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## **Stigma and Identity Formation in Young Adults with Chronic Mental Illness: An Exploration through Personal Narrative and Art-Making**

Kerri Lynn Blackstone  
*Loyola Marymount University*

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Stigma and Identity Formation in Young Adults  
with Chronic Mental Illness:  
An Exploration through Personal Narrative and Art-Making

by

Kerri Lynn Blackstone

A research paper presented to the

Faculty of the Department of  
Marital and Family Therapy  
Loyola Marymount University

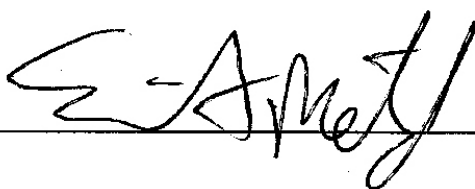
In partial fulfillment of the  
Requirements for the Degree  
Master of Arts

May 12, 2013

**Signature Page**

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Kerri Blackstone, MA Candidate, Marital and Family Therapy and Art Therapy Trainee;  
Researcher



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Einat Metzl, PhD, ATR-BC, LMFT; Research Mentor

### **Acknowledgments**

My sincerest thanks to the faculty for giving me the opportunity to begin this new chapter of my life, surrounded by the supportive and inspirational family that is the LMU Art Therapy program. The strong foundation you've provided and the compassionate example you've set will stay with me as I strive to be of service to those in need. Special thanks to my research mentor, Dr. Einat Metzl whose patience, encouragement, and insight have been invaluable to this project.

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To my family, your love and support have allowed me to stay connected to my roots even when I feel the need to wander around in the stars.

A very special thanks to Dave Leon for helping organize this project, and to the five members of my focus group without whose courage and creativity this research would not have been possible.

### **Dedication**

This research project is dedicated to my first clients at my first practicum whose compassion, resiliency, and ability to laugh in the face of adversity renewed my belief in the strength of the human spirit and inspired me to take an active role in fighting the stigma of mental illness. Thank you for letting me be your therapist even when it was clear that I had far more to learn from you than you ever could from me.

### **Abstract**

This research explores the experience of stigma and its effect on identity formation in young adults who suffer from chronic mental illness. Data was gathered in the form of personal narratives and art-making through a semi-structured, qualitative focus group. It was categorized and coded in order to better understand the experience of both public and internalized stigma in relation to the developmental milestones that characterize the important transition from adolescence to adulthood. Analysis of the data resulted in the emergence of three overarching themes: 1) The challenges of coping with a stigmatizing system, 2) Internalized stigma as it relates to the formation of adult identity, and 3) The use of art to combat stigma and facilitate self-discovery. These themes were examined against existing literature pertaining to the stigma of mental illness, identity formation in young adults, and the use of art to combat stigma and promote healthy identity. The findings of this research emphasize the insidious nature of stigma and offer support for the ability of art-based programs to empower young adults who face the challenges of mental illness.

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## **Introduction**

### **The Study Topic**

This research paper explores the relationship between stigma and identity formation in young adults with chronic mental illness. Both narrative and art-based data are examined in order to provide a deeper understanding of the lived experience of this population as they strive to move beyond adolescence towards the formation of adult identity. Stigma has been described as “the process by which the reaction of others spoils normal identity” (Cathro & Devine, 2012). Recent studies have attempted to break stigma down into co-occurring components including labeling, stereotyping, separation, status loss, and discrimination (Link & Phelan, 2001), and have added that for stigmatization to occur, a power differential must be exercised (Eisenhauer, 2008). Being a member of one or more stigmatized group can result in what Link and Phelan (2001) describe as “a dramatic impact on the distribution of life chances, whether those refer to career, earnings, social ties, housing, criminal involvement, health, or even life itself” (p.381).

Throughout history, individuals who suffer from mental illness have been portrayed as dangerous, disheveled, unpredictable, weak, self-involved, or even possessed. These negative portrayals continue to evoke feelings of fear, mistrust, and anger, as well as avoidance and discrimination by members of the dominant group at the personal, professional, and institutional level (Eisenhauer, 2008; Quinn, Shulman, Knifton, & Byrne, 2011; Bathje & Pryor, 2011). Extensive research agrees that members of this stigmatized group are likely to experience a potentially devastating effect on social functioning, interpersonal relationships, housing, employment, medication compliance, and treatment success (Jenkins & Carpenter-Song, 2009; Link & Phelan, 2001). In addition to combatting prevalent public stigma, this population must also confront in-

ternalized (self) stigma. When the stigma surrounding mental illness is internalized, it may manifest as poor self-esteem, lack of empowerment, and feelings of alienation (Quinn et al., 2011).

Because the age of onset for many mental illnesses is late adolescence or early adulthood, these factors are likely have a negative impact on the formation of adult identity for this vulnerable population. In their discussion of the unique developmental experiences of young adults, Park, Mulye, Adams, Brindis, and Irwin (2006) identify a gradual transition to adult roles and responsibilities as well as the weakening of the safety net that supports adolescents. Being stigmatized at this critical time may prevent or delay young adults from reaching these important developmental milestones. It may also decrease their rate of recovery and lead to greater social and familial problems. As stigma is thought to be the greatest barrier to seeking treatment, the reduction of stigma is now considered central to the promotion of mental health (Crabtree, Haslam, Postmes, & Haslam, 2010).

According to Rosal (1993), art-making promotes self-responsibility and can help people integrate their condition into their identity without internalizing the stigma of mental illness. Community programs following the “clubhouse” model have begun to incorporate art-making into their strength-based recovery approach. Using this model, participants are referred to as “members” rather than “patients” and are expected to take ownership of their group and contribute to its success. The limited research on young adults in these programs indicates that members embrace the opportunity to cultivate their identity as an artist and often feel an increased sense of empowerment when given the opportunity to publicly display their art (Lipe et al., 2012). For this population, the use of art may contribute to creating a sense of meaning and purpose, developing new coping mechanisms, fostering hope, and rebuilding identity

(Spandler, Secker, Kent, Hackings, & Shenton, 2007). Because *The Painted Brain* is an art-based organization created specifically for young adults who suffer from mental illness, working with members of this group provides a unique opportunity to better understand the lived experience of stigmatization as well as the impact of art-making in relation to adult identity formation in young adults with chronic mental illness.

