Unmasking Brain Injury

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Abstract
Due to recent medical advances, individuals suffering from Traumatic Brain Injuries (TBIs) now have a much higher survival rate; however the number of programs and facilities cannot meet the needs of this population. With increasing awareness of the long term implications of this injury, more resources will ideally become available for individuals enduring a sustained TBI. This semester I worked with Hinds Feet Farm, an Asheville organization and facility that seeks to understand and support individuals living with a TBI. At Hinds Feet, individuals have the opportunity to spend their afternoons in a safe, reassuring, and encouraging environment. Over the course of the semester, I worked on a project called Unmasking Brain Injury, which allows individuals who have experienced a TBI to express their injury and journey through an artistic outlet. In North Carolina alone, the Unmaking Brain Injury project has distributed over 600 blank masks, and collected over 200 completed masks. My engagement in the project involved working one-on-one with individuals at Hinds Feet Farm, as well as the Crumley House to create masks and injury descriptions, which represented their voices and stories. Beyond my involvement helping clients make the masks and arranging and displaying the masks at events, the final product I created is a poster representing the masks made by individuals with a TBI. This product is one that can be sold at events, in order to raise money for the project, as well as to continue to increase awareness surrounding this issue. This final poster product was encouraged by the director of Hinds Feet Farm, as a way of continuing to circulate the powerful message within the Unmasking Brain Injury exhibit. Through this process of assisting in the creation of masks and working on the final poster product, I have begun to realize the power, potential, and importance of these individuals having this voice to raise awareness and change within our society.
Background/Origins of the Project

In the United States, 1.7 million individuals suffer and sustain a Traumatic Brain Injury (TBI) each year and 1.4 million are treated medically and then discharged, where the journey to recovery begins.¹ According to the Center of Disease Control and Prevention, 5.3 million individuals live with a disability caused by a traumatic brain injury.² These eye opening statistics demonstrate the prevalence that this injury has within our population. Although many injuries go unrecognized, the following chart presents data, which exhibits the ways in which documented TBIs are obtained. The two most common documented causes being falls, followed by motor vehicle accidents.³

![Figure 1. Leading Causes of Traumatic Brain Injury Within the United States.]

As stated in the *Journal of Head Trauma Rehabilitation*, “Even mild TBI, including concussion, can cause long-term cognitive problems that affect a person's ability to perform daily activities and to return to work. As a result of these consequences, TBI is one of the most disabling injuries.”³ Traumatic Brain Injury will continue to affect our population, and it is our responsibility to continue to raise awareness in order to improve treatment options for those who have endured this injury.

In recent years, there has been a substantial rise in brain injury awareness, and the potential implications it has for individuals. As Amy Zellmer acknowledges in her book titled *Life With a Traumatic Brain Injury*, this injury has been recognized through “professional sports lawsuits, to NASCAR drivers, to our troops returning home.”⁴ She continues by expressing, “The long age of silence that surrounds brain injury is coming to a close.”⁴ Although the recognition of brain injury as a serious issue is beginning to gain momentum, it is crucial that this awareness goes
beyond statistical values and that we strive to understand the voices of those experiencing this trauma. When Amy Zellmer published her book, she received hundreds of emails, thanking her for expressing her journey in an articulate manner in which they were not able to. These gracious mementos allowed Zellmer to realize the power her story had in eliminating the disconnect between loved ones and those who have experienced a TBI. She voices this idea by stating, “They were sharing my story with their family and friends so that these people could better understand what their loved one was going through. It was at this point that I knew I had stumbled onto something. There was a huge void in the TBI world, and I could use my words to help fill it.” Zellmer’s story not only speaks to those who have endured a TBI, but it also works to eliminate the preconceived notions and stereotypes which surround the “invisible injury”.

Due to misconceptions surrounding brain injury, stereotypes are projected onto this population, subsequently leading to the perception of individual’s character and capabilities being skewed by their disability. This idea is exemplified in a qualitative study conducted by the US National Library of Medicine, which focuses on “One Adult’s Reflections on Social Interactions After a Traumatic Brain Injury Sustained as an Adolescent”5. Within this in-depth qualitative piece, researchers analyze and extract themes from participant Kevin’s journal entries over the course of two years. Within these entries, Kevin expresses a social disconnect which he began to notice after his injury: “I feel that because of the head injury other people, mostly relatives and those who don’t know me or just met me, treat me like a small child.” Throughout this piece, Kevin attributes his loss of social status, and extreme isolation to his brain injury. Kevin's journey and experiences further demonstrates how individuals with a traumatic brain injury are at risk for being defined by their impairments, impacting their social interactions, and increasing their risk for isolation.

