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MENTAL HEALTH MEMORIES: A WEB-BASED ARCHIVE FOR MENTAL HEALTH STORIES

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MENTAL HEALTH MEMORIES: A WEB-BASED
ARCHIVE FOR MENTAL HEALTH STORIES

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Arts
in
Social Sciences and Globalization

by
Amanda Elizabeth Castro

June 2017

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Approved by:

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ABSTRACT

The *Mental Health Memories* project is an online archive created in order to display and preserve the personal histories of those with mental health experiences. The project aims to fill a void in available material culture related to the history of mental health and its preservation. Participants' contributions include: oral histories, personal items, documents, and audio. Bringing together multimedia sources, the MHMemories website allows for the preservation of these items and stories through the digitization of contributions. This method allows for participants' items to stay in their possession while also becoming part of the archive. In order to recruit participants, the *Mental Health Memories* project teamed up with the Psychiatric Stories Archive, based at California State University San Bernardino, and the San Bernardino County Behavioral Health Clubhouse. Three collection days facilitated the gathering of materials. The final product is the MHMemories.org/.com website which showcases the contributions of participants. The *Mental Health Memories* project helps to illustrate the diversity of mental health experiences.

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Having the opportunity to create a resource for future researchers and those interested in the history of mental health has been the most fulfilling experience of my academic career. I would like to thank Tiffany F. Jones who was both my advisor and also the founder of the *Psychiatric Stories Archive*. Without Tiffany's guidance in understanding the complexities of the history of the mad, I, nor those who contributed, would not have had such an opportunity. I would also like to thank the Graduate Coordinator, Cherstin Lyon, for her patience and guidance in all of my academic endeavors for the past five years. The financial support I received in 2016 from the Graduate Studies Office allowed me to travel to Baltimore, Maryland for the National Council on Public History Conference which enabled me to explore other projects in the field and shaped this undertaking greatly.

DEDICATION

To Mary Figueroa, Katherine Edwards, Tracy Lopez, Nicolas Ellis, Emily Ellis,
and Hunter Campbell.

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CHAPTER ONE

INTRODUCTION

The *Mental Health Memories* project was developed to fill a void in resources available that represent the mentally ill within historical discourse. Those deemed mad or those who define themselves as mentally ill have countless experiences that have been captured in oral history projects with little to no other resources being used to document their personal histories. As a history based project, the goal is not to assess the subjects' mental state but rather to document their conscious contributions and stories.

There is a negative stigma that surrounds those with mental illnesses. One way to fight back against the perpetuation of these negative stereotypes is by those with mental illness telling their stories of everyday life and in some cases treatment. This multidimensional approach allows for participants to individually contribute to the collective story of the mad throughout history. In order to understand any portion of participants' lives, it is of the utmost importance to hear their stories on their own terms. By allowing participants to share not only oral histories, but also visual, audio, and material culture, it is my hope that we will gain a more profound and heterogeneous understanding of individuals' experiences with their mental health.¹

¹ Mark Klemptner, "Navigating Life Review Interviews with Survivors of Trauma." *Oral History Review* 27, no. 2 (2000): 80.

This project focuses on the collection and presentation of personal histories, using an online format. While the online exhibit is the main component of the project, this written thesis is a supplementary exploration of the framework and challenges involved in the design and production of the exhibit. Chapter One explores the representations of those with mental health experiences throughout history. Chapter Two discusses the need for a variety of material culture to be used as an alternative way to capture personal histories and examines other projects whose format shape this project. Chapter Three outlines the steps taken to create the online layout in preparation for collected information to be inputted, discusses the choosing of participants and accumulation of information, and concludes with the process of implementing the material into its digital format. Chapter Four explores the future of the project, as well as, offers concluding thoughts and recommendations to those who plan to create a similar project.

Historiography and Literature Review

The history of “madness” is a field of study aiming to understand the concept of madness throughout history and how various social and political forces affected these concepts. By understanding how the mad have been analyzed and portrayed in the past, scholars tend to give certain sources authority over others. One of the key foci of the histories of the mad has been the asylum. The development of the asylum in the 1800’s, the questioning of the

asylum's legitimacy in the 1960's and 1970's, the reliance on community care and the transformation from asylum to mental hospital beginning in the mid 1900's are the three major transformations that affect literature produced about mental health. With this focus on the institution, writings on the history of psychiatry tend to focus on psychiatry's development into a recognized field of practice starting with Europe's first psychiatric hospital, Bethlem, in 1403. When patients were mentioned in these histories, it examines how people under psychiatric care were diagnosed and institutionalized.² The history of psychiatry asks why these designations and institutions were created in the first place and how they remained in use for such a long period of time.

During the 1800's representations of the mad centered on the asylum experience. Analysis of autobiographical sources act as evidence and justification for their admittance to asylums and for a means to promote the asylums necessity. "Illustrations of Insanity Furnished by the Letters and Writings of the Insane," published in the *American Journal of Insanity* in 1848 is an example of the ways in which the mad were depicted, using their own words as evidence of madness. Written by an unidentified author, it presents correspondence and personal writings from patients housed in Utica Asylum, by the name of N.Y. in 1847. Mr. N.Y.'s letter to the governor, for example, explain

² Edward Shorter, *A History of Psychiatry: From the Era of the Asylum to the Age of Prozac* (New York: John Wiley & Sons, 1997), 4.

his need to be discharged. He states Almighty God and the fulfillment of scripture as reasons for his attempted burglary.³ T.C.L.'s letter to his father cite the "pleasant times" he has at the asylum.⁴ Publications such as these use the direct words of the mad, with additional commentary on their diagnosis, as a disclaimer to shape the reader's perception of the patients sanity and life inside an asylum.

In order to survey the inner workings of the asylum, Elizabeth Jane Cochrane Seaman, a journalist working for a paper titled *World* faked mental illness in 1887 in order to write about her experience within the Insane Asylum on Blackwell's Island, New York. Changing her name to Nellie Brown she was admitted and housed for 10 days within the asylum. Her experience with supper, bathing, promenading with lunatics, and violent patients are among the topics explored. In this exposé she highlights the negative experiences of the asylum. Seaman speaks of Tillie Mayard, a patient who had a cold from the harsh conditions of the asylum, whose treatment worsened while sick. Seaman recalls:

I watched the insanity slowly creep over the mind that had appeared to be all right I secretly cursed the doctor, the nurses and all public institutions. Some one may say that she was insane at some time previous to her consignment to the asylum. Then if she were, was this the proper place to send a woman just convalescing,

³ Anonymous, "Illustrations of Insanity Furnished by the Letters and Writings of the Insane," *American Journal of Insanity* 4 (1848): 291.

⁴ Ibid., 299.

to be given cold baths, deprived of sufficient clothing and fed with horrible food?⁵

Seaman's writings show the inner workings of the asylum while taking into account the methods in which someone is admitted to an asylum. These personal writings allow for readers to see not only the realities of the asylum, but also the opinion of the writer. In the case of the anonymous writer for the *American Journal of Insanity* it is the justification for the need of the asylum and for Seaman it is the question of whether the asylum is useful at all which drives their portrayals of the mad. Although achieving different ends, both writings center around one emphasis, the asylum.

The most influential work to ask why madness and confinement developed was published by Michel Foucault. Foucault's 1963 *The Birth of the Clinic: An Archaeology of Medical Perception* outlines the shift from various modes of care for illness of all kinds, ranging from home to community care, to care within an institutionalized setting. The creation of the clinic changed the interactions that existed in medical experiences in modern times. This new idea of the clinic came about after the French Revolution and quickly became a center for treatment that was different from the existing sources of treatment. Foucault argues that this new medical system focused on the all-seeing "gaze" which formed a different

⁵ Nelly Bly, "Ten Days In a Mad-House," *World* (New York, NY), 1887.

relationship between patient and practitioner. The patient now became the subject of the “gaze” who judged sickness and health within its own standardized parameters. This created a hierarchy of practitioner and patient, with the practitioner holding the power in the newly formed relationship. Foucault describes this creation of the “gaze” as:

So many powers, from the slow illumination of obscurities, the ever-prudent reading of the essential, the calculation of times and risks, to the mastery of the heart and the majestic confiscation of paternal authority, are just so many forms in which the sovereignty of the gaze gradually establishes itself — the eye that knows and decides, the eye that governs.⁶

The hierarchy, which came from this new clinical setting, has played a major role in views of those mediating people with mental illnesses. The majority of practitioners and the public judge those that have mental illnesses by their outermost actions. This new perception of medical care shaped one’s view of themselves along with the way their family and their community interacted with them. The fact that someone has a mental illness automatically creates what Foucault calls, “a form of a disease of the disease.”⁷ A disease of any kind being assessed in this gaze has social ramifications. With this new development came a new definition of mental illness and a new perception of where those deemed

⁶ Michel Foucault, *The Birth of the Clinic: An Archaeology of Medical Perception* (New York: Pantheon Books, 1973), 108.

⁷ Ibid., 39.

mentally ill fit within each community. Foucault's clinical "gaze" helps in the development of the "other" when discussing those with diseases and illnesses. These ideals became prominent throughout Europe and thus the western world. The relationship of the mentally ill to their community therefore was transformed.

Foucault's seminal work on madness also provides stimulus for his study of institutionalization. His 1965 book focused on confinement of the insane. *Madness and Civilization: A History of Insanity in the Age of Reason* surveyed the creation of deviant classes and their subsequent confinement in state created prisons and mental hospitals under the guise of custodial care. Foucault chooses 1656 as the beginning of this confinement, when Paris decreed the opening of the Hospital General. Foucault argues that this was not only a reform, but an administrative reorganization.⁸ This new administration now gave Paris the authority to accept, house, and feed those who were sent there. This new relationship between the capitalist needs of the state and the regulation of the population had a profound impact on deviant classes. This new power of authority over those in need of care became a way in which the state prompted the designations and labeling of deviant behaviors, which exhibited need for assistance. Whether necessary or not, this transformation in the use of national power in order to develop these designations prompted the state to categorize

⁸ Michel Foucault, *Madness and Civilization: A History of Insanity in the Age of Reason* (New York: Pantheon Books, 1965), 37.

the insane as the “other” while aiming for reinforcement of social norms. While Foucault’s work helps us understand how institutionalization and the othering of the Mad occurred, Foucault does not use the voices of patients to understand this transformation, making him more concerned about how madness was a product of state centered evaluation and control.