### **Significance of the Study**

Although a great deal of literature exists on stigma, a relatively small amount focuses on the impact of stigma and art-making during this developmental phase of life. Researchers agree that the formation of adult identity is an important developmental milestone for people in their twenties (Tesch & Cameron, 1987) and that the stigmatization of people who suffer from mental illness can negatively effect this process (Thoits, 2011). In order to allow for healthy identity formation, the effects of both public and internalized stigma must be confronted and processed. Strength- and recovery-based programs like *The Painted Brain* strive to break down the stigmatization and isolation of young adults with mental illness by creating community and empowering members to define themselves in their own terms as artists, writers, educators, and activists. Current art therapy literature supports the idea that art-making has the potential to empower individuals by bringing about greater personal awareness and insight while simultaneously challenging society's negative representations of mental illness (Mango, 2011). In addition to creating art for the benefit of self-discovery, the public display of art may potentially serve as a bridge to educate previously unreachable groups within one's community (Barney, Griffiths, Christensen, & Jorm, 2009).

This study offers a holistic investigation into the lived experience of stigmatization and identity formation in young adults with chronic mental illness. The inclusion of an art

directive allows meaning to be revealed visually as well as verbally, and may serve as an example of the role of art in research. Using both verbal and visual exploration, this study gives a voice to members of an often marginalized population and allows them to communicate their authentic, unsensationalized experience with others. Their unique perspective and insight may inspire new ways of conceptualizing the treatment of mental illness while their courage and resiliency may promote increased empathy, compassion, and respect for the challenges that face this population. Providing an in-depth look at the community created by *The Painted Brain* may prove useful for therapists and community organizations searching for an appropriate way to integrate art into their mental health services. It may also serve to increase awareness of the benefits and risks of organizations like *The Painted Brain* that publicly display art created by a stigmatized group, and may inspire much-needed research on the complex relationships between stigma, art-making, and identity formation in young adults who suffer from mental illness.

I became increasingly interested in the impact of stigma on the identity of young adults with chronic mental illness throughout my first-year art therapy practicum at Daniel's Place, a community mental health organization in Santa Monica. Working with young adults at Daniel's Place allowed me to observe members' reactions to external stigma as well as the internalization of the negative stereotypes of mental illness. Through leading art therapy groups and attending a meeting of *The Painted Brain*, I had the opportunity to witness the powerful impact that art-making can have on this population. As members grew more confident and embraced the creative process, I grew curious about the meaning given to the art as well as the role that it plays in combatting stigma and developing adult identity.

## **Background of the Study Topic**

### **Stigma**

Historians, anthropologists, and political scientists agree that the social exclusion and exploitation of the stigmatized “out-group” by the dominant “in-group” is characteristic of human culture around the world and has been a part of social dynamics for as long as human interaction has been recorded (Kurzban & Leary, 2001). In the past, the concept of stigma was understood by its literal definition as “a mark of disgrace” and could be viewed as society’s fear-based need to create boundaries between “us” and “them” (Eisenhauer, 2008). The identity of stigmatized groups is not necessarily universal. It is often linked to prominent cultural norms of a particular time and place such as the hereditary caste systems in India, the enslavement of African-Americans in the United States, Nazi Germany’s extermination of Jews, the AIDS epidemic, and the treatment of the mentally ill (Kurzban & Leary, 2001).

In the early 1960s, the concept of stigma was explored by influential sociologist Erving Goffman in his book, *The Presentation of Self in Everyday Life*. Goffman defined stigma as “the process by which the reaction of others spoils normal identity” (Goffman, 1963). His work inspired extensive research into the nature, sources, and consequences of stigma, which resulted in major advances in understanding the process of stigmatization. Since the 1960s, several theories have been used to discuss stigma including labeling theory, which proposes that a person who is labeled as deviant or different will conclude that they are in fact deviant or different and label them self with that stereotype or stigma (Thoits, 2011). Modified labeling theory adds that young children develop negative conceptions of stigmatized groups as part of the process of socialization, and that members of stigmatized groups will continue to apply these learned expectations of

rejection and devaluation to themselves as adults (Link & Phelan, 2001). Symbolic interactionist theory states that the self cannot be separated from the society in which it is located and that our self-esteem is a direct consequence of the views others hold of us. Similarly, social constructionist theory asserts that a person's self-esteem is formed socially on the basis of others' views and that, when others appraisal is negative, this becomes internalized and results in low self-esteem (Crabtree et al., 2010). Evolutionary theorists view on stigmatization suggests that humans are designed to exclude members of the group that may be poor partners or health risks from social interactions in order to further the species (Kurzban & Leary, 2001).

In the last twenty years, researchers have studied stigmatization in relation to a wide variety of subjects including cancer, AIDS, mental illness, unemployment, welfare, wheelchair use, stepparents, debtors, and lesbian mothers with results almost always revealing negative effects of stigma at the personal, social, and institutional level. Current studies stress the importance of examining the unique circumstances of a stigmatized group as well examining the dominant group that continues to exclude and reject (Link & Phelan, 2001).

### **The Stigmatization of Mental Illness**

Throughout history, the stigmatization of mental illness has been rooted in social, economic, and cultural forces that are directly linked to the context of a particular time and place (Kurzban & Leary, 2001). Prior to the Renaissance and the Industrial Revolution, many cultures associated mental illness with demonic possession, moral deviancy, witchcraft, and the occult. The mentally ill were commonly blamed for their condition and treated/punished as the church saw fit. Fear of the unknown caused this group to be labeled as dangerous and, in some cases, less than human, in order to justify permanent incarceration or placement in workhouses

with horrific living conditions. During the 17th and 18th centuries, a growing middle class began to place importance on social identity, worthiness, productivity, and health. This new middle class majority found that they could better establish themselves as successful members of society by placing their identity against easily marginalized members of their communities, including the mentally ill, who were increasingly placed in asylums for behavior considered outside the norms of society. In 1753, Dr. Benjamin Rush attempted to change the inaccurate portrayal of mental illness, referring to it a “disease of the mind” and calling for dignified and compassionate treatment of patients at the first mental health hospital in the United States. Dorothea Dix continued his efforts in the 1800s, lobbying for more than thirty government sponsored hospitals (Fabrega, 1991).