Although it is important for survivors to relate and connect to other stories and experiences such as Kevin's and Amy Zellmer’s, it is also significant for all individuals who have suffered from a Traumatic Brain Injury to have the opportunity to express their own story. Unmasking Brain Injury is a national project that invites individuals with TBIs the opportunity to artistically express their journey through life with a sustained traumatic brain injury. Blank masks are distributed to various facilities across the United States, where individuals have the ability to share their thoughts, emotions, and feelings surrounding their injury. As Robert Kegan states in his book titled The Evolving Self, “what is most important for us to know in understanding another is not the other’s experience, but what the experience means to him or her”.6 This project allows individuals to have a voice, and express how their injury has impacted their day-to-day life, health, and happiness. When working one on one with these individuals at Hinds Feet Farm as well as the Crumley House, the majority of the individuals expressed genuine excitement, and gratitude when informed that their creations would be displayed at various exhibits. This is an opportunity for their story, struggles, as well as grand achievements to be shared and valued. In addition, this project encourages individuals to come face to face with obstacles, hardships, as well as successes, which have stemmed from their injury. This form of therapy is a release for individuals, which allows them to recognize that their story is appreciated.

Below, are three examples of masks made by individuals at facilities located in North Carolina. Each mask uses colors and images to represent an individual’s experience and journey through life with a traumatic brain injury. I have also included a description, which is made with every mask. This includes, an explanation of the injury, as well as an opportunity for the creators to reveal how their experience with a sustained TBI is depicted through their mask. When viewing
the masks it is clear that each product changes significantly depending on the experiences and journey the creator has faced. As a result of this, it is imperative that when instructing participants, we reinforce the notion that there is no right or wrong way to exhibit self-expression.

![Examples of Masks](image)

Figure 2. Examples of Masks

Brain Injury: **Fall at age 4**
Explanation of Mask: **Hands over my mouth representing my shame, being torn, afraid, unwanted, and sadness. Glitter for my sparkling personality, and stars to show my desire to be a celebrity.**

There are multiple reasons for my desire to get involved with this particular population. This past summer, my younger brother was in a serious car accident and suffered from a subdural hematoma. Although my brother is making a great recovery, it initiated an interest for me to get involved with individuals who have greatly suffered from head trauma. Through this experience with my family, I feel as though I have a new perspective on traumatic brain injury and how it directly and indirectly impacts individuals, friends, and family members. In addition, through my experience with my brother, I have had first-hand experience in the limbo stage individuals face after being discharged from the hospital and are in desperate need to find medical and emotional services. This need for support and services post injury is recognized within *Journal of Head Trauma Rehabilitation* where it states “anecdotal reports and the limited research to date suggest
that the ‘invisible disability’ that persons with cognitive but not obvious physical problems experience poses unique problems for persons with TBI in accessing health services and maintaining a healthy lifestyle.” Due to the lack of awareness from health care providers, these barriers and obstacles faced by families and individuals experiencing brain injury are not being met. The facility I worked with in this public service project is Hinds Feet Farm, located in Asheville, North Carolina. Hinds Feet Farm is a day program devoted to working with people who have sustained a traumatic brain injury. This program works to understand, engage, and motivate individuals in a welcoming and secure environment. In reference to their experience with Hinds Feet Farm, an individual stated, “right when I walked in the door, I felt so welcomed. Everyone was so real, honest, funny, and relaxed; you couldn’t help but feel at home.”

Hinds Feet Farm provides a holistic approach when assessing and treating those who have experienced a traumatic brain injury.

Prior to meeting the director of Hinds Feet Farm, I initially met the members, who were doing a balance workshop on campus. I began talking with them, which led me to learn about Hinds Feet Farm. From there I did research on the facility, and soon emailed the director, Erica Rawls, where I explained my interest in working with Hinds Feet Farm over the course of the spring 2016 semester. When I met with Erica in December of 2015, she expressed the desire for me to get involved with the Unmasking Brain Injury project by helping with exhibitions, as well as assisting individuals in creating masks. In addition to creating and presenting awareness masks, I have also been working to create a poster, which can be sold at events in order to raise money for the project and organization. This poster represents the stories, which are connected to each and every mask, and allows awareness to be spread in schools, community centers, and homes.