Highly influenced by Foucault’s questioning of the authority and power the state gained when creating these institutional settings, Thomas Szasz’s seminal work *The Manufacture of Madness: A Comparative Study of the Inquisition and the Mental Health Movement* written in 1970 argues that the designation of mental illness solely serves a social function. By comparing the concepts of witchcraft in the late Middle Ages to the development of mental illness, Szasz likens the moral and political consequences in both cases as socially driven developments. Countering medical historians’ view of psychiatry’s development, he argues that the change from heretic to mentally sick, “...happened because of the transformation of a religious ideology into a scientific one: medicine replaced theology; the alienist, the inquisitor; and the insane, the witch.”⁹ Though Szasz is not analyzing the self-proclaimed mentally ill, only those who are given the designation, his work helps bring to light how the social ideas of deviance change over time. The overarching theme of this work is that roles are social artifacts in

⁹ Thomas Szasz, *The Manufacture of Madness: A Comparative Study of the Inquisition and the Mental Health Movement* (New York: Harper & Row, 1970), XX.

all cases with the state, family, and medical professionals all playing a role in the life of the mad since the 1800's.¹⁰ The mad being a social deviant is seen as someone that is alien rather than society's chosen notion of normality. With this comes the need to validate the "Self as Normal" which invalidates the "Other as Evil."¹¹ This focus on the socially defined designations between "normal" and "other" is an important development within the field of the history of madness. The power of societal designations of mad are a reality in which people still live today. In order to give power back to those with mental illness it is important to understand how they fit within their communities and society as a whole, while also attempting to negotiate these designations.

Szasz is indicative of the major socio-political shift that was occurring in Western writings about psychiatry during the 1960s and 1970s. David Rothman cites three reasons for the shift from asylum and treatment-centered writings to ones that question the asylum's legitimacy during this period. Rothman's *The Discovery of the Asylum: Social Order and Disorder in the New Republic*, argues that the new development in the exploration of the history of the working class shed a new light on the fate of marginal men and women and the distribution of power within society. The second major shift derived from Michel Foucault. His study of confinement and madness became a seminal work in the field that, since

¹⁰ Ibid., xxvi.

¹¹ Ibid., Xxvii.

its publication, has brought focus to the authoritative power distribution within asylums in various disciplines including history, sociology, literature, and architecture. The third shift is the declining social legitimacy of institutions, citing the prison riots in the early 1970's and the writings that exposed horrible institutional conditions in both Attica prison in New York and Alabama's Bryce State Mental Hospital.¹² Working within these new parameters, Rothman contends that there were a number of forces that influenced the confinement of various deviants within the United States during the Jacksonian era, the mid-1800's. Analyzing both the prison system and asylum creation, Rothman focuses on the changing social, political, and religious aspects of society that helped to create separations within society, between deviation and societal cohesion and order. This history is argued to be a liberating discipline that is not final, a message that was well received in the 1970's. His work prompted a new focus on the legitimacy of the asylum rather than the justification for its existence. Focusing on the power of society over madness rather than on asylums' power over the mad, he shifted the power from the asylum to the people. By reviewing Michel Foucault's analysis of state power and madness Rothman's arguments become more clearly a product of a post-Foucaultian transformation of the field of the study of madness.

¹² David Rothman, *The Discovery of the Asylum: Social Order and Disorder in the New Republic* (Boston: Little, Brown, 1971), xx.

The developments of the 1960's and 1970's had a profound effect on the literature of the coming decades. A shift in literature occurred in which the patient was now given the authority to be used as a historical source. Autobiographical works of the mad took center stage as legitimate sources of historical and social developments in the history of the mad. Roy Porter's "The Patient's View: Doing Medical History from Below" written in 1985 argues for a patient centered historical interpretation that is not seen in the plethora of psychiatric history timelines and narratives. Porter uses examples of patient's medical histories from Europe during the 1600's to grapple with the lack of representation of the sufferers' role in the history of healing, which has been routinely ignored by scholars.¹³ In order to understand the complex relationship between those with mental illness and those around them, Porter argues the various interactions and the role these interactions play in their lives must become a source of study. Porter sees the development of doctor-centered care as the stage on which this power struggle occurs. He follows a historical timeline which starts with the management and treatment of sickness which remained largely in the hands of the sufferers' themselves and their social circles. The invention of doctors then became the one and only weapon available in their therapeutic arsenal.¹⁴ Porter

¹³ Roy Porter, "The Patient's View: Doing Medical History from Below," *Theory and Society* Vol. 14, (1985): 176.

does accept the point of Foucault and his school of thought that the, “modern “patient” is in some sense a fabrication of the “medical gaze,” a role scripted by the overall scenario of the medical system.”¹⁵ With this development and creation of a hierarchy, Porter sees the need for a patient, or sufferers’, history to become the central narrative that drives the study of the mad in history.

Porter also builds the argument within his writing that it is not enough for the sufferer to become the only voice used to build this history. Porter states that: “...for it is precisely the dynamic interplay between sufferers and practitioners that requires study, the tug-of-war supply of supply and demand, patient power and doctor power.”¹⁶ Although this argument is vastly important in understanding the dynamic of treatment, it should not overtake the narrative of the mentally ill. This struggle between patient and practitioner is a widely recognized struggle but is not true for all who have been designated with a mental illness. Even though there are large numbers of people with mental illnesses that seek medical help not all those with mental health experiences seek help through medical professionals. Others receive a diagnosis in a medical setting but their relationship with institutional care or clinical care is one that is not universal. In order to address this struggle between patient and practitioner there must be an understanding that this struggle is not always present in a negative way but can

¹⁴ Ibid.,182.

¹⁵ Ibid.

¹⁶ Porter, 185.

also be a positive experience for some. The complexities of these relationships are a building block upon which this project is based, and therefore it is important to include a wide variety of stories and experiences.

While Roy Porter argues for a patient-centered historical narrative, Sander Gilman's *Difference and Pathology: Stereotypes of Sexuality, Race, and Madness*, published in 1985, argues for the deconstruction of stereotypes surrounding the mad and by doing so the patient-centered historical narratives' complexities can be better understood. By addressing the issue of "othering" that is present in discourse regarding the mentally ill, its context can be a better understood. Stereotyping of the mad is harmful to the individual, as well as to the historical narrative. Sander Gilman examines the stereotypes ranging from the Middle Ages to the twentieth century, and much like Porter, focuses on Western European stereotyping which subsequently reached the United States. Those deemed mad become under the scrutiny of their communities with the development of the "clinical gaze" throughout this time period. Their actions and symptoms now became part of what define them. Since the definition of a mental illness was equal to having a disability they were susceptible to "othering."

This phenomenon of "othering" defined by Gilman is, "not merely a label (any more than is geography or skin color). It exists in reality. But the Other's 'madness' is what defines the sanity of the defining group."¹⁷ This is to say that

the defining group is now the group who has the power to define the reality of the mentally ill. This development was not able to successfully define the group but rather create generalizing definitions of the group, all of which set the group apart from the majority. This is problematic because stereotypes are never wholly representative of any group and thus lead to a misunderstanding of groups. Thus, stereotypes work to divide and categorize those as “others” who are not equal to the defining group. As Gilman explains, “the image of the dangerous Other serves both as the focus for the projection of anxiety concerning the self and as the means by which the Other defines itself.”¹⁸ When discussing those with mental illness it can become easy to fall into these predetermined narratives which follow institutionally-centered histories with no inclusion of those who experienced these historical developments first hand. In order to include the mad within this narrative it is important to understand that although all stereotypes are farfetched, they do tell truths of the defining group and their perceived image of self. Both Porter and Gilman place the mad at the center of their narratives with authority over their representations of the past.

In the 21st century, authors are taking Porter and Gilman’s work even further by using narratives as a means to take a stand as activists and advocates. Demonstrative of this, Geoffrey Reaume’s “Lunatic to Patient to

¹⁷ Sander Gilman, *Difference and Pathology: Stereotypes of Sexuality, Race, and Madness* (Ithaca: Cornell University Press, 1985), 129.

¹⁸ *Ibid.*, 130.

Person: Nomenclature in Psychiatric History and the Influence of Patients' Activism in North America" and his course "Mad People's History" are examples of framing the realities of the mad within historical context. Both sources argue the need for the voices of the mad to be the center of study. Reaume's "Lunatic to Patient to Person" chronicles the death of Edmund Yu on February 20, 1997 by the Toronto police. Mr. Yu was diagnosed as a paranoid schizophrenic. Reaume argues his death to be representative of "the attitudes of police and public transit officials...revealed the derogatory views held towards people with mental disorders as being "loons."¹⁹ His course "Mad People's History" works to break the silences that mad people endure. Reaume describes his course as not just the history of madness but rather mad people's history where the diverse ways mad people have expressed themselves can be examined and respected. Highlighting stories that range:

...from the most virulent protests by some people who insisted that they were not insane to people who argued that mental illness does not exist while others claimed that it does to people who express positions on various sides of the medical model debate, without the stark contrast of completely accepting or rejecting one concept or another²⁰

¹⁹ Geoffrey Reaume, "Lunatic to Patient to Person: Nomenclature in Psychiatric History and the Influence of Patients' Activism in North America," *International Journal of Law and Psychiatry* 25, no. 4, (2002): 405.

²⁰ Geoffrey Reaume, "Syllabus: Reaume, "Mad People's History," *HistoryPsychiatry.com*, Sep. 6, 2010, <https://historypsychiatry.com/2010/09/06/syllabus-reaume-mad-peoples-history/>.

he places emphasis on not only analyzing the stories of the mad, but also respecting the diverse concepts of madness. By understanding both the realities of the social implication being deemed mad has on an individual to understanding the complexities within the community, Reaume has become an advocate for the mad. For Reaume it is important for the mad to be heard, but also more importantly, to be respected and understood on their own terms.

