at a final decision regarding a director of photography. When the time came, the visual components of the film were co-created in a way that was distinct for each subject, while striving to create a complementary final product.

For Melanie, we had intended to film in the art department at York University where she had studied visual art. This period in her life was also when she developed the acquired disability described in the film. Since Melanie had not painted since her senior year at York, we had together envisioned we would craft a timelapse of her return to the canvas. Although this was a fear-inducing thought to Melanie who has long felt that the "visually creative" element of her brain had gone along with her stroke and subsequent disability, she was also simultaneously excited to reconnect with this art form. Unfortunately, the risks of the pandemic made this unfeasible for *Each Brain*. However, given the personal significance of the concept, Melanie and I are committed to creating this separately when it is safe to do so.

As an alternative, Melanie and I worked together to pair aesthetic stock and found footage to align with her story. Melanie and I would discuss her remembered experience, the textures and fragments of lights she experiences as a person living with profound vision barriers. I worked to capture this through any content that the editor and I could source, and at times put together abstract shoots where I could film a variety of techniques and lighting to articulate the abstract nature of her vision experience.

For Hana, her experience as an artist and photographer meant she could choose and create the visuals to accompany the story. She sent audio, video and photography from previous installations, her experiences in childhood, and her experiences in the hospital as she navigated her diagnosis. In addition, she was able to create custom content specifically for *Each Brain*, to ensure the visual story was an accurate representation of her experience.

Through collaboration, I was able to work with both Melanie and Hana to ensure their input and perspectives were captured in all aspects of the film. While I still see where my original vision of animation could have fit into *Each Brain*, I have since come to accept and appreciate the way this film came together.

Post-production

I had worked for nearly one and a half years with an editor who helped to clarify the vision for *Each Brain*. However, she moved on from the project for personal and professional reasons. From this version, I hired Marrissa Wheler to finish the film. Marrissa's work was prompt and expertly executed. Our connection was clear and communication was key as we only worked

together virtually, through phone calls, video calls and Zoom meetings. In many ways, Marissa was an art director as well as a director of photography, in that she was critical in connecting imagery with audio, which in this film did not take place through traditional cinematography but rather by weaving imagery with the story to establish cadence and tone.

In terms of challenges, the audio was a concern from the start. Based on my experience in film and audio production, including podcast production, I was acutely aware of the difficulties with recording over Zoom. To mitigate this challenge, I provided both Melanie and Hana with microphones and did a workshop with them on how to record so we could maintain as close a continuity of recording quality and texture as possible. This worked very well. The film's music was an evolving soundtrack which carried over from the earlier edited version of the film. The end result was mixed and mastered by Graydon James who ensured there was cohesion with the separately recorded tracks, as well as the recordings of the sounds of seizures from Stanford University.

We integrated these recordings of the sounds of a seizure into key scenes within the film. This highlighted this intersection of science and art, with reference to the medical field while not taking away from the art and storytelling.

Distribution Plan

I see this film working in smaller festivals that accept more abstract pieces. The current length of the film may inhibit its programming future; however, the film is meant to be shared for advocacy purposes related to representation and lived-experience with disability. Distribution could be considered through smaller buyers looking for advocacy and feminist-focused content, or within a social impact category on a platform like CBC Gem. Festivals like the shorts category at TIFF, ReelAbilities, and Rendezvous with Madness may also be a possibility for festival submissions.

Ethical Issues

Accurate representation and participation were key ethical issues in the development of *Each Brain*. As noted, mainstream media has historically had poor representations of people with a range of disabilities (Davis 2017, Thrower 2013). For example, the wildly popular TV show *Glee* has a particularly problematic representation of a wheelchair user. In addition to casting a non-disabled actor to play this character (Artie), in one episode he is gifted leg braces which enable him to walk. Prior to this episode, there is an intricate dream sequence which shows Artie dancing without the use of a mobility aide. The combination of these plot devices highlighting Artie's and the audience's perception of self-worth being so connected to his ability to walk is an ableist view of disability.

Fortunately, there have been significant improvements and reflective approaches by writers, producers, directors and filmmakers within film and television when it comes to the representation of persons with disabilities (Wilde 2022). My approach to filmmaking includes the belief that those with lived experiences should be heavily involved in the structuring and design of the narratives and content created when those pieces are woven together to make a film like *Each Brain*. This ethical imperative impacts every stage of production, for the better.