Since the introduction of psychotropic drugs in the 1950s, institutionalization has given way to community treatment programs based on a model of wellness and recovery, with mixed results. Despite significant advances in the understanding of mental illness, members of this population continue to be portrayed as violent, murderous, and unpredictable, which results in fear and avoidance by misinformed members of the community. This inaccurate and harmful portrayal can be seen in Wilson et al.’s 2000 study, which sampled children’s television programs and found that 46% used derogatory terms to refer to mental illness (Byrne, 2001). Due to its pervasive negative consequences, the Surgeon General has identified stigma as “the most formidable obstacle to future progress in the arena of mental illness and health” (Lyons & Melton, 2005, p.316) and listed the reduction of stigma as an important public health goal. Organizations like NAMI (National Alliance on Mental Illness) and campaigns like Changing Minds support this goal, working to reduce the stigma of mental illness by taking away the

label that separates “us” from “them.” For example, instead of being called “schizophrenic” which implies that the diagnosis is a person’s entire identity, the person is instead said to “have schizophrenia,” which leaves room for other elements of the self. These programs and others like them have been successful in empowering the patient to become an advocate and in assisting people with mental illness to reclaim their identity (Byrne, 2000; Smith, 2002).

### **Mental Health Programs and Art-Making**

Much of the existing literature on art-based interventions has focused on the psychotherapeutically oriented forms of art therapy that are associated with Freudian analysis and the principles of psychotherapy. However, the recovery movement of the last twenty years has shifted the focus of mental health treatment from the removal of symptoms to the creation of a better quality of life achieved by learning how to live well despite symptoms. The success of this model has led to an increased interest in the therapeutic value of the creative process itself (Heenan, 2007). Community mental health programs have begun to incorporate art and other forms of creative expression into mental health treatment with the intent of increasing hope, empowerment, and inclusion while decreasing the effects of stigmatization on an individual’s sense of self (Lipe, 2012). Although the art is sometimes viewed as a confidential part of treatment, Mango (2011) and Potash and Ho (2011) studied community-based mental health programs and found that members also benefit from sharing their artwork with the community. Participants in these studies demonstrated higher levels of self-esteem and social skills and expressed the belief that art exhibits can act as an impetus for social change by challenging the public’s perception of mental illness. Because identifying publicly as a member of a stigmatized group may leave a person open to verbal and/or physical assault, more research is needed regarding the benefits and risks

of mental health programs that publish or publicly display the art of group members.

A limitation of existing research on this topic may be the tendency for stigma to be studied and defined by people who haven't had the lived experience of the stigma being studied. The exclusion of the words and perceptions of the people being studied may result in incorrect assumptions and misunderstandings (Link & Phelan, 2000).

### **Literature Review**

The following is a review of the existing literature on stigma, identity formation, and art-making in relation to young adults who suffer from chronic mental illness. It begins with an examination of literature focused on the universal concept of stigma, and includes a review of definitions, theoretical understandings, levels, and the effects of stigmatization on groups and individuals. It then examines literature focused on the specific stigmatization of mental illness, and includes a discussion of the portrayal and treatment of the mentally ill throughout history as well as an exploration of the manifestations of both public and internalized stigma on individuals who suffer from mental illness. Next, the paper presents literature focused on the developmental milestones of emerging adulthood, the prevalence of mental illness within this cohort, and the challenges specific to young adults who are diagnosed with mental illness. The paper then reviews the existing research on stigma reduction methods including individual and group therapy, support groups, psychoeducation, public initiatives, activism, and community programs based on the clubhouse model, with specific emphasis given to programs tailored towards the needs of young adults. Finally, research regarding the use of art to combat the stigma of mental illness is reviewed, the benefits and risks of creating and exhibiting artwork are examined, and potential implications for identity formation are explored. Cultural considerations including race, gender, socioeconomic status, and religion will be considered throughout this review.

### **Stigma**

**Definitions.** The word “stigma” is derived from the Greek “stig,” meaning “mark” (Brown & Bradley, 2002). Prior to the 16th century, the word stigma was broadly used to refer to a tattoo or mark for religious purposes or a brand placed on criminals and slaves to display

their inferior social status and allow them to be identified if they ran away (Stuart, 2008). Stigma is now defined by the American Heritage College Dictionary (2006) as “a mark of disgrace, shame, or degradation.” Individuals become stigmatized when they have a characteristic that is different from others, and that has been designated as inferior (Crabtree, Haslam, Postmes, & Haslam, 2010). To be stigmatized is to be discredited, undesired, and reduced from whole and usual to tainted and discounted (Livingston & Boyd, 2010). At its most extreme, a group is reduced entirely to its label and is no longer seen as fully human, allowing for the justification of horrific treatment including the slavery of African-Americans and the unethical medical experimentation on the mentally ill (Link & Phelan, 2002). Stigma can also be viewed as a deficit of the dominant group. This is seen in Lamb’s (2009) description of stigma as a problem of knowledge that is demonstrated by ignorance, a problem of attitude that is demonstrated by prejudice, and a problem of behavior that is demonstrated by discrimination. Definitions and descriptions of stigma vary for two main reasons: every group has unique circumstances that result in a different conceptualization of the stigma, and the concept of stigmatization is multidisciplinary and includes the perspective of psychologists, sociologists, anthropologists, political scientists, and social geographers, all of whom operate within different cultural and theoretical frameworks. Current studies stress the importance of examining the unique circumstances of a stigmatized group as well as examining the dominant group that initiates the stigmatization (Link & Phelan, 2001).

**Theories.** Although the current use of the word “stigma” is thought to have appeared in the late 16th to early 17th century (Stuart, 2008), historians, anthropologists, and political scientists agree that the social exclusion and exploitation of the stigmatized “out-group” by the

dominant “in-group” is characteristic of human culture around the world and has been a part of social dynamics for as long as human interaction has been recorded. The identity of stigmatized groups is not necessarily universal, more often being linked to prominent cultural norms of a particular time and place, such as the hereditary caste systems in India, the enslavement of African-Americans in the United States, Nazi Germany’s extermination of Jews, the AIDS epidemic, and the treatment of the mentally ill (Kurzban & Leary, 2001). Social, economic, and political forces determine which differences are signaled out and influence how these categories are sustained (Link & Phelan, 2001). Kadri and Satorius (2005) address the cultural function of stigma using a social dominance approach. They hypothesize that threatened identity and self-esteem motivate discrimination, and that it is beneficial for the dominant group to justify the systems that work to their advantage in order to maintain their perceived superiority. To assure their place in society, the dominant group categorizes groups in terms of worthiness and deserving, which enables them to justify the poor circumstances of the out group and allows the unequal roles to feel reasonable. From a psychodynamic perspective, stigmatization of the out group can be understood as a projection of the dominant group’s own unattractive or shameful feelings (contempt, aggression, despair, fear of failure) onto a disadvantaged group in order to distance oneself from what feels unacceptable (Smith, 2002). Social psychologists view this process through a relational lens, citing four phases of the stigmatization process: 1) the in group distinguishes and labels differences, 2) dominant cultural beliefs link labeled persons to undesirable characteristics, 3) labeled persons are placed in distinct categories in order to solidify the separation of us from them, and 4) labeled persons experience loss of status and discrimination (Link & Phelan, 2001).