With the changes in definitions of madness, to confinement of the mad, and finally to the advocacy of the rights of the mentally ill, the changes over time have affected how the mad have been discussed and portrayed. By analyzing which authors and sources had authority over others throughout these three distinct time periods, the 1800's, 1960's through the 1970's, and the 2000's, the developments in the field of the history of the madness are noticeably linked. Seeing the links between author and sources used illustrates the power sources have on perceptions of the writer, as well as, the audience. In line with recent patient advocacy literature, this project aims to add to the promotion and advocacy of patient centered and patient created sources in today's discourse about mental health.

Theoretical Methodology

In order to properly recognize the project's collection methods connection to social history and interactions between the stories of the mentally ill and the

general public, the project thesis utilizes the theoretical methodology of Thomas Szasz. By recognizing that the designation of mentally ill as a social artifact and changes in different periods throughout history, this project's place within the development of the 21st century can be better understood. Although Szasz only focuses on those who are given the designation of mentally ill rather than those who are self-proclaimed, his arguments can help to illustrate both groups as part of this type of social interaction.²¹ When conducting interviews and collecting items, an emphasis was put on how participants feel they fit within their community and family networks. This helps the projects outcome point to the social interactions and designations within which they see themselves fitting. The *Mental Health Memories* project portrays mental health as a social construction but by allowing participants to choose and contribute to the exhibit's design in their own ways they are able to create their own definitions and explanations of their mental health experiences.

To better analyze previous sources of knowledge on the experiences and representations of the mentally ill Szasz argues it is imperative to understand that there is no human interaction between the hospital psychiatrist and the committed patient, but rather the patient's input should be viewed as pure

²¹ Thomas Szasz, *The Manufacture of Madness: A Comparative Study of the Inquisition and the Mental Health Movement* (New York: Harper & Row, 1970), XXII.

“clinical material.”²² Taking this approach will allow for the differentiation between psychiatrists’ notes as primary sources that represent the personal histories of the mentally ill and sources that are created on the participants’ terms. Since this project focuses on the latter it is important to recognize the ways in which this project is attempting to represent participants using their own words rather than evaluated representations of their words. Both Roy Porter and Dale Peterson represent the mentally ill using autobiographical works of mental patients, as well as, mad people to present their experiences. Representing mad people’s history by way of mad people’s experiences is essential to the primary goal of this project. Dale Peterson argues that in order to give agency to those with mental illness the most serious, difficult, and complex issues should be addressed by mad people and mental patients themselves.²³ The *Mental Health Memories* project follows this theoretical method by allowing participants to engage with various topics and present their own views on various issues. Using these theoretical frameworks, the project was created and implemented in a way that gives agency to participants while also allowing them a stage in which to become part of the historical narrative, one of which they have historically been left out.

²² Ibid., 283.

²³ Dale Peterson, *A Mad People's History of Madness* (Pennsylvania: University of Pittsburgh Press, 1982), xiv.

Roy Porter's organization of *A Social History of Madness: The World Through the Eyes of the Insane* allows readers to explore the 'foreign country' that is madness.²⁴ By exploring various themes such as “Madness and Power” and “Madness and Genius” rather than historical periods the stories of the mentally ill are presented as human experience rather than exclusively exhibiting the history of the mad. This form of representation is central to the overall thesis of this project, in that, it is the human experience that must take center stage.

Terminology

This project aims to give a voice to those silenced or shunned from the historical narrative of the history of madness. The *Mental Health Memories* project is therefore another avenue in which the telling of individuals' experiences with mental health can take place. It aims to bring an understanding of the realities of their lives. Thus, the terms used throughout the project in totality must be sensitive to the wider community while also allowing for each individual to identify themselves, i.e. using the terms they feel best describes them autonomously. Various terms that describe this community include mad, insane, crazy, lunatic, distracted, mentally ill, survivors, consumers, clients, and a host of

²⁴ Roy Porter, *A Social History of Madness: The World Through the Eyes of the Insane* (New York: Weidenfeld & Nicolson, 1988), 9.

other terms.²⁵ For example, those who identify themselves as psychiatric survivors have had largely negative experiences within an institutional setting.²⁶ Throughout this project each participant has had the opportunity to label themselves however they feel best describes their identity. This is especially true for those who are designated by outsiders as having a mental illness. Using certain terms can be a way in which individuals can reclaim their identity on their own terms.

For much of this description, however, the designation of “mad” will be used throughout because of its greater implications in grappling with the medically charged word “mental illness.” Because there are varying ideas with regards to the causes of mental ill-health, i.e. some see the etiology as purely biological, some see it as social, and others see it a combination of both, the terms used can often denote one’s belief. However, it is important also to note that at the time that this project was developed, the term “mentally ill” is widely accepted and used by practitioners and society as a whole, more so than “madness.” Thus, the term mentally ill and mental health will also be used to describe this group throughout the project and online exhibit. It also serves as a convenient way to collectively name those with experiences in the mental health

²⁵ Geoffrey Reaume, “Syllabus: Reaume, “Mad People’s History,” *HistoryPsychiatry.com*, Sep. 6, 2010, <https://historypsychiatry.com/2010/09/06/syllabus-reaume-mad-peoples-history/>.

²⁶ “What is MindFreedom International?”, “*MindFreedom.Org*. <http://www.mindfreedom.org/mfi-faq>.

sector and sometimes replace terms that are specific to any type of diagnosis or action. Although using a term which groups a complex community into a specific term can be dangerous it is necessary in order to be better understood and accepted in the public domain. Although labels, like “mentally ill” can create an image of a stereotyped visual representation of madness which is used by society to identify the mad absolutely, without such a term, the goals of the project may be lost.²⁷ The term mentally ill has become the most widely used in popular discourse, and although it eludes to a connection between biological factors in the development of mental health, it has come to describe the mad wholly.

Research Questions

The *Mental Health Memories* project aims to give agency to those with mental health experiences by giving them a forum to share their stories via oral histories, artifacts, images, and sound. The website exhibit is dedicated to patients’ experiences and lives while in the mental health system and in some cases self-care. Although this topic has a negative stigma surrounding it, it is necessary for the greater community to understand what experiences a portion of their community have went through. With the help of the *Mental Health Memories*

²⁷ Sander Gilman, *Disease and Representation: Images of Illness from Madness to AIDS* (Ithaca: Cornell University Press, 1988), 48.

website I hope to give patrons a multi-sensory experience where they can feel they are witness to the history and select participants lives. My research questions are as follows:

1. What are the multiple views and experiences of individuals with mental health experiences?
2. What social roles do individuals with mental illness see themselves fitting into within their community and family?
3. How do individuals with mental illness want their stories to be remembered?
4. What role does material culture play in remembering each individual's mental health experiences?

The *Mental Health Memories* project consists of a collection and presentation of personal histories in order to answer these research questions using an online format. The MHMemories.org/com website is a product of this project and is the final format in which participants' stories, memories, photographs, and documents are shared.

CHAPTER TWO

REPRESENTATIONS OF PERSONAL HISTORIES

Material Culture as Storyteller

In order to add a more complex dimension to the presentation of individuals' mental health experiences, the *Mental Health Memories* project uses both material culture and sound to display personal narratives. Mieke Bal, author of "Telling Objects: A Narrative Perspective on Collection," argues that narrative acts as a discursive mode of collection which functions socially, ideologically, and historically.²⁸ Bal reasons that although verbal text narratives are studied regularly, academics should take into account that:

Language is just one medium, perhaps the most conspicuous one, in which narratives can be constructed. Images, as the tradition of history painting demonstrates, can do so as well, not to speak of mixed media like film, opera and comic strips.²⁹

As Bal points out there are a number of mediums in which an individual can create their personal narratives, and language is just the beginning. Personal stories can be portrayed and embodied in physical and audio form.

²⁸ Mieke Bal, "Telling Objects: A Narrative Perspective on Collecting" in *The Cultures of Collecting*, ed. John Elsner and Roger Cardinal (Massachusetts: Harvard University Press, 1994), 95.

²⁹ Ibid., 99.

The importance of the material world cannot be overlooked because of its role in creating narratives and not just being defined by narratives. The material world surrounds all individuals and thus can be seen as part of the human experience. *Material Cultures, Material Minds: The Impact of Things on Human Thought, Society, and Evolution* written by Nicole Boivin, explores aspects of history, culture, and narrative and their connection to material culture. Boivin explores the history of human engagement with the material world as a history in which, “mind and matter, and form and substance continually bring each other into being...”³⁰ By arguing that material culture and the individual bring one another into being the author makes clear the relationship in which one needs the other to exist. The *Mental Health Memories* project recalls this relationship making the existence of both the narrative and item inseparable. In order to have a deeper understanding of the material objects presented, the individual must give it meaning and the individual explores their experience within the frame of the item.

Taking Bal and Boivin’s views on the relationship between narrative and object into consideration the exercise of connecting experience with objects brings context to an object. By adding an experience or memory to material culture it takes on a different representation than it had when first created. The

³⁰ Nicole Boivin, *Material Cultures, Material Minds: The Impact of Things on Human Thought, Society, and Evolution* (New York: Cambridge University Press, 2010), 23.

current question collectors must ask themselves is: What should replace or supplement material culture inheritance?³¹ Author Peter Jenkinson argues that people's experience, which is mainly revealed in oral history and reminiscence, and by using film, video, and photography, can aid in this quest for supplemental information.³² Primary resources are most useful when the context behind its creation, use, and memories associated with them are part of its description. In order to create more useful primary sources through the *Mental Health Memories* project it is necessary for context and memories that are connected with each item collected to be shared and exhibited with participants playing the lead role in their representation. By giving participants the option to share their own experience and its tie to various types of material culture the *Mental Health Memories* collection gives researchers and the general public a more complex understanding of the realities of those with mental health experiences. Since the production of history is centered around the analysis of primary sources as a starting point for research it is imperative that context come with each item.

As the lead investigator, I am in a position of collector and thus a narrative agent with my own personal motivation part and parcel of the subject

³¹ Peter Jenkinson, "Material Culture, People's History and Populism: Where Do We Go From Here?," in *Museum Studies in Material Culture*. ed. Susan Pearce (New York: Leicester University Press, 1989), 145.