Another ethical consideration I navigated was the importance of representation. Inspiration porn can be defined as “(a) an image of a person with visible signs of impairment who is (b) performing a physical activity, preferably displaying signs of physical prowess, and is (c) accompanied by a caption that directs the viewer to be inspired by the image in question.” (Grue 2016, 839). It is an informal term which denotes the portrayal of people with disabilities as being

inspirational to able-bodied people, on the basis of their life circumstances. With this in mind, it was crucial to consider the matching of imagery which was not shot uniquely for use in this documentary. Consciously, the editor and I did not want to pair images initially that would intentionally or perhaps more importantly unintentionally elicit emotions derived from the circumstances of the subjects pertaining to their acquired disabilities.

Although this piece set out to represent persons with disabilities accurately and to involve subjects who identify as persons with disabilities in the making of this film, ethically I was faced with a version of representation which I was not equipped to take on. Though I am not a person with a disability I worked closely with those who appeared in the film to identify experiences and capture the way in which these would be converted into a film. Conversely, when setting out to make this film I connected with a potential subject who brought an entirely different perspective to the subject matter. This individual, who I will herein identify as “K” in order to preserve his anonymity, was a person of colour as well as a person with a disability. K was at first eager and interested in participating in the film due to the fact that he was also a visual artist. K had grown up in West Africa and experienced extreme bias and religious persecution because of his Nystagmus, a condition that affects the eyes, as well as a diagnosis of epilepsy. K’s experience with a disability was entrenched in mysticism and religious intolerance. As this was central to the theme I wished to explore, I ensured early on in our discussions that we would explore the story together but predominantly through his recollection of experiences with his explicit and complete discretion.

Eventually, as K provided a deeper explanation of his past and the traumatic events where his community performed exorcisms on him due to beliefs which stemmed from religion vs. science-based understanding of his conditions, he was concerned that sharing his experiences would lead to misunderstanding and further biases against his culture. While I assured K that he would have complete control over his story audibly and visually, he was not interested in pursuing the film any further. Although this was somewhat disappointing at the time, I decided not to include the notion of this cultural and religious practice relating to epilepsy and the mysticism that surrounds it in the film. That is not my story and not my culture. Representation is often about what is seen reflected through media, however, an element of representation is also related to the stories which are untold by those who do not have the agency or right to engage with the content. In this specific context, I was a white, secular cisgender woman looking to explore a culturally complex experience. Once K's involvement was removed, the pursuit of this aspect of the story ended. This was a conscious act of allyship and acknowledgement that despite its existence, not every story is a story for me to document, capture or tell through filmmaking.

Conclusion

Each Brain was a challenging film to make. At many points in production, the odds felt stacked against us - while in most artistic endeavours there are difficulties and unforeseen issues, the context of the COVID-19 pandemic made this experience and its challenges distinct. We overcame our challenges in part by leveraging technology like Zoom and sharing and providing instruction on new equipment, but it was the relationship of collaboration and trust that was ultimately instrumental in achieving our shared objective of capturing the stories of these two women in a genuine way.

There were many experiential parallels throughout the making of this film. For instance, the situational isolation in which we were operating, within the context of a global pandemic, was not dissimilar to some of the experiences of Melanie and Hana through the early days of their journeys with acquired disability. We were collectively embarking on creating within confines and circumstances none of us had before. In some ways, this was freeing to have few expectations, and embrace the at times chaotic and untidy process, in pursuit of an authentic form.

When approaching this content from an ally perspective and working with the content available and created by the subjects, it became clear that while non-typical, this production style and method can produce a thorough and intimate look at the experiential subject matter. With an emphasis on representation and “nothing about us without us,” I focused on input over direction, and collaboration over a concrete vision. In this way, *Each Brain* achieves a distinct framework

for creating cinema through genuine collaboration and highlights the possibility of documentary filmmaking with interabled partnership and allyship as the driving force.

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Appendices

Appendix A: Audio Description with Melanie Taddeo-Nxumalo:

[Link to audio description content recorded with Melanie and Lizz October 2022](#)