In 1959, the concept of stigma was explored by influential sociologist Erving Goffman in his book, *The Presentation of Self in Everyday Life*. His description of stigma as “the process by which the reaction of others spoils normal identity” inspired extensive research into the nature, sources, and consequences of stigma, which resulted in major advances in understanding how people construct categories and then link those categories to a stereotyped belief (Goffman, 1963). Since the 1960s, several theories have been used to discuss stigma including labeling theory, which proposes that a person who is labeled as deviant or different will conclude that they are, in fact, deviant or different and will therefore label them self with that stereotype or stigma (Thoits, 2011). Modified labeling theory adds that young children develop negative conceptions of stigmatized groups as part of the process of socialization, and that members of stigmatized groups will continue to apply these learned expectations of rejection and devaluation to themselves if they are diagnosed with mental illness as teens or young adults (Link & Phelan, 2001). Symbolic interactionist theory states that the self cannot be separated from the society in which it is located and that self-esteem is a direct consequence of the views that others hold of the person. Similarly, social constructionist theory asserts that a person’s self-esteem is formed socially on the basis of others’ views and that, when others appraisal is negative, it becomes internalized and results in low self-esteem (Crabtree et al., 2010). Evolutionary theorists suggest that humans are designed to exclude members of the group that may be poor partners or health risks from social interactions in order to further the species (Kurzban & Leary, 2001).

Recent studies attempt to break stigma down into co-occurring components including labeling, stereotyping, separation, status loss, and discrimination, and add that for stigmatization to occur, there must be an imbalance of power between the dominant (in) group and the stigmatized

(out) group (Link & Phelan, 2001). Eisenhauer (2008) supports the necessity of a power differential for stigmatization to occur and speculates that the fear-based need of the dominant group to mark or stigmatize the “other” in order to create boundaries between us and them is at the root of stigmatization throughout history.

**Levels.** Extensive literature discusses the existence of stigma at the institutional, social, and personal level, and provides evidence for both external and internal manifestations of stigmatization (Bathje & Pryor, 2011; Link & Phelan, 2001; Livingston & Boyd, 2010; Smith, 2000; Thoits, 2011). Structural, or institutional, stigma exists at a systems level and involves policies and procedures that restrict the rights and opportunities of people who belong to a stigmatized group. This type of stigma perpetuates the exclusion of the stigmatized group and legitimizes the power differential that allows the dominant group to maintain control of systemic policies. Social stigma exists at a more personal level and includes discrimination by employers, housing officials, and community organizations based on a negative stereotype attributed to the stigmatized group. Social stigma also includes the reactions of friends, family members, and acquaintances with whom relationships may become strained when a person identifies as a member of a stigmatized group. Structural/institutional and social stigma are sometimes referred to as public stigma and are characterized by exclusion, rejection, blame, and devaluation of the stigmatized group by those outside of it (Bathje & Pryor, 2011). In response to public stigma, individuals of the out group may develop internalized stigma. Also referred to as self- or felt-stigma, this phenomenon manifests in the form of negative feelings that a person internalizes and believes about them self as a result of their exposure to the dominant group’s perception of their differences (Thoits, 2011). When individuals internalize public stigma, they anticipate rejection due to the belief that

they are not valued members of society. This may cause them to withdraw from activities or to engage in self-sabotaging behavior which reinforces the dominant culture's stereotype of the stigmatized group (Livingston & Boyd, 2010).

**Effects.** Since the 1990s, researchers have studied stigmatization in relation to a wide variety of issues including cancer, AIDS, mental illness, unemployment, welfare, wheelchair use, stepparents, debtors, and lesbian mothers with results almost always revealing negative effects of stigma at the personal, social, and institutional level. A 1995 study by Steel and Aronson highlighted the insidious nature of internalized stigma in African-American youth: When the youth were told that they were being tested for intellectual ability, African-American students scored much lower on an SAT test than their Caucasian classmates but, when the test was labeled differently, African-American students' scores rose and were nearly identical to their Caucasian counterparts. This study demonstrated the students' internalization of the dominant, but inaccurate view that African-Americans are less intelligent than Caucasians. Kadri and Satorius (2005) noted the vicious cycle highlighted in this and similar studies, wherein seeing evidence that supports the stereotype (lower test scores) causes the stigmatized group to further accept the stereotype, and therefore become less likely to challenge structural forms of discrimination that block opportunities for their group. Furthermore, they state that living with this discrimination is likely to decrease self-esteem while continuing to increase disability as a result of the stigmatized group's restricted access to social and financial resources. Ultimately, they found that the stigmatized individual is left with diminished reserves with which to resist the discrimination that intensifies and becomes more deeply entrenched with each repetition of the cycle.

The degree of stigmatization that an out group faces varies, ranging anywhere from merely annoying to life-threatening. Kurzban and Leary (2001) examined variables that contribute to the degree of stigmatization imposed on a group and found that influential factors include visibility of the “mark,” perceived danger or disruption to the dominant group, origin and course of the condition, and perceived responsibility of the individual or group. Existing research may be limited by the tendency for stigma to be defined and examined by people who have not personally experienced the stigmatization that is being studied. The exclusion of the stigmatized group’s perspective and description of their own lived experience may result in incorrect assumptions and misunderstandings which should be taken into consideration before interpreting the data on this subject (Link & Phelan, 2000).