³² Ibid.,145.

development of plot.³³ The relationship between participants and their material culture are the key facet to this project but the ways in which these objects are collected and displayed lends to the narrative portrayed. Each subject conceives their existence partly through the material world which lies outside of him or her.³⁴ By forming the collection there is now a relationship that has been developed between me and each individual item and story. As lead collector, it is my goal to give agency to participants through the presentation of their narrative through their voice, objects, and sounds. Their verbal narrative helped to portray their personal experiences bringing the material culture, and thus the online exhibit, to life. The act of choosing which material culture that is represented is in the hands of the participants since picking out the “right stuff” cannot be done without bias which may trivialize or romanticize their stories through an outsiders’ interpretation.³⁵ With the power in participants’ hands they are able to choose what aspects of their lives they want to share to the public in order to represent parts of their personal history. It is also important to note that each item and recording collected stayed in the possession of the participant in order to serve its purpose in years to come for the individual. For example, if a participant is

³³ Mieke Bal, “Telling Objects: A Narrative Perspective on Collecting” in *The Cultures of Collecting*, ed. John Elsner and Roger Cardinal (Massachusetts: Harvard University Press, 1994), 112.

³⁴ Susan Pearce, “Collecting Reconsidered,” in *Museum Languages: Objects and Texts*, (New York: Leicester University Press, 1991), 139.

³⁵ Judy Attfield, *Wild Things: The Material Culture of Everyday Life* (Oxford: Berg, 2000), 95.

willing to share a personal journal with the project, they will be able to have their personal writings to ensure posterity on their own terms as well. The digital life of the item will serve as a primary resource for researchers without taking from the individual what they may hold close to their memory and thus want to keep.

By understanding the relationship between participants and the material world the creation and representation of narrative can be accomplished in a way in which participants gain agency. Visitors to the *Mental Health Memories* website are able to explore an individual curated history with mental health experiences in order to gain insight into the realities of mental health through a multi-sensory experience. With the help of the participant, each entry and its description have become a new form of personal narrative in which both language and material culture work together to build the participant's personal narrative.

Mental Health Stories Web-Based Projects in California

With the rise of the 1960's advocacy movement, a new voice was given to those within the community of mentally ill patients, consumers, and psychiatric survivors and their families. With this nationally recognized voice there has been a surge of projects that aim to collect their stories and present them to the public. In making these stories accessible to the public, these groups are giving those with mental health experiences a stage in which they can tell their stories in their

own words and with their own imagery. There are various examples of these types of projects throughout the United States. In order to better understand how this project will fit into the already existing discourse of mental health storytelling we will explore projects in California. These projects have variations in mission and theme but will help to show how this project will aid in giving a new dimension to this type of storytelling. The projects that will be discussed are those who have been created most recently in various mediums such as online exhibits, archives, and physical exhibitions.

The method in which material is presented has an effect on the experience of the audience. When analyzing the projects that were created in previous years it is important to understand the audience with whom the projects are trying to connect. The type of information, images, and stories portrayed are chosen in order to tell a specific story. When analyzing a project, it is also important to understand that those who are telling their stories have a message they are trying to convey as well. Whether this message has undertones of advocacy, or is blatantly anti-psychiatry or pro-institutionalization they all should be understood on their own terms. When listening to and viewing other projects it is important to understand that these modes of storytelling are helping to give voice to a community. Internet sources are a widely used method of presentation since they are a highly accessible mode of information sharing. With web-based projects, the audience is much broader and can cross nations and cultures alike.

Projects that are physically based exhibitions have a more limited audience. This can be combatted by making materials available via internet platforms. With the ease of access to these projects, the messages being portrayed are, now more than ever, an important addition to the perpetuation of thoughtful recognition and analysis of the stories of those with mental health experiences.

The *Walk in Our Shoes* project was created with government funding allotted to the California Mental Health Services Authority by counties through the voter-approved Mental Health Services Act (Prop 63).³⁶ This project is affiliated with the *Each Mind Matters* mental health movement. Through government funding, this group works to bring awareness to advancements in mental health throughout California. It prides itself on being an inclusive group of millions of individuals and thousands of organizations that work to unite all of those who, "...share a vision of improved mental health and equality."³⁷ The *Walk in Our Shoes* project is an internet-based interactive webpage. It's core audience is children and young adults.

The homepage of the *Walk In Our Shoes* website follows a click-to-expand layout that has various cartoon shoes in boxes with the name of the person whose story is told. The only text present on the homepage is the introduction to the project which welcomes visitors with:

³⁶"CalMHSA and Prop. 63," *EachMindMatters.Org*. <http://www.eachmindmatters.org/about-us/>.

³⁷ "About US," *EachMindMatters.Org*. <http://www.eachmindmatters.org/about-us/>.

Hello! Are you curious about what it's like to be in someone else's shoes? Do you want to learn about other people's lives? Curiosity and learning are great, so lace up, strap on, or slip on your sneakers and let's learn about mental health. Learning about other people can help you understand that they're still a lot like you — they're just on a journey in different shoes.³⁸

The theme of putting yourself in someone else's shoes is carried throughout the website. This allows for the viewer to connect to the stories while asking themselves the question "What if this was me?" Once visitors click on a story there are a number of ways stories are portrayed. People and scenes are shown in cartoons whether it be an animated short story or an image at the top of the page. The person telling their story has a voice recording uploaded to the page. Children and their parents learn of how each person has a different experience with mental illness. For example, Laura's story focuses on her identity and labels that were given to her that she questioned and even rejected. Laura explains, "I never liked the word disorder."³⁹ There is also an area that provides an opportunity for children to send in their own stories that can be uploaded.

This project portrays stories of children and young adults who had their first experience with mental illness at a young age. This helps children learning about their story to connect on an even deeper level because they may identify

³⁸ "Walk in Our Shoes," *WalkInOurShoes.Org*. <http://www.walkinourshoes.org/#/our-stories>.

³⁹ "Laura's Story," *WalkInOurShoes.Org*. <http://www.walkinourshoes.org/our-stories/laura>.

with some of the feelings they are going through. The project has a musical production component that portrayed six different stories in a theatre performance during 2013. This statewide school performance tour was able to reach nearly 20,000 students in 31 counties.⁴⁰ With funding from the government, this project allows for a much wider audience within California to have access to materials. With this type of reach, the project is a useful resource for younger audiences to understand the complexities of family, school, and friend life that come with having a mental illness and how these relationships can help someone. These relationships can either hurt or help people that are going through changes in their mental condition, and luckily these differences are discussed in various stories.

There are also projects like University of California of Los Angeles's (UCLA) collaboration with the Los Angeles Department of Mental Health (LADMH) titled *Hope Story*. This project gives voice to those who have been patients and users of government-funded treatment. The collaboration began in 2010 with the help of Dr. Marvin J. Southard, Director of LADMH, and Dr. Joel Braslow, Neuroscience History Professor at UCLA. They sought to commemorate the 50th Anniversary of the Los Angeles County Department of Mental Health. Through this collaboration, they decided to create an archive at

⁴⁰ "For Grown-Ups," *WalkInOurShoes.Org*. <http://www.walkinourshoes.org/for-grownups>.

UCLA and an educational website.⁴¹ The educational website is geared toward adults and families who are likely in need of the services explored through previous or current patient's experiences. This goal of educating the public about government-funded services the community of patients and users are overwhelmingly portrayed as having positive outlooks on using these services.

With the help of Oral History, Archival Repository, and Voices of Mental Health pages' visitors of the website are able to explore various modes of storytelling. There is a lack of interaction in each component that makes the site feel more like an informational resource than a storytelling experience. Although the webpage's main focus is portraying the history and the stories of those with mental illness, there are no other mediums used to portray their experiences. Only their oral histories and videos of interviews are available. There are various oral histories with transcripts that can be read with images of the person telling their story put next to a short biography. Although less interactive, the use of long format oral histories aids listeners in having more detail of a person's story and the development of their connection to their mental health experience. With this type of storytelling there are more opportunities for each person to explore their thoughts about various aspects of their life.

⁴¹ "About Us," *Regents of the University of California*, 2017, <http://histpubmh.semel.ucla.edu/about>.

Art has become one of the most popular avenues for those with mental illness to tell their story. Art allows those in the mental health community to tell their stories using their emotions and skill. They are able to use their frame of mind in order to create scenes of self-expression. Although it is not an interview or video recording, art can allow viewers to explore the thoughts and experiences on their own terms. As self-expression and understanding is the goal of each story, art is an obvious medium that can allow those with mental illness a way to tell of their realities, thoughts, and even in some cases their aspirations. Art can also be used as a method of healing and a source of treatment. This method of art making is greatly accepted by the public who go to various art shows around the nation. It is likely so because viewers feel they are able to connect with the person on a different level. Art allows for the expression of feelings that sometimes words alone cannot express.

One such example is UCLA Master's in Communications student Angela Lan-Anh Nguyen's art show titled *Mental Health Tattoo Art Exhibition* during March of 2016. This show was a physical exhibition within the UCLA Powell Library. The connection between the tattoos of those with mental illness sought to explore their relationship between body art as a way of exhibiting identity, as well as breaking down stigma around both tattoos and mental illness. As Nguyen explains her goal was to "try to fight the stigma against mental health and tattoos. The stigma against mental health, mental illness, and tattoos is prevalent

in American society, which shames and discriminates against people with mental health issues, tattoos, and/or both.”⁴² Throughout the library, images and text worked together to tell the story behind the tattoo and its connections to their experience. The image of each tattoo shows the various ways in which people connect with their mental health experiences. For example, one student’s story centered on her attempt at suicide. Psychobiology student Katie Patel’s tattoo was a phrase that a police officer told her after he arrived on the scene of her attempt. The text on her rib cage reads, “This too shall pass” with the semicolon at the end. The semicolon is a symbol inspired by the *Semicolon Project*.⁴³ With the use of Patel’s oral history interview and image of her body art Nguyen is able to connect her audience with art and stories.