**Methods and Work Undertaken**

Throughout the semester I have had multiple meetings with the director of Hinds Feet Farm, which have been focused on creating a timeline, as well as discussing my role within this project. Over the course of the semester, I had the opportunity to assist in the creation of masks, work at exhibits displaying the masks, as well as to create a poster in order to raise money for the project and brain injury awareness. These different roles allowed me to push myself, and grow as an individual as I set and pursued the organizations goals.

**Making Masks**

In February of 2016, I spent a day in Johnston City assisting individuals at the Crumley House to create a mask paired with a description of their creation. This aspect of the project allows individuals express how their injury is represented through their mask. Before meeting with these individuals I went over the manual, which led me through the process of guiding this project. Prior to assisting with the creation of masks at the Crumley House, I was able to meet with the director, as well as other volunteers where I explained the project and communicated the process, outlined in the manual, of leading and directing individuals. I conducted a similar process in the first week of March when I assisted individuals at Hinds Feet Farm design and construct their mask and description. In addition to assisting with the creation process, I also typed and formatted all handwritten descriptions made by individuals at The Crumley House, as well as Hinds Feet Farm. These write-ups were then sent to the director of Unmasking Brain Injury who arranged for masks and description to be plastered to a black backdrop, ready for presentation. From this experience I was able to learn how to understand individual’s capabilities before
making assumption of what they may or may not need help with. For example, with each individual I would show them the list of descriptive words that could be used to express their personality, journey, injury, etc. In some instances, individuals would need little to no assistance in circling words they connected with. However, with other participants who were either non-verbal, easily distracted, or benefited from extra assistance, it was necessary to guide them through this process. One individual was nonverbal, therefore I would show each word and wait for a head motion to signal me to either circle or move on to the next adjective. Through this process we were able to communicate and work together to create her mask. For other individuals it was necessary to gently remind them to stay focused on the task at hand. By working on the creation stage with participants, I quickly realized the importance of understanding an individual’s capabilities before making assumptions on how to guide, and assist.

Exhibitions

On March 12th, I had the opportunity to travel to the Brain Injury Awareness Ball, also known as the Checkered Ball in Charlotte, where I presented the Unmasking Brain Injury exhibit to hundreds of individuals. Prior to the event I met with the program coordinator to review expectations and guidelines. I also reviewed statistics and data regarding the project, in order to effectively present the exhibit. At the awareness ball I was expected to explain the project, its significance, and answer any questions individuals may have. In addition to assisting individuals in creating masks, and presenting the exhibition, I have been working with UNC Asheville to set up an exhibit on campus. Due to the short timeline, this exhibition is not one that is foreseeable during the spring semester, but instead during the fall of 2016.
Final Product:

The final product I am creating is an *Unmasking Brain Injury* poster, which can encourage an open dialogue surrounding traumatic brain injury. This poster will potentially be displayed at exhibits, and events, and can be sold to raise money for brain injury awareness. In addition to raising money for the cause, this poster is suitable to be displayed in homes, schools, and community centers in order to promote change surrounding how we view, interpret, and connect to members of the community. On the poster is a quote by Robert Kegan, “What is important for us to know when understanding another is not the others experience, but what the experience means to him or her”. The quote encourages individuals to recognize damaging assumptions that negatively impact this population of people. This poster is simply one more step towards eliminating the gap between perceptions of people with TBI and their reality. This movement is created through tools such as this poster which will spark a conversation about the project and convey to the audience how valuable one’s voice is.

Below is the rough draft version of my *Unmasking Brain Injury* poster, which was created using illustrator, as well as Photoshop. I initially created a rough paper version of this, and from there my images came to life in the design lab at UNCA. At the time of writing on this paper, I am still working to finalize this poster.
In months to come, I plan on continuing my involvement with Hinds Feet Farm, by creating a 2017 calendar which will display finished masks. I also plan on attending future conferences, and events where I will share my knowledge and experience working on the Unmasking Brain Injury project.
Challenges Faced and Responses to those Challenges:

While working on this project I faced three major challenges. These challenges included giving directions and efficiently explaining the project to individuals during the creation stage, lack of skills when making the poster in illustrator, and time management when balancing commitments.

I found that when I attended the Crumley House, I initially struggled to explain the project in a concise yet effective manner. With some individuals it was evident that my wordy explanations sufficed, however other times it was necessary to be meaningful with my word choice, and show visual examples to support my directions. Although I was familiar with information regarding the project, I wasn’t prepared to change my language depending on the individual I was working with. During my time at the Crumley House, I quickly realized that I needed to adjust my strategy in order to effectively convey directions. This led to an increase in visuals, such as using the example masks, as well as asking individuals questions in regards to what they may or may not need help with. I quickly overcame this challenge, due to the fact that I tweaked my technique in order to meet the population.