### **The Stigmatization of Mental Illness**

**Portrayal and treatment throughout history.** Ancient cultures varied in their understanding and treatment of mental illness. Some locked the mentally ill outside the doors of the city or placed them in ships with no port to disembark, while others, like the Egyptians, viewed mental illness as similar to physical illness and treated it holistically. Prominent Greek and Roman thinkers including Aristotle, Hippocrates, and Galen, were early advocates for the compassionate treatment of mental illness, recommending the incorporation of conversation and story telling (a precursor to talk therapy) as well as humor, music, nutrition, and exercise into treatment (Byrne, 2001). Despite these early models of care, many European cultures continued to associate mental illness with demonic possession, moral deviancy, witchcraft, and the occult. During the Middle or Dark Ages, the mentally ill were often blamed for their condition which was believed to be sinful, and were punished or imprisoned as the Christian church saw fit (Arboleda-Florez & Stuart,

2012). Although the Renaissance saw a decline in the influence of supernatural beliefs, mental illness was still not clearly understood and fear of the unknown caused this group to continue to be labeled as dangerous and, in some cases, less than human in order to justify permanent incarceration or placement in workhouses with horrific living conditions. During the 17th and 18th centuries, the Industrial Revolution caused increasing importance to be placed on issues of social identity, worthiness, productivity, and health. During this time, the growing middle class found that they were better able to establish themselves as successful members of society by placing their identity against marginalized members of the community. This included the mentally ill who were given little say in their treatment, often being permanently institutionalized in asylums for behavior considered outside the norms of society (Smith, 2002). In support of the negative stereotypes associated with this population, individuals who suffered from mental illness were commonly portrayed by influential visual artists of the time in an unflattering manner, often being represented as beasts, violations of nature, and/or possessed by the devil (Quinn, Shulman, Knifton, & Byrne, 2011; Bathje & Pryor, 2011). This can be seen in Goya's "Casa de Locos," Sir Charles Bell's "Madman," Fuseli's "Mad Kate," and Lawrence's "Mad Girl" (Eisenhauer, 2008).

During the 1700s, a small group of physicians and administrators strived to change the public perception of mental illness. Dr. George Cheyne attempted to reframe the affliction of anxiety from "madness" to a body disorder in order to understand and treat it as a medical condition (Cheyne & Porter, 1990). Phillippe Pinel and Jean-Baptist Pussin introduced more humane treatment methods in European hospitals, removing shackles and listening to patients' complaints while Dr. Benjamin Rush advocated for mental illness to be referred to as "a disease of the mind" and called for dignified and compassionate treatment of patients at Pennsylvania Hospital, the first

mental health hospital in the United States. Although approaches such as bleeding, hot and cold baths, mercury pills, and gyroscopes were still used, mental health treatment also saw the emergence of homeopathic medicine, occupational therapy, and talk-based approaches that emphasized the importance of understanding, hope, and moral responsibility (Morrissey & Goldman, 1986).

Dorothea Dix continued the campaign for mental health awareness and humane treatment in the 1800s, lobbying for more than thirty government-sponsored hospitals in the United States (Fabrega, 1991). The increasing acceptance of mental illness as a condition similar to physical illness had both positive and negative consequences for those who were institutionalized. Hospital conditions improved and treatment became more humane, but the connection between mental illness and heredity sometimes caused a degenerative stigma to be placed on the entire family of the institutionalized person. As a result, some hospitals sterilized patients against their will in order to prevent the perpetuation of the genes thought to cause mental illness (Arboleda-Florez & Stuart, 2012).

The twentieth century saw the rise and fall of the lobotomy and electroconvulsive shock therapy as well as the introduction of psychiatric medication. The success of antipsychotic and mood-stabilizing medications in the 1950s led to the deinstitutionalization of the mentally ill. Patients who would previously have been permanently hospitalized were able to be discharged and return to their families where they were treated at community-based programs using a model of wellness and recovery. Although medication and community mental health organizations have proven to be successful for many people, deinstitutionalization remains controversial with opponents citing the increase of homelessness and incarceration in people with mental illness (Morrissey & Goldman, 1986).

**Manifestations.** Literature supports the assertion that the lives of people with mental illness are negatively affected by structural, social, and internalized stigma. Many areas of a person's life may be effected including personal relationships, social functioning, employment, living situations, medication compliance, treatment success, participation in community activities, and self-esteem (Bathje & Pryor, 2011; Byrne, 2001; Jenkins & Carpenter-Song, 2009; Link et al., 2004). Kadri and Sartorius (2005) believe that the stigma of mental illness may be the main obstacle to accessing care. Brown and Bradley (2002) agree, reporting that at least one fourth of people who live with mental illness don't seek treatment due to fear of stigmatization and discrimination. Stigma can play a debilitating role at every stage of mental illness: presentation, diagnosis, treatment, and outcome (Gyrne, 1997) with individuals being marginalized, disenfranchised, excluded, and denied the human rights and social entitlements that others take for granted (Arboleda-Florez & Stuart, 2012). Quinn and Chaudoir (2009) found that people who feel stigmatized report more symptoms from their mental illness and attribute these symptoms to the added anxiety of living with stigma. Ilic et al., (2011) also point to the additional burden and stress of stigma as an impediment to recovery. While research regarding the lifespan of people with mental illness varies with diagnoses, studies have shown it to be ten to twenty-five years less than that of the general population, in part due to the negative consequences of stigma (Arboleda-Florez & Stuart, 2012). As a result of these and other similar findings, reduction of stigma is now considered central to the promotion of mental health (Crabtree, et al., 2010).

***Public stigma (structural/institutional and social).*** Public stigma regarding mental illness can manifest in cognitive, affective, and/or behavioral reactions. Cognitive reactions include beliefs that people with mental illness are dangerous, unpredictable, lazy, unintelligent, and

responsible for their condition. Affective reactions include fear, anger, irritation, pity, and lack of empathy. Behavioral reactions include discrimination in employment, housing, and health care, as well as limited social interaction (Bathje & Pryor, 2011). Being a member of one or more stigmatized group can result in what Link and Phelan (2001) describe as “a dramatic impact on the distribution of life chances, whether those refer to career, earnings, social ties, housing, criminal involvement, health, or even life itself” (p.381). Byrne’s 1999 study reported that 47% of people with mental illness have been abused or harassed in public, 14% have been physically assaulted, 34% have been fired or forced to resign from a job, and 26% have moved back home because of harassment in other living situations. Extensive research agrees that members of this stigmatized group are likely to experience a potentially devastating effect on social functioning, interpersonal relationships, housing, employment, medication compliance, and treatment success (Jenkins & Carpenter-Song, 2009; Link & Phelan, 2001).

Literature suggests that the public stigma of mental illness is common and generally accepted in our cultural discourse, and that discrimination, fear, mistrust, anger, and avoidance of individuals who struggle with mental illness often goes unchallenged (Brown & Bradley, 2002, Eisenhauer, 2008). Crabtree et al. (2010) found that people with mental illness are thought to be less competent and fundamentally different from “normal” people and are often disliked, derogated, and discriminated against. A similar study by Falcato (2004) found that people with mental illness are seen as unpredictable and threatening, and that those perceptions cause people in the dominant group to maintain a “safe” distance. Crisp, Gelder, and Meltzer (2005) also demonstrated that people who have not experienced mental illness believe the the mentally ill are difficult to talk to and assume that they are inherently different from “normal” people. Within

the context of these studies, the beliefs and perceptions of the dominant group manifested in social distancing and a continued lack of familiarity with the realities of the sufferers' experience. The implications of public stigma appear to apply to health care professionals as well as the general public. This was demonstrated in a 2008 study by Jones, Howard, and Thornicroft that found evidence of "diagnostic overshadowing" in cases of people with mental illness who sought treatment for physical concerns. The study showed that patients' psychiatric histories are often factored into the treatment of their primary complaint, for example, a patient with acute back pain who was previously treated for depression might be prescribed an anti-depressant instead of receiving a more complete physical investigation of the presenting symptoms.