With the help of social media, the project has been able to stay on the minds of students on campus. With students at UCLA the main target audience, they were able to use students frequent focus of social media to their advantage. The *Mental Health Tattoo Exhibition* Facebook is a way that students at UCLA

⁴² Angela Lan-Anh Nguyen, “Mental Health Tattoo Art Exhibit: Stories & Struggles of Mental Health through Photographs of Permanent Body Art,” *UCLA Library Events*, last modified February 29, 2016, <https://www.library.ucla.edu/events/mental-health-tattoo-art-exhibit>.

⁴³ Ishita Gambhir, “Tattoos Relate Mental Health Stories in Art Exhibition,” *Daily Bruin*, last modified March 1, 2016, <http://dailybruin.com/2016/03/01/tattoos-relate-mental-health-stories-in-art-exhibition/>. and “Project; Your Story is Not Over,” Project Semicolon, 2017, <https://projectsemicolon.com/>. Project Semicolon works as a suicide prevention resource. It operates under the mission of reducing the rates of suicide around the world. The website also is a forum for those to share their personal stories of mental health experiences.

are still able to see the artwork and stories.⁴⁴ Social media played a large part in getting the word out about the project and those involved with creating it. Their audience had a direct impact on the exhibition. As Nyugen explains:

We are intentionally exhibiting mental health tattoos with the goal of contributing to the openness of campus atmosphere, and ultimately, we look forward to seeing more people feeling comfortable sharing their tattoos and stories.⁴⁵

Each tattoo displayed in the *Mental Health Tattoo Exhibition* shows a wide range of mental health experiences: anxiety, depression, obsessive compulsive disorder, addiction, and other mental health issues.⁴⁶ With such an array of issues discussed, the project attempts to be as inclusive as possible. This inclusivity allows visitors to see that body art is a way that people with a number of mental conditions can use this medium to express themselves and in some cases, remind themselves of their past. Rather than hiding from their past, these subjects are able to embrace it and help to open dialogue as Nyugne intended. The idea that mental health issues can be expressed, organized, and discussed

⁴⁴ Angela Nguyen and Sarit Kashanian, "Mental Health Art Exhibition," last modified March 14, 2016, <https://www.facebook.com/events/215096588832538/>.

⁴⁵ Angela Lan-Anh Nguyen, "Mental Health Tattoo Art Exhibit: Stories & Struggles of Mental Health through Photographs of Permanent Body Art," *UCLA Library Events*, last modified February 29, 2016, <https://www.library.ucla.edu/events/mental-health-tattoo-art-exhibit>.

⁴⁶ Ibid.

through art has become a recurring theme in projects that are created throughout the nation and in California in particular.

One other project worthy of discussion is an example of an art display that is more than an exhibition but a program designed for self-expression for those within the mental health community and also a venue to spur understanding for those who are not. The *Arts End Stigma* program was available at the Orange County Center for Contemporary Arts During July to August of 2013 in Santa Ana, California. The program was funded by the County of Orange Health Care Agency, Behavioral Health Services, Prevention and Intervention Division, Mental Health Services Act /Prop. 63.⁴⁷ This program included an art exhibit, workshops, and performances all with aims to end stigma around mental illness. While participating in different activities, those with mental illness and community members worked together to better understand one another and themselves. Self-expression and exploration was the way in which the program aimed to end stigma.

The *Art Ends Stigma* art exhibit titled *Connect Heal End Stigma* has its aspirations within its title. The goal to *connect* various communities and families is evident in the fact that the program was free and open to the public which made it highly accessible to the surrounding communities. The word *heal* speaks to the power of art to help heal the emotional traumas and effects that sometimes

⁴⁷ "Connect End Heal Stigma," OCCCA.Org, last modified 2017, <http://www.occca.org/AES.html>.

come with mental conditions and may even be describing the healing happening for those who now feel more understood. In order to *end stigma*, the exhibition uses art that connects viewer and artist. Paintings, sculptures, and multi-media pieces are on display in a white walled gallery. The exhibit features, "...original artwork by professional artists, who are also: mental health advocates, community builders, arts educators, and/or family members and/or are persons diagnosed with a mental illness."⁴⁸ With the varied artists' backgrounds, visitors are able to see multiple perspectives within their community and the community of individuals with mental health experiences.

The workshops and performances available during the *Arts End Stigma* event allowed visitors to have an interactive experience as well. Watercolor, print-making, and drawing out stigma workshops, among other activities, were available during this month-long event. These experiences were seen to help enhance the lives of participants by:

helping to reduce stigma, anxiety and stress and raise self-esteem, while providing a sense of joy and productivity derived from a positive access to their imagination and the healing process of creativity.⁴⁹

This positive experience was also helpful in allowing participants to explore negative experiences in their life in a safe space. This safe space was used to

⁴⁸ Ibid.

⁴⁹ Ibid.

allow participants to create art and interact with one another in new ways. The theatre production of *I Live in Your World* attempts to portray the feeling of “them and us” for those who have been diagnosed with a mental illness. The production, “gives voice to a marginalized population of persons with mental illness, communicating personal stories and messages that engage the audience on an intimate and universal level.”⁵⁰ As the finale to the program, the production was a culminating experience for the community members who had been working together throughout the previous weeks.

The project was able to collect stories from their interactions to be collected and turned into a catalogue of the event that is available on the project’s website. This project was the most interactive because its main theme was exploration through creating new forms of expression through art. The voices given a stage throughout the project were truly diverse. Not only was there a recognition of various types of mental illness but there was also a recognition that the wider community should be held responsible in understanding and respecting those with mental illness. Giving voice to both communities is different from the other projects analyzed. The first three examples are those that are trying to tell their stories to outsiders while the *Art End Stigma* used different mediums to tell of the complex relationships between those who have mental illness and those who work to understand them.

⁵⁰ Ibid.

The above analysis is evidence of the many variations that narratives of those with mental health experiences have been created in recent history. With so many ways for storytelling to take place it is clear that audience, funding, location, and material culture play a major role in the way a project is organized. All projects have similar missions to give a platform to those who want their stories to be heard. They are also working to fight stigma and promote advocacy for people within their community to understand and respect them. In order to promote these ideals, they use their stories to portray their experiences on their own terms. There are a number of ways to share these stories including: online exhibits and archives, art projects, and art programs.

Though the stories themselves are an important way to connect to a person's experience, the use of visual mediums of expression are also important to help people connect in different ways to many aspects of a story. For example, when body art was used in the *Mental Health Tattoo Art Exhibition* visitors were able to connect to the individual's story by the art they chose to mark their skin with. This discussion of stigma through an art that already has an existing stigma surrounding it was a way that the complexities of identity and self-expression were explored among their stories of mental illness.

The use of multiple mediums to aid in storytelling is exemplified in each project. By analyzing the four examples mentioned above, the importance of using oral histories, images, and art is seen as an important component of the

project. If such an impact can be made using oral histories and art, the inclusion of everyday items, music, and documents would only add to this positive affect. Though these items were not used in any of the above projects it is clear that only audio recordings are not as effective as audio accompanied with personal pictures or art which is much more affective. With the creation of an online archive this project gives the authority and choice to those who are telling their stories. In all above examples those who wished to participate were able to tell of their experiences and express their thoughts about these experiences. With the help of a multimedia filled collection and website the *Mental Health Memories* project aims at combatting stigma as these previous examples that have been analyzed.

CHAPTER THREE

WEBPAGE CREATION AND COLLECTING

Reclaim Hosting and WordPress Development

As one of the most accessible forms of information sharing, a website was the best option for the type of collection the *Mental Health Memories* project aims to facilitate. The collection of materials, without taking physical ownership of the items, was one aspect of the project that needed to be taken into consideration from its inception. Audio recordings, of course, are now almost entirely done via computer technology. As a graduate student project, there was no clear way that the collection, storage, and management of a physical collection could be made possible. The decision was made to create a project which would digitally collect, store, and display participant's collections. Since the *Mental Health Memories* project is a website, the choice had to be made about what hosting site would be used. Due to price and their focus on educators and institutions, a dual student domain was purchased via Reclaim Hosting.⁵¹ Having both .org and .com domains for the website allows for those who put either to be directed to the page. The option of creating a personalized domain name made the creation of

⁵¹ "Take Control of Your Digital Identity," *ReclaimHosting.Com*, Last modified 2017, <https://reclaimhosting.com/>.

the *Mental Health Memories* website easily accessible to those interested in the project and able to simply type in the project's name to get to the webpage.

The Reclaim Hosting service allows for creators to use WordPress plugins in order to create various page layouts and also to apply color and style themes to the website, making it completely customizable. In order to organize the MHMemories.org/.com site the addition of subsections keeps viewers aware of what they are exploring on each page. Under the Navigation menu there are the About, Archive, and Contact to Contribute sections. The "About" section gives the synopsis:

This project was developed to fill a void in resources available that represent the mentally ill within historical discourse. The stories of individuals with mental health experiences have been captured in oral history projects with little to no other resources being used to document their personal histories. As a history based project the goal of the archive is to document participant contributions and stories. There is a negative stigma which surrounds those with mental illnesses. One way to fight back against the perpetuation of these negative stereotypes is by those with mental illness telling their stories of everyday life and in some cases treatment. This multidimensional approach can individually contribute to the collective story.

In order to understand any portion of their lives it is of the utmost importance to hear their stories on their own terms. By allowing participants to share not only oral histories, but also visual and material culture, it is my hope that we will gain a more profound and heterogeneous understanding of individuals' experiences and new resources can become available for contemplation.⁵²

⁵² Amanda Castro, "About," *MHMemories.com*, Last Modified May 12, 2017, <http://mhmemories.com/about-2/>.

The Archive page allows for viewers to explore the various collections of images and audio contributed during the collection process. The Archive page is divided into subpages where each participant has been assigned their own page. In order to allow possible participants to contact the lead investigator my name and email, as well as, Professor Jones office number were added to the website.

The theme chosen is intended to be easily accessible with minimum images in the background and clear text via Arial font. The sole image connected to the website layout is a royalty free image of a group of adults.⁵³ This image allows for website viewers to connect, or see themselves, within the group. The representation of a variety of people within the collection and also as viewers is representative of the image which is a goal of the project.