Another challenge I encountered while working on this project was my unfamiliarity with graphic design. For my final product, I decided to create a poster, which required the use of illustrator as well as Photoshop. Although I am unaccustomed to both of these design tools, I was able to work with teachers in the design lab who were able to guide and assist me in the process. Although these challenges seemed daunting at the time, I had the capability to effectively overcome them in a sufficient manner.

When working on this project I came across challenges when trying to manage brain injury awareness events and my academic schedule. This challenge arose multiple times due to the fact that I have been attempting to balance this project, with my job, as well as my class schedule. Although this was an obstacle I faced, I was able to establish open communication with the director of Hinds Feet Farm, in order to effectively discuss scheduling conflicts.

Project Outcomes & Sustainability

Working with this population has encouraged me to pursue a career with individuals who have endured a traumatic brain injury. The work I have done with this community has led me to feel inspired by the determination, optimism, and true gratitude exhibited by the individuals I had the opportunity to get to know. Not only do I hope to obtain a job within the field of traumatic brain injury, but I also plan on continuing to spark the conversation concerning the power of one's voice. In Chimamanda Adichie’s speech titled The Danger of a Single Story, she states “Stories matter. Many stories matter. Stories have been used to dispossess and to malign. But stories can also be used to empower, and to humanize. Stories can break the dignity of a people. But stories can also repair that broken dignity.” By allowing those who have experienced a traumatic brain injury to express their own experiences, we can begin to understand how each individual is touched by brain injury in a different way, and from there we can understand brain injury on a continuum, as opposed to a single statistical value.

Due to the momentum, and attention Unmasking Brain Injury has received, the sustainability of this project is very likely. This project was recently presented at Capitol Hill, as well as at The Intermountain Brain Injury Conference hosted by East Tennessee State University. By opening these events with this powerful project, it encourages a greater understanding concerning the magnitude traumatic brain injury has on individuals. As a result of the positive feedback this
project has received over the past year, I am confident that it will continue to be presented at various events, and locations. This will further the conversation, and increase support and awareness surrounding the influences of traumatic brain injury. In the future, I sincerely hope that UNCA students will express an interest in working on the *Unmasking Brain Injury* project through partnering with Hinds Feet Farm. As the faces of the future, students play a significant role in initiating change, especially in regards to treatment options and available resources, specifically for those who have endured a TBI. An article titled “Attitudes and access: advancing the rights of people with disabilities” discusses the importance in changing the attitude towards people with disabilities by establishing programs that work to understand the individual: “Family physicians and other professionals must work with communities to change the attitudes, beliefs and behaviors of policy-makers and the public. Until significant progress is made on this front, problems of access that serve to marginalize people with disabilities will persist."\(^1\) *Unmasking Brain Injury* is one example of many which works to diminish these false perceptions and unwarranted attitudes which subsequently negatively impact treatment and care options.

Through working on this project, I’ve had the opportunity to connect with a population and an issue that is personally important to me. Growing up with an older brother with Autism, as well as having my younger brother endure a traumatic brain injury in 2015, I have a deep and meaningful passion for working with people who have a disability. This personal relationship to the cause had led me to truly value and recognize the importance in the work I have conducted with Hinds Feet Farm, as well as initiated my journey in looking for potential career opportunities within the field. Working on this project with Hinds Feet Farm has improved my ability to teach and effectively communicate information, as well as further led me to realize my passions, therefore influencing my future career path.

**Ties to Academia**

Through this project I have had the opportunity to learn and understand how traumatic brain injury has impacted people on an individual level. In order to fully understand traumatic brain injuries, it is crucial to listen to how the injury has impacted each and every individual in a different way. The experience also has connected my academic courses and professional interests to broader issues in our society.