In addition to affecting the individual, public stigma may affect family members and caregivers which in turn threatens the support system of the person diagnosed with mental illness. Family members report feelings of shame, blame, and even a fear of "catching" the mental illness (Corrigan & Miller, 2004). The impact of stigma on caregivers is further reinforced by Link, et al.'s 2004 study which found that 70% of caregivers believe that people with mental illness are devalued and 43% believe that the person's family is also devalued and stigmatized.

***Internalized (self or felt) stigma.*** Literature shows that when the stigma surrounding mental illness is internalized, it manifests as poor self-esteem, lack of empowerment, low self-efficacy, and feelings of alienation. The negative consequences of internalized stigma may prevent timely access to treatment, delaying recovery and decreasing positive outcomes for people suffering from mental illness (Bathje & Pryor, 2011; Quinn et al., 2011). According to Crabtree et al., (2010), stigma continues to be a pervasive and serious concern amongst individuals with psychiatric diagnoses in mental health support groups, day centers, crisis centers, and hospitals, with

approximately one third of individuals diagnosed with severe mental illness acknowledging high levels of internalized stigma with negative implications for recovery. This population consistently reports high levels of hopelessness, demoralization, pessimism, thought confusion, and sadness in response to incidents of discrimination and/or stigmatization (Quinn, Shulman, Knifton, & Byrne, 2011; Munoz, Sanz, Perez-Santos, & Quiroga, 2011; Link et al., 2004). Ehrlich-Ben Or, et al., (2012) discuss the implications of internalized stigma using a “why try” framework that addresses (a) awareness of and agreement with the stereotype that is applied to the self, (b) the resulting reduction in self-esteem that leads to the avoidance of life goals, and (c) a lack of involvement in these activities that leads to a feeling of meaninglessness. Thoits (2011) proposes that the shame and poor self-esteem associated with accepting a stigmatizing label makes social interactions difficult and less genuine, and often leads to isolation. When a person is unable to feel genuinely connected to the others, it becomes difficult to fully accept helpful feedback, knowing that the world is not actually seeing the true self. Pachankis (2007) adds that internalized stigma is often coped with through secrecy, which can lead to a preoccupation with thoughts surrounding stigma. The need to suppress these thoughts while keeping a diagnosis secret can be a burdensome process for an individual to endure alone.

It is important to note that the manifestations and implications of internalized stigma may differ between males and females. Link and Phelan (2001) found that females diagnosed with mental illness tend to feel inferior because others may think less of them for having a mental illness or being in treatment, while males are more likely to feel inferior because of the diagnosis or treatment itself. More research is needed into other cultural elements that may play a role in the process of internal stigmatization. Based on these and many other similar

studies, it is clear that the internalization of stigma is detrimental to the treatment of mental illness and it stands to reason that programs designed to help prevent and/or cope with the insidious manifestations of internalized stigma could be highly beneficial to people who suffer from mental illness.

### **Mental Illness and Identity Formation in Young Adults**

**Developmental challenges of young adults.** Researchers agree that the formation of a coherent and cohesive personal identity is an important developmental milestone for young adults (Tesch & Cameron, 1987; Cote, 2006; Erikson, 1980). Although brain growth is complete, young adults develop the capacity to apply knowledge and use their analytic capabilities, and continue to experience changes in the frontal lobes of the cerebral cortex that effect judgment, planning, speaking, and some muscle movement into their early twenties. Erikson and Freud both identified emerging adulthood as an important time for individuals to form intimate relationships (Darling-Fisher & Leidy, 1988). Piaget identified this stage with achieving the capacity for flexibility in thought, being able to understand multiple opinions on an issue, and knowing how to approach a problem from different angles. Unlike adolescents, Piaget believed that young adults are no longer set on finding absolute truths (Benson & Elder, 2011).

Researchers identify the developmental experience of young adults as a gradual transition to adult roles and responsibilities as well as a weakening of the safety net that supports adolescents (Park, Mulye, Adams, Claire, & Charles, 2006). Young adults engage in identity exploration with greater freedom and fewer constraints as they work towards developing successful careers and achieving independence from their families-of-origin (Pepper, Kirshner, & Ryglewicz, 2000). The post-industrial economy, along with changes in women's roles, have allowed for

more variability in the timing and order of young adult transitions such as leaving home, entering and graduating from school, entering the workforce, and forming a family. These changing social norms have allowed this phase of life to last longer than in past generations, sometimes extending the period between parental control and the expectation to start a family into the early thirties (Benson & Elder, 2011; Darling-Fisher & Leidy, 1988). As with all issues of identity, it is important to acknowledge cultural differences regarding the timing and value placed on this separation from the family-of-origin.

Despite the unique challenges and transitions that face young adults, this stage of life is given relatively little attention, with programs for young adults often being grouped with those for adolescence despite important differences in access to health care, support systems, routines, and expectations (Park, et al., 2006). More research is needed regarding young adult health issues, programs, and policies that could be beneficial during this important phase of life.

**Prevalence of mental illness in young adults.** Young adults have a higher prevalence of mental illness than other age groups. It is estimated that 25.3% of young adults (age 18-26) in the United States suffer from a moderate or mild mental illness and that 6.5% suffer from a serious mental illness in a given year. The most common diagnoses for this population are major depressive disorder, specific phobia, bipolar disorder, alcohol abuse, and social phobia. In addition to the Axis I diagnoses, some studies report that approximately 20% of young adults meet the criteria for an Axis II personality disorder (Byrne, 1999). Amongst young adults receiving social security or disability insurance, the most common diagnoses are schizophrenia and other psychotic disorders, affective mood disorders, anxiety disorders, and personality disorders (Park et al., 2006). Because these numbers are based on a survey that does not include young adults who

are homeless, institutionalized, or incarcerated, the actual numbers may be significantly higher (Pepper, Kirshner, & Ryglewicz, 2000).