The *MHMemories* website was created before the collection of materials and oral history interviews were conducted. This was a necessary step because it allowed for those who were interested in participating to see where their information would end up once the project was complete. A generic participant page was created with text and images that showed the possible layout of information. This allowed for possible participants to visualize what the website would look like once their information was inputted. By creating a layout that was both clear and concise the public as well as participants are able to navigate the

stories that are presented on the webpage. By accessing information more easily the focus is able to stay on the information and stories.

Choosing of Participants

Recruitment of participants was initiated by sending a flyer, formal project proposal, and contact information to the San Bernardino County (Appendix G: Project Flyer). Behavioral Health Clubhouses located in the Inland Empire and the Psychiatric Stories Archive at CSUSB. Recruitment also took place by word of mouth. Participants were required to be at least 18 years of age, former patients, or individuals who have had any type of mental health experience. Participants were not able to be under conservatorship of the county, incarcerated, or being held under any type of 51/50 (mentally unstable) hold in any hospital or locked institution. This ensured the rights of the participants were fully taken into consideration and participants are not considered to be part of a vulnerable population. All Health Insurance Portability and Accountability Act of 1996 (HIPPA) laws were abided by while recruiting with emphasis on potential participant confidentiality.

The San Bernardino County Behavioral Health Clubhouses⁵⁴ are located throughout San Bernardino county and aim to support those with lived mental

⁵⁴ "Clubhouses," *San Bernardino County Department of Behavioral Health*, Last modified 2017, <http://wp.sbcounty.gov/dbh/mental-health-services/adults/clubhouses/>.

health experiences who are over the age of 18. The centers have support groups and social activities that focus on helping their peers recover. An emphasis is placed on participation and education for Clubhouse members. Most members visit the Clubhouse multiple times a week, and some everyday they are open. One Clubhouse, in particular, was interested in the project, the name of which will remain confidential to protect the identity of those who participated, and will be called the Clubhouse hereafter. Once interest was shown at the Clubhouse I was invited to do a presentation about the project in order to outline the project more clearly and also to answer any questions those interested in the project may have. This was instrumental in spurring interest in participation.

In addition, the Psychiatric Stories Archive is a newly created archive located on the CSUSB campus.⁵⁵ This collection is dedicated to making available oral histories of those who have come in contact with the mental health system in the United States and around the world. Participants are not only previous psychiatric patients but also those who worked in the medical field or families of those connected to various institutions dealing with mental health. Although the *Mental Health Memories* project focuses only on those that have mental health experiences, the Psychiatric Stories Archive allowed for me to reach out to those that did have mental health experiences and give them the opportunity to contribute their stories.

⁵⁵ Tiffany Jones, "Home," *PsychiatricStoriesArchive.com*, <http://psychsarchive.com/>.

Both the San Bernardino Behavioral Health Clubhouse and the Psychiatric Stories Archive worked to get the word out about the project while also advocating for the need to participate. This was a great help in getting participants interested because the project was being talked about with possible participants from people they were familiar with and had trust in. The Clubhouse director Lydia Vasquez was instrumental in getting Clubhouse members interested in the project. She worked to help me understand what information the Clubhouse members would need to best understand what I was asking of them. She also gave me information about members who may need more help in understanding the project by talking to them one-on-one. Since the Clubhouse members fit all the criteria for possible participation, all who were interested were able to participate. The choosing of participants was made easier in that no one had to be turned down. Working with both programs allowed for the vetting process to be nearly non-existent allowing for a more positive feel for the project and allowing all those interested to feel heard.

Data Collection

The *Mental Health Memories* project strives to follow ethical and safe protocol in order to keep participants and investigators free from harm. The procedural methodology of collection of information and presentation of information via the *Mental Health Memories* website follows IRB approved

protocol which is in accordance with federal, institutional, and ethical requirements.⁵⁶ To insure all participants fit the criteria recruitment locations were chosen that, as an organizational restriction, only service those 18 and over. A pre-interview was not completed for all participants due to last minute interest. For those who were able to have a pre-interview an email exchange allowed for the assessment of the ways in which the individual would like to participate in the project i.e. oral history and/or types of material culture. This email exchange also allowed for the participant to see the material culture questions in order to have them in mind when looking for what they wanted to contribute. By outlining the project beforehand potential participants were able to decide whether they wanted to share or not. Giving participants a clear outline of what the projects goals and outcomes were going to be was important in ensuring that their contributions would be respected and displayed in a way that they agreed to.

Creating a working relationship with those that helped facilitate participation was key to the success of this project. Tiffany Jones, the creator of the Psychiatric Stories Archive, as well as, Lydia Vasquez of the San Bernardino County Clubhouse were instrumental in gaining interest for the project. With their help, participants were able to have a deeper understanding of the goals and outcome of the project. The fact that potential participants were able to have

⁵⁶ "CSUSB Institutional Review Board: Welcome," *California State University of San Bernardino*, June 17, 2015, <https://irb.csusb.edu/>.

someone close to them that advocated for their participation and talked to them on a personal level, allowed for them to have a better understanding of how important sharing their story was. Working closely with the Clubhouse allowed for me to set up three collection dates that allowed for participants to have a set time and location to participate. This became one of the most important organizational aspects of collecting participant contributions. I was able to work with the manager of the Clubhouse who was not only interested in the project but wanted to facilitate the project any way possible. In order to make collection easier and more comfortable for participants, the library of the Clubhouse was used for collection, this allowed for participants to be in a familiar place where their transportation was not an issue. There was only one participant recruited through the Psychiatric Stories Archive. This interview was conducted in the office of the participant and allowed for a safe and quiet place for her as well.

In order to conduct the collection meetings, I started by creating a checklist of all of the things I would need in order to collect stories. This list included: audio recorders, a portable scanner, my laptop, consent forms, interview questions, and the resource list created in case any triggers prompted the need for participants to contact some type of help (Appendix B: Community Resource List). The in-person interviews and collection meetings lasted approximately one hour and no longer than two hours per participant. For those who did not have an email pre-interview and did not have the chance to attend the project

presentation, all information was outlined at the start of the collection meeting. Once they agreed to participate, the consent form was read through, all questions were answered, and the document was signed (Appendix C: Consent Form). Participants had the option for confidentiality before the collection of their contributions and had an opportunity to choose how they wanted to be addressed during the project whether that be with a pseudonym or the use of their initials. There were two sets of questions which facilitated the interviews and collecting, one for the oral histories and one for material culture (Appendix E: Oral History Interview Questions and Appendix F: Material Culture Questions). Interviews were audio recorded, and material culture scanned and saved via flash-drive leaving the original items in the ownership of the participant. For those that wanted to contribute memories connected to songs, they were questioned about their memories and stories connected to the audio. With this information, I was able to implement music, video clips, and portions of lyrics in order to display their song selections.

Once collection was completed a copy of the digital files, including oral history files and images of artifacts were uploaded to the website hosted by Reclaim Hosting <http://mhmemories.org/>. If confidentiality was requested all materials were edited in order to remove all identifying information before uploading to the website. In order to maintain confidentiality a spreadsheet was created with participants' personal information and their pseudonym in order to

be sure that all information can be retraced back to the participant if needed. A copy of the digital files created were given to the participant upon request. Some portions of the interviews were transcribed for website display purposes. Oral histories are to be fully transcribed if participants chose that option on the consent form or request it in the future. Although there were not participants that requested a full transcript they still have that option upon request. The website includes transcribed portions of the interviews that correspond to the objects, images, or audio that they provided during the collection meeting. The participant had the option of seeing all transcribed portions of the interview before posting upon request. Posting a quote or section of the oral history was decided upon in order to give website visitors insight into their story before they choose to listen to the whole recording.

Results

The collection days at the Clubhouse were immense successes and resulted in the collection of six oral histories, two of which resulted in the collection of digital images of items and songs that connected to participants' stories. The collection days fell on May 4th and May 9th of 2017. On each collection day I took with me all the required equipment from my previously discussed checklist. Consent forms were scanned and printed to return to each

participant at the Clubhouse, which allowed for them to keep in their personal files.

The final result of the collection process was the creation of webpages to display each participant's contributions. These webpages include images, text, and audio. Every participant of the project preferred to have an oral history interview recorded in order to share their story, so each participant page includes the audio from their interview. A SoundCloud account was created in order to upload the oral histories in order to create an easier format for website visitors and also to reach a wider audience. For the participants that requested anonymity, their initials were used throughout the webpage and their oral interview was edited for sensitive content that may have revealed personal information about them that could distinctively identify them. Those who contributed items have an image of their item accompanied by a caption which describes the item. Those who chose a song to help illustrate their experience have a YouTube video linked to their page. This was useful since YouTube holds the rights to music videos, which enabled me to include the song on their page without worrying about copyright infringement.

Once each page was completed I paid another visit to the Clubhouse in order to get feedback from those that participated in the project. I asked that they look over the webpage that displayed their story and let me know if there were any questions or concerns about the content. This allowed for the participants to

not only check for discrepancies but also to see and modify the final product of their contribution. In order to allow control to stay in the hands of participants it was important for them to be the last say to how the public viewed their story. This meeting also allowed time for participants to share with other Clubhouse members about their webpages.

In order to give back to the Clubhouse that participated in the project a tour of Patton State Hospital's Museum, which I am an intern at, was offered to those interested. Since the Clubhouse plans excursions for its members every week it was possible to plan a visit to the museum since their transportation and lunch would be planned and paid for. It was a nice way to wrap up the project, as well as give back to the Clubhouse for all of their help and support. Having the opportunity to give back to the Clubhouse was an important way to wrap-up the project. I also plan to provide the Clubhouse with a copy of the link to this written thesis in order for them to read and also share with their family and friends.