As I've studied in my UNCA classes, a population's identity can potentially be influenced by outside community members. This construction of identity can have an impact on self-worth and self-perception. An example of how this misrepresentation can affect group identity was the focus of my senior seminar class project, as well as my undergraduate research. I studied how the perceived identity of the Native American population has shifted due to the influence of Westernization. Lucy Ganje, professor at the University of North Dakota, and an author of a chapter within *Images that Injure Pictorial Stereotypes in the Media*, discusses the consistent and damaging stereotypes that continue to surround the population. Ganje begins by touching on the misrepresentations of the Native American community, and how these distortions are displayed through sports team names, mascots, toys, media entertainment, and corporate iconography, such as food, clothing, automobiles and alcohol.\(^2\)

Although this public project focuses on a different population and different reasons for social exclusion, it is concerned with the elimination of barriers and misunderstandings experienced by individuals with a sustained traumatic brain injury. These distortions can be internalized and contribute to further health disparities. As stated in the *Journal of Head and Traumatic
“Traumatic brain injury can result in long-term or lifelong physical, cognitive, behavioral, and emotional consequences.” These long-term effects can impact an individual’s ability to perform daily tasks, as well as obtain a job. Discussed within the *Journal of Applied Research in Intellectual Disabilities*, access to preventative care is reduced for individuals with a disability. This idea is further supported in the *Journal of Head and Trauma* article in which the authors state, “A recent population-based study indicate that from 1 to 3 years post injury, compared with the general population, people with TBI are 1.8 times as likely to report binge drinking, 11 times as likely to develop epilepsy, and 7.5 times as likely to die.” Results also show that individuals who have experienced a TBI show a 1.5 increase in their risk of developing depression. Due to the lack of awareness surrounding this invisible injury, the needs of this population are not being adequately met. Until healthcare providers begin to understand the potential lifelong impacts TBI has on individuals, these disparities will continue to disproportionately target this population.

This project also relates to a class on Mental and Emotional Health, which delved into the social stigmas, attached to mental health conditions, and how these negative connotations and stereotypes impact the health and wellbeing of these individuals. Again, although this course emphasizes a different societal group, it is connected to a similar notion of the impact that preconceived ideas have on the health, and happiness of individuals. This project targets those stigmas, and focuses on accurately informing the public of how a traumatic brain injury can potentially forever affect individuals, however it does not define them. Not only does this project allow for individuals voices to be heard, but it's also informative, and works to encourage acceptance, among our society and community members.

Through my experience at UNC Asheville, I’ve had the opportunity to learn how organizations engage the community in order to gain awareness, and momentum surrounding a cause. Through education and advocacy, the intended population can gain empowerment over their health and happiness. By initiating discussion, welcoming volunteers, and reaching out to the community through media and events, organizations can begin to gain awareness, spark conversations, and raise funds that are designated towards support of the population and program of interest. By establishing an organization within its designated community, it allows for support and encouragement, leading to movement towards the goal of the specific organization. When enrolled in a community engaged course at UNC Asheville, I had the opportunity to volunteer with Girls on the Run, where I taught lesson plans, as well as encouraged elementary school girls as they worked towards achieving their fitness, and nutrition goals. Each semester, Girls on the Run hosts a 5k run/walk within the community. This event is one way in which this organization was able to create community support, as well as raise awareness surrounding the health and happiness of girls. In addition, this event empowers this population by establishing a goal in which participants are able to work towards and ultimately achieve. This is one example of many where organizations are able to raise funds and awareness, while promoting the health of a specific population through self-empowerment. In order to continue self-empowerment for a specific population, awareness surrounding the cause needs to remain constant within a community. This allows for future generations to further be informed, and educated of the proposed cause, which promotes the continual health of an intended population.

As a health promoter and through reflection, I have confirmed and challenged some of my pre-existing ideas while working on this project. During my time at UNC Asheville I have placed an emphasis on the importance of preventive care, and how crucial it is to foresee an illness, injury,
or disease before it targets an individual. Although, I still believe this to be true, I have also begun to recognize how in some instances care post-injury, -disease, or -illness is equally as valuable. Although there are absolutely important preventive measures to enforce in order to decrease traumatic brain injuries through car accidents, falls, violence, etc., I have realized that there is also importance in assisting individuals who have endured the injury. Part of this is due to my personal connection to those who have experienced a traumatic brain injury, or have a disability. In addition, I agree with the idea that no matter the level of preventive care, brain injury will continue to impact individuals through many different means, and as a health promoter I have decided to assist, guide, and support this population as they are facing struggles, and conquering obstacles.

Conclusion

This project with Hinds Feet Farm may bring us one step closer towards improving care, and treatment options for individuals with a sustained traumatic brain injury. Through this project, I have further recognized the importance in assessing and understanding an individual before projecting potential misconceptions, and assumptions. By working with Hinds Feet Farm, I have assisted in the progression of the project *Unmasking Brain Injury*, and have provided a poster that will be sold at events to raise awareness and support the cause. Further, the project has initiated my journey to spread awareness surrounding brain injury, which will persist as I sustain my work with Hinds Feet Farm and continue my involvement with the community.
References