Many illnesses, including bipolar disorder, major depressive disorder, anxiety disorders, and schizophrenia, are first diagnosed in the late teens or early twenties, during a period of frontal lobe development in the brain. The median age of onset for both men and women is twenty for bipolar disorder and mid-twenties for major depressive disorder. The median age of onset for schizophrenia is eighteen for men and twenty-five for women. Most literature on this subject agrees that approximately three out of four adults diagnosed with mental illness display symptoms before the age of twenty-five (Mossakowski, 2011).

**Challenges for young adults with mental illness.** A large body of research has explored the stigmatization of mental illness, but there is comparatively little known about the experience of stigma specific to young adult members of this population (Moses, 2009). The existing research does agree that being stigmatized at this critical time is likely to decrease the rate of recovery, lead to greater social and familial problems, and increase anxiety as a result of living with the day to day experience of stigma (Biddle, Donovan, Sharp & Gunnel, 2007). As previously stated, the transition to adulthood is marked by life transitions that include the completion of higher education, successful employment, marriage, and parenthood. Mental illness often delays these milestones or leaves them unfulfilled, resulting in chronic stress, impatience, frustration, and a weaker sense of personal control over one's life. Young adults with mental illness may feel permanently stuck between the parental support of childhood and the adult autonomy they desire (Pepper & Ryglewicz, 2000). Mossakowski (2001) conceptualizes this as a troubling incongruence between the ideal self and the actual self, and reports that the disappointment of

unfulfilled expectations may be internalized as depression. Individuals who experience depression during this phase of life have a higher tendency towards eating disorders, violence, and suicide than older individuals and often report an insecure sense of identity, unsatisfactory relationships, and feelings of isolation.

Chickering and Reisser (1993) discuss seven commonly agreed upon tasks of emerging adults that may be affected by mental illness:

1. Achieving competence: intellectual skills for academic success, manual skills for manipulating the environment, and social and interpersonal skills for relating to others.
2. Managing emotions: resolving authority (child/parent, student/professor) relationships, controlling sexual impulses.
3. Moving from dependence through autonomy to interdependence: use of well-adapted coping behaviors to become self-sufficient, self-directed, and goal-directed; collaborative and team skills.
4. Developing mature interpersonal relationships: tolerance for a wider range of people and beliefs, capacity for intimacy.
5. Establishing identity: clarifying personal values, solidifying a sexual identity, selecting an ethical and moral position for oneself, answering the questions “Who am I?” and “Where am I going?”
6. Developing purpose: appropriate and attainable education or career plans, deciding upon a lifestyle to meet one’s personal needs.
7. Developing integrity: personally valid set of beliefs, humanizing values, congruence between personal values and behavior, social responsibility.

In comparison to children and adolescents, people who are diagnosed as young adults report a greater struggle to develop a cohesive adult identity within the context of having a mental illness, often expressing the need to “find or adapt to their real self” following diagnosis. Young adults also differ from older adults with mental illness in that they are new to the adult mental health system and may be struggling to understand and access the resources available to them. Those who received services through DCFS or school-based programs as adolescents may feel overwhelmed when they are suddenly expected to seek out their own services. Having been with a cohort of age-mates throughout their school years, young adults who begin experiencing the symptoms of mental illness may feel a sense of failure if they fall behind their peers in reaching developmental milestones such as higher education and independent living. When young adults are unable to keep up with peers, they are likely to become withdrawn and/or rebellious which can result in self-medication via alcohol and drug abuse. Having not yet learned to take full responsibility for themselves, young adults are more likely than older adults to place anger and blame on parents, landlords, police, mental health professionals, and society as a whole, which may make them less inclined to seek treatment (Pepper & Ryclewicz, 2000).

Biddle, Donovan, Sharp and Gunnel (2007) state that less than one third of young adults with mental illness seek treatment, and Pepper and Ryclewicz (2000) add that for every one who does seek treatment, there are likely between two and ten in the community who are incarcerated, homeless, or living in dysfunctional families. Several factors account for this population’s resistance to treatment. Studies show that young adults have a polarized view of mental illness and are hesitant to assign the label to anything less than rare and permanent conditions associated with major breakdowns. All other suffering is categorized as normal, universal, inevitable,

or a phase that will pass and therefore, does not warrant treatment. Young people also report that, once placed in the group that does require treatment, a person may be permanently stigmatized, avoided, and denied the right to be “normal” like everyone else. For this population, it is possible that seeking help makes the mental illness feel too real and turns a private problem into something that is public and official. When viewed as a public acknowledgment of a change in identity that is marked by an irreversible passage to a lower status, it is easy to understand why young adults are resistant to seeking treatment (Biddle et al., 2007). This population may also be vulnerable to pressure from family members, via rejection or denial of the condition, that mental illness should not be discussed outside of the family. Lipe et al.’s 2012 study revealed that, although not completely rejected by friends and family members, youth commonly report negative changes in their interpersonal relationships following their diagnosis, hospitalization, or disclosure of treatment, stating that they feel as if they are viewed as being different, defective, and no longer worthy of trust.

The integration of young adults with older adults who struggle with chronic mental illness raises many interesting issues. Although older adults may be able to help young people learn to navigate the mental health system, they may also invoke fear and despair in young adults who had different plans and dreams for their future. Within residential treatment centers, older, de-institutionalized patients may have different challenges and needs than young adults due to the advances in medications over the last fifty years. It is not uncommon for young adults in these residences to report symptoms of depression in regards to what the future holds for them. More research is needed on the benefits of alternate residential programs that are specifically tailored to the needs of the young adult population (Pepper & Ryclewicz, 2000).

## **Stigma Reduction**

The Surgeon General has identified stigma as “the most formidable obstacle to future progress in the arena of mental illness and health” (U.S. Department of Health and Human Services, 1999) and listed the reduction of stigma as an important public health goal. The literature on stigma reduction examines the use of individual and group therapy as well as psychoeducation to lessen the experience of internalized stigma for people with mental illness and their families (Barney, et al., 2009; Crabtree et al., 2010; Pachankis, 2007; Smith, 2002). It also reviews media campaigns and public programs aimed at the reduction of institutional and social stigma that continue to negatively affect this group (Byrne, 1999; Kadri & Satorius, 2005; Stuart, 2008). Art therapy literature examines the increasing number of recovery-based mental health programs that follow the clubhouse model of treatment. These programs often incorporate art-making and/or exhibiting as a therapeutic tool for combatting both public and institutionalized stigma (Heenan, 2007; Lamb, 2009; Lipe et al., 2012; Mango, 2011; Meeson, 2012; Potash & Ho, 2011). Most of the literature from the past twenty years has focused on holistic, recovery- and strength-based interventions that emphasize personal growth and the development of purpose beyond the symptoms and stigma of mental illness (Heenan, 2007). Recovery is viewed as a journey that involves the relinquishing of the old self so that a new, equally valid sense of self may emerge (Van Lith, Fenner, & Schofield, 2011).

**Individual and group therapy.** Research on the reduction of internalized stigma focuses primarily on cognitive-behavioral, narrative, and creative therapies. Cognitive-behavioral therapy interventions were used successfully by Livingston and Boyd (2010) in a group setting for people with mental illness. Researchers measured participants’ internalized stigma, quality of life, feelings of devaluation, and incidents of discrimination, and participants reported having a better

understanding of the origins of their negative self-thoughts and a stronger ability to cope with public stigma as the group progressed. A study by Yanos, Roe, West, Smith and Lysaker (2012) implemented the Beck Hopelessness Scale and found that cognitive restructuring geared toward teaching people with mental illness the skills to challenge negative self-beliefs resulted in improved scores regarding pessimism about the future. Yanos et al. (2012) combined narrative and cognitive-behavioral therapy in a four-part group that allowed clinicians to assess the subjective experience of stigma in people with mental illness. The group proved successful in enhancing members' ability to reflect upon and deepen their personal narrative and also showed an increase in members' coping skills, strategies to deal with symptoms of mental illness, and psychosocial functioning. Thoits (2011) offers support for the use of narrative therapy, stressing that "self-restoration is an important coping mechanism after experiencing social devaluation" (p.12).

**Support groups.** Researchers agree that connecting with others who share similar concerns and challenges is often beneficial for people with mental illness who may otherwise have difficulty establishing a strong support system. Social identity theory reinforces the key role that group membership plays in determining an individual's self-esteem. In addition to reducing isolation, support groups allow people with mental illness the opportunity to help others and be acknowledged as a valued part of a group (Thoits, 2011). Branscombe (1999) addresses the benefits of support groups using a rejection-identification model to understand how disadvantaged populations deal with prejudice through stigma resistance and stereotype rejection. He states that within a group that shares a stigmatized identity, members are able to find a safe space for giving and receiving the social support as well as the emotional, intellectual, and material resources needed to resist stigma. A study of seventy-three women diagnosed with mental illness (bipolar

disorder, borderline, depression, OCD, psychosis, and schizophrenia) in England found that the level to which a person identifies with a support group predicts their likeliness to resist both the public and internalized stigma of mental illness (Crabtree, et al., 2010). A similar study interviewed seventeen people with mental illness and found that being involved in a community of people who share similar challenges gives people the strength to reject negative stereotypes and the compassion to embrace themselves as they are. Participants in this study reported an increase in personal resources for coping with stigma-related stress, specifically citing their use of humor to cope with challenges (Ilic, et al, 2011).

While support groups often provide a much-needed sense of community and belonging for people with mental illness, it's important to note that the literature on this subject also addresses potential risks of membership. Identifying as part of a stigmatized group may be dangerous in some communities and may put a person at risk for further judgment and discrimination (Hall & Cheston, 2002). Although publicly acknowledging membership in a stigmatized group may be painful, and personal safety should always be a priority, most research does support the long-term benefits of the self-enhancement, community involvement, and collective re-empowerment that are made possible by the group.

**Psychoeducation.** Researchers agree that psychoeducation regarding the biological constructs of mental illness are beneficial in combating the harmful effects of stigma on self-esteem. Shin and Lukens (2002) tested the impact of a brief psychoeducation intervention in addressing the needs of Korean-Americans with schizophrenia. For ten weeks, participants received weekly group therapy as well as individual supportive sessions aimed at enhancing participant learning and increasing understanding of the disease. Compared with a control group, the participants

showed a significant decrease in stigma perception and severity of psychiatric symptoms as well as an increase in coping skills, suggesting that culturally appropriate psychoeducation programs can be an effective short-term treatment for people suffering from mental illness. Psychoeducation is also effective for families of people with mental illness. Researchers agree that interventions must be attuned to cultural values and norms regarding family structure and beliefs about mental illness and treatment (Brown & Bradly, 2002).

**Public initiatives and activism.** Over the last thirty years, public initiatives such as media campaigns, legislative reform, social activism, and contact-based psychoeducation have been implemented in several countries with the goal of reducing the stigma of mental illness (Arbole-da-Florez & Stuart, 2012). Literature shows that while education and empathic media portrayal can help reduce the stigma of mental illness, the most effective intervention may be having a person with mental illness relay their life story and experience of illness to others in their own words. Hearing an individual's lived experience seems to have a broader impact on stigma reduction than education alone (Corrigan et al., 2007). In 1998, the World Psychiatric Association (WPA) initiated the global "Program against stigma and discrimination because of schizophrenia – Open the Doors," which currently exists in at least twenty countries around the world (Sartorius & Schulze, 2005). In Turkey, "Open the Doors" collaborated with The Friends of Schizophrenia to create a one-day stigma reduction program designed to change public attitudes amongst medical students at Harran University. The intervention group received two hours of education regarding the causes of stigma associated with schizophrenia, common myths about schizophrenia, and the relationship between schizophrenia and violence. In addition, a person with schizophrenia introduced himself and discussed his experience with the students. Finally the students

watched *A Beautiful Mind*, a film about a brilliant mathematician who suffers from schizophrenia and his difficulties at work and in personal relationships (Altindag et al., 2006). Students in the intervention group had a more favorable view after the stigma reduction program in regards to their beliefs about the causes of schizophrenia, their intermediate social distance to people with schizophrenia (co-workers, neighbors), as well as their attitudes toward the care and management of people with schizophrenia (Livingston & Boyd, 2010). The literature suggests that people with mental illness who live in countries where the general public feels more comfortable talking about mental health problems report lower levels of internalized stigma and higher levels of empowerment. This may reflect the impact of anti-stigma programs at the national and/or local level and the importance of promoting the social inclusion of those with mental illness (Corrigan et al., 2001; London & Evans-Lacko, 2010).

Supporting the notion that contact is crucial to changing public opinion, activism amongst those with mental illness, including the work of NAMI (National Alliance on Mental Illness) and the Changing Minds anti-stigma campaign, has been shown to lessen public stigma while simultaneously improving the psychological well-being of the activists who are empowered by their ability to bring about social and political change (Crabtree et al., 2010; Kurzban & Leary, 2001). These groups emphasize normalization of mental health differences as