CHAPTER FOUR

CONCLUSIONS

Future of Project

The *Mental Health Memories* website will be online for a one-year period with the possibility of renewal. All information collected during the project's duration was donated to the Psychiatric Stories Archive located at CSUSB once the project was complete. The Psychiatric Stories Archive project has been IRB approved (#14083) and therefore abides by confidentiality regulations. This will ensure that confidentiality is maintained indefinitely. Professor Tiffany Jones, who is the creator of the Psychiatric Stories Archive, will have access to the files created from the project. There is a link placed on the Psychiatric Stories Archive webpage that directs visitors to the *Mental Health Memories* project website in order to reach a wider audience. Since anything put up on the web is then open and even if removed, copies of it may remain any use of information must be cited.

Although growing the project would be useful to future researchers it must be taken into consideration that this is a culminating project so this may be the final product. This means that additions or changes are not guaranteed. The potential of adding to the *Mental Health Memories* project will be determined by the amount of interest that comes from the initial launch of the website. If there is

an immense influx of people who become interested in contributing their stories it would prompt me to continue collecting stories and adding to the archive.

Another possible way that the project could grow is if future students become interested in helping collect stories. The main focus is on making sure that the website is accessible for the one-year period. It is also important for those who are interested in using the archive as a resource to know that information can be accessed by request via the Psychiatric Stories Archive if the website is no longer in existence after the one year period. The files will be kept on the CSUSB campus making the edited audio and documents accessible to future researchers keeping the stories accessible indefinitely if the website is no longer in existence.

Conclusions and Recommendations

The *Mental Health Memories* project aims to fill the void in material culture available which tells the story of those with mental health experiences. By choosing to highlight the stories of those that are currently working to improve their mental health, the stories did not just address their past, but gave them a platform to discuss the current and future struggles. The option of confidentiality allows participants to share more openly, leading to richer oral histories. By putting participants in the position of source creator and curator of their own stories their storytelling is done on their own terms from start to finish. The process of conducting interviews was powerful because of the raw emotions that

came from each story. By conducting oral history interviews the participant is in an empowered position because they dictate the stories being told. The goal of collecting the stories of participants to document their conscious contributions and stories rather than assess their mental state was reached.

Although there are similarities seen in participant's stories, a closer look highlights just how unique each individual's story is. For example, a majority of participants have, at points in their life, isolated themselves from their support system since being diagnosed. One reoccurring reason for this disconnect was that participants felt their loved ones were safer if they were not exposed to the negative emotions or actions that were taking place at the time of an episode. There was a minority of participants that did not want to keep any type of memorabilia such as photographs or keepsakes. They explained that looking at these items brought back memories connected to a negative time in their life that they would rather not visit those memories. Though these similarities highlight a common experience it is important to note that every participant's story is a unique and invaluable resource. Their stories reveal not only their own personal histories, but also tell us a lot about the strengths and limitations of the mental health sector and society as a whole. The most significant outcome of the *Mental Health Memories* project is the voice and visuals of participants' experiences being made available to the public, giving them a place to reach a wide audience because of the web-based format.

There are number of recommendations I would make to those that are interested in recreating or doing a similar project. The first would be to complete the Institutional Review Board process as soon as possible if it is required. The IRB process took two months to complete which set back the timeline greatly. This left less time to organize and implement information collected. I would also recommend having a presentation built into your project plan. This gives possible participants an opportunity to meet you as well as hear about the project in your own words rather than reading it from a flyer. Rather than wait for it to be requested it would be more beneficial to be the one to suggest and plan for a presentation. The questions that were asked after my presentation at the Clubhouse were questions that could not have been answered by a simple flyer or email. It turned into an open forum in which people voiced their opinions about the project and were able to ask questions about the project's goals. Being able to physically show them the website and the ways in which their contribution would be implemented allowed them for a greater understanding of what they were contributing to.

The *Mental Health Memories* project's goal is to give agency to those with mental health experiences by giving them a forum to share their stories via oral histories, artifacts, images, and sound. The MHMemories webpage is dedicated to the upheaval of negative stigma that surround those with mental health experiences. With one visit to the site, visitors are able to experience and have a

new understanding of the various experiences of participants. Taking into consideration the openness of a public website, it took courage for participants to be as open as they were. Each story does contain the negative aspects of having a mental health experience or illness, but by listening to the various stories it becomes clear that it does not define them. At the end of each interview participants were asked how they want their stories to be remembered and what advice they may have for someone going through the same experiences. Each participant answered with uplifting advice; most just wanted for listeners to know they are not alone. Being able to share their stories gave participants the authority to not only educate the public but also advocate for understanding.

APPENDIX A
PARTICIPANT S.L.'S
ONLINE COLLECTION

S.L. Collection

S.L.'s Oral History Interview:

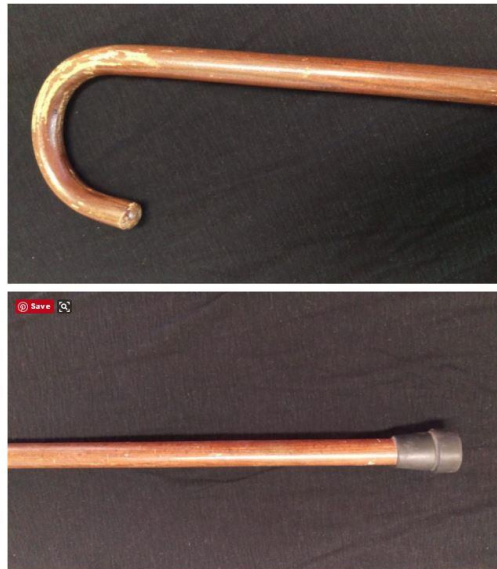


NAVIGATION

- About
- Archive
 - S.L. Collection
- Contact to Contribute

SEARCH THE ARCHIVE

S.L.'s Collection:



S.L. Item 1 - Wooden Cane

Below S.L. explains the significance of the wooden cane.

Below S.L. explains the significance of the wooden cane.

- Describe the object:
 - This is a walking cane I was given when I was released from the hospital after my suicide attempt in 1993. I needed the cane to walk because I had nerve damage and a blood clot in my left leg as a result of the overdose and subsequent coma from my suicide attempt.
- What comes to mind when looking at this object?
 - Everything that happened as a result of my suicide attempt is very fuzzy in my memory. What comes to mind when I look at the cane is bits and pieces that I remember from the experience: trying to walk, the pain in my leg, the emotional state I was in while recovering, and the people who helped me recover.
- Do you find this object brings on any emotions? If so explain.
 - Because this happened so long ago and because I'm fully in remission from my mood disorder now, it feels more like a dream than reality. It's difficult for me to remember just how hopeless I felt at the time. I almost feel like it happened to someone else.
- How long have you owned this item?
 - I've owned the cane for 24 years now.
- Why have you kept this item?
 - I'm not sure why I have bothered to keep it. I think it's because the cane symbolizes my youth and the struggles I went through, and it reminds me of how far I've come. I can't really explain why I felt the need to hold onto it for so long.
- Does anyone know the significance of this item other than you?
 - My husband is the only person who knows the significance of the cane.
- Does this item remind you of good/bad times?
 - Mostly bad times but a little bit of the good times. It reminds me that I survived.
- Does this item remind you of a place?
 - Yes. It reminds me of the hospital I recovered in and it reminds me of the apartment I lived in at the time.
- Do you think this item is a representation of your experience with mental health? In what way?
 - Yes, it is absolutely a representation of my experience with mental health, or actually, with mental illness. Though I struggled for years with suicidal thoughts, this was my only real suicide attempt. I remember how calm I felt as I counted out over 120 pills, lined them up and began swallowing them one by one during my suicide attempt. A sort of resolution and a sense of peace came over me while I took the pills. Then I went to bed. I woke up three days later in the hospital and was told that I had been in a coma. I was angry that I had lived. I remember thinking "I can't even kill myself right."



S.L. describes the memory connected to Pink Floyd's *Brain Damage*

"On the open ward you go out in the yard. And I remember sitting in the yard on a chair, on the grass, listening to Pink Floyd and the song Brain Damage over and over and over. It takes me straight back there but I don't remember the pain I was in. I just remember it was a turning point in my life because I was doing something about it." – S.L.

APPENDIX B
COMMUNITY RESOURCE LIST

There are no foreseen risks for the participants. However, because of the revisiting of negative experiences surrounding their mental health this topic may act as a trigger for feelings associated with negativity and stigma they experienced. I will provide participants with mental health resources supplied by CSUSB that they are be able to contact for professional help. These counseling and psychological services include:

1. Community Hospital of San Bernardino, Behavioral Health Services

- a. 1805 Medical Center Drive
San Bernardino, CA 92411
(909) 887-6333, ext. 3900
- b. Programs include the Adult Inpatient Program, Psychiatric Medical Program, Partial Hospitalization Program, and an Involuntary Adult Inpatient Program.
- c. **Referral Hotline: 800-962-HELP**
- d. Visit the CHSB Behavioral Health Services website.
- e. Provides 24-hour confidential information and referral hotline, provides information on inpatient and outpatient screenings, crisis intervention services, personal interviews, community referrals, psychiatric nursing assessments and 5150 screenings and evaluations.

2. Arrowhead Regional Medical Center (ARMC)

- a. Emergency Psychiatric Unit
400 N. Pepper Avenue
Colton, CA 92324
(909) 580-1800
- b. TDD for the Deaf and Hard of Hearing: (888) 743-1481
24 hours a day/7 days a week
- c. Visit the ARMC website.
- d. The Arrowhead Behavioral Health Center provides in-patient psychological treatment for children and adults. People in crisis and suffering chronic psychiatric disorders, such as severe depression, anxiety disorders, schizophrenia and other mental health problems are helped.

3. County of San Bernardino Department of Behavioral Health

- a. For Emergency Walk-In Mental Health Services After Hours, visit the:
Extended Hours Triage (for Adults 18 and older only)
Behavioral Health Resources Center (BHRC)
850 E. Foothill Boulevard
Rialto, CA 92376
Phone: (909) 421-9342
Walk-In Hours of Operation: Monday through Friday 5:00 p.m. – 10:00 p.m. Open Holidays 2:00 pm – 10:00 p.m.

Visit the San Bernardino County Department of Behavioral Health website.

4. Loma Linda University Behavioral Medicine Center

- a. 1710 Barton Road

Redlands, CA 92373

(800) 752-5999 or (909) 558-9275

Email to: hshah@llu.edu

Visit the LLU Behavioral Medicine Center website.

- b. Services Offered: Senior Psychiatry Program, Youth Program, Eating Disorder Program, Chemical Dependency Program (inpatient detoxification, inpatient rehabilitation, outpatient full-day hospital, outpatient partial-day hospital, evening outpatient, continuing care, chronic pain and medication dependency program and dual diagnosis), intensive outpatient—child, adolescent, and adult, a 5150 designated facility, involuntary child, adolescent, adult and senior care, and rapid stabilization tract for adults.

APPENDIX C
CONSENT FORM



College of Social and Behavioral Sciences
Department of History
Informed Consent

I am a graduate student at CSUSB working on a project for my M.A. program my name is Amanda Castro. I am developing a Mental Health Memories online archive at California State University, San Bernardino (CSUSB), under the direction of Professor Tiffany Jones. This study has been approved by the CSUSB Institutional Review Board.

Contact Information: Amanda Castro
Email: casta372@coyote.csusb.edu
Professor Tiffany Jones Phone: (909) 537-3792

The purpose of this research is to create an online collection of personal items, documents, images, audio, oral histories that provide a better understanding of people's different experiences with mental health (mhmemories.org). I want to know more about how objects/audio can act as a link to a person's memories. I also want to know how these individuals viewed and continue to view their experiences with mental health.

You are being invited to participate in this research because you are a person who has a mental health experience, are at least 18 years of age, and your experience can help give us a more informed view of people's experiences with mental health.

If you agree to participate, you will have a one-on-one interview with Amanda Castro that will last approximately one hour but no longer than two hours. Interviews will take place at CSUSB or somewhere else that is quiet, and distraction-free. During this interview, scans and/or pictures of the items you provide for the project will be collected and/or an oral history interview will be conducted.

Your participation in this project is voluntary and involves no foreseeable risks. You will be one of many persons who contribute, and if you choose to remain anonymous, there will be no way to connect you with the stories you contribute. Your privacy is important. You will be free to raise questions or concerns with Amanda Castro before and throughout the study. You will be asked questions about your background, your experience with your personal mental health, and the memories you have connected to your personal items/images. As some of the information you share may be personal and sensitive, you do not have to answer any question that makes you uncomfortable. You may stop the interview at any time. Please be assured that you are under no obligation to participate in the interview.

The entire interview will be recorded. If you choose, the information recorded will remain confidential, and no one else except Amanda Castro and Dr. Tiffany F. Jones will have access to original information collected.

This project is asking for a scan/copy/or audio interview of your personal contributions. Your personal items will stay in your possession. A transcript may be made of the interview, but if you choose, no one will be identified by name in the transcript. If you consent, any transcripts created may be made available for use by researchers, but their results may not be published,

909.537.5524 • fax: 909.537.7645

5500 UNIVERSITY PARKWAY, SAN BERNARDINO, CA 92407-2393

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Maritime Academy • Monterey Bay • Northridge • Pomona • Sacramento • San Bernardino • San Diego • San Francisco • San Jose • San Luis Obispo • San Marcos • Sonoma • Stanislaus



College of Social and Behavioral Sciences

Department of History

duplicated, or displayed without written permission of Amanda Castro. The materials may also be used for public display or publication by the Mental Health Memories Project creator Amanda Castro. However, neither your name nor the names of anyone mentioned in your interview will be used in any resulting publications or public displays.

Benefits: Although the findings of this study will not directly benefit you, by agreeing to contribute and/or interview you will be adding to a broader understanding of mental health experiences. You may also have the satisfaction of knowing that you are helping to preserve the history of the people affected by their mental health.

Confirmation Statement: I have read the information above, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study. I have received (or will receive) a copy of this consent form.

I prefer to remain ☐ OR, I consent to the use of my name. ☐
anonymous ☐

Yes ☐ No ☐ I consent to be audio recorded.

Yes ☐ No ☐ I consent to the scanning/copying of my personal items

Yes ☐ No ☐ I consent to my personal images and audio being displayed on the projects website (mhmemories.org)

Yes ☐ No ☐ I would like to review and edit the transcript, if one is made, prior to its use.

Yes ☐ No ☐ I consent to the deposit of the recordings/copies in the Public and Oral History Archives of California State University, San Bernardino

Name: (Please print)			
Telephone:			
Address:			
Signature:		Date:	

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Maritime Academy • Monterey Bay • Northridge • Pomona • Sacramento • San Bernardino • San Diego • San Francisco • San Jose • San Luis Obispo • San Marcos • Sonoma • Stanislaus

APPENDIX D
IRB APPROVAL LETTER

Date: 5-30-2017

IRB #: IRB-FY2017-136
Title: Mental Health Memories Project
Creation Date: 3-9-2017
End Date: 4-13-2018
Status: **Approved**
Principal Investigator: Amanda Castro
Review Board: CSUSB Main IRB
Sponsor:

Study History

Submission Type	Initial	Review Type	Expedited	Decision	Approved
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Key Study Contacts

Member	Amanda Castro	Role	Principal Investigator	Contact	004248633@coyote.csusb.edu
Member	Tiffany Jones	Role	Co-Principal Investigator	Contact	tjones@csusb.edu
Member	Tiffany Jones	Role	Co-Principal Investigator	Contact	tjones@csusb.edu
Member	Tiffany Jones	Role	Co-Principal Investigator	Contact	tjones@csusb.edu
Member	Amanda Castro	Role	Primary Contact	Contact	004248633@coyote.csusb.edu
Member	Amanda Castro	Role	Investigator	Contact	004248633@coyote.csusb.edu

APPENDIX E
ORAL HISTORY
INTERVIEW QUESTIONS

Interview Questions

The questions listed below were developed by Amanda Castro and Tiffany Jones. Not all of the below will be applicable to all interviewees. Specific questions from the following list will be selected depending on the applicability to each interviewee:

1. What is your date of birth?
2. Where were you born?
3. Where did you grow up?
4. What race/ethnicity do you see yourself as?
5. Do you have any distinct childhood memories?
6. Where do you currently live?
7. What is your first (home) language?
8. Do you speak any other languages?
9. What is your current occupation, if any?
10. What other jobs have you held?
11. Tell me about yourself. What defines who you are?
12. Tell me a little about your life before you had your mental health experience.

13. I understand you have experiences with relating to your mental health, do you have experience in the mental health system/spent time in a mental hospital/community centered care/self-care? When was this?
14. How did you end up under mental health care?
15. What word would you use to describe your experience with your mental health? Why did you choose that word?
16. When did you have your first mental health experience? What do you remember about that day? What happened?
17. Do you feel your life changed that day in any way?
18. Have you ever felt stigmatized for your mental health?
19. In what ways has that experience changed your life?
20. Have your relationships with family/friends/people close to you changed since then?
21. What types of care have you experienced?
22. What are your main recollections about your life under mental health care?
23. How long was your stay/treatment?
24. Were you given a diagnosis? What was it and how was it treated?
25. Was this treatment adequate?
26. Describe the facility/ies that you were admitted to.
27. Describe the types of services you accessed. Were these adequate?

28. Do you think you were treated fairly and were helped by the psychiatric system?
29. Do you think you were treated fairly and were helped by the types of treatment or care you sought?
30. Did you see any positive aspects or abuses within the institutions/services you were affiliated with?
31. Do you think people of different backgrounds/gender/race/ethnicity were treated differently? If yes, in what ways?
32. Have you ever experienced any discrimination in your contact with mental health services?
33. What in your opinion are the main causes of mental illnesses?
34. What do you think of the mental health system in this country?
35. Were your friends, family members affected by your experiences with the mental health system? In what way?
36. Do you believe there is a cure for mental illness? If yes, what do you think it is?
37. Tell me about your life after your experience with the psychiatric services.
38. Are there any objects that remind you of your mental health experience? If so what is it and what does it remind you of?
39. Are there any songs that remind you of your experience with mental illness?

40. Do you have any photographs that bring back memories of your mental health experiences?
41. Who did/does your support system consist of? Who were the people who have helped you to cope with your mental health experience? Why?
42. How do you want your story to be remembered? What lessons have you learned that you would like to pass on to those who hears this interview?
43. What activities do you pursue for personal enjoyment?
44. Is there anything important about the mental health system or yourself that you would like to tell me that we haven't already touched on?

APPENDIX F

MATERIAL CULTURE QUESTIONS

Material Culture Interview Questions:

The questions below were developed by Amanda Castro. The word item can be interchanged with: image, song, document.

1. Describe this object?
2. What comes to mind when looking at this object?
3. Do you find this object brings on any emotions? If so explain.
4. How long have you owned this item?
5. Why have you kept this item?
6. Was this item a gift?
7. Does anyone know the significance of this item other than you?
8. Does this item remind you of good/bad times?
9. Does this item remind you of a person?
10. Does this item remind you of a place?
11. Do you think this item is a representation of your experience with mental health? In what way?
12. Has this item been able to help you in any way?
13. Has this item hurt you in any way?
14. How does possessing this item make you feel?

15. If someone was looking at this item on the project website (*Mental Health Memories*) what do you want them to learn about you by seeing this item?
16. How do you think your item fits within the larger narrative of mental illness?
17. Do you see this item as a good representation of your mental health experience?
18. Does this item only give insight to a short period of your life?

APPENDIX G
PROJECT FLYER

SHARE YOUR STORY

with the

MENTAL HEALTH MEMORIES PROJECT

Contribute to an online archive that captures the diverse stories of those with mental health experiences!

All participants must be 18 or older.

Currently looking for participants to tell their stories through:

- Personal items
- Photographs
- Documents: letters, posters, art pieces, personal writings
- Songs or Audio
- You can also share your story through an interview with a trained history student

For further information contact:
Amanda Castro
Masters in Social and Behavioral Science
Student at CSU-San Bernardino

Email: casta372@coyote.csusb.edu
Tel: 1 (909) 537-3792

This project has been approved by the Institutional Review Board (IRB) at CSUSB.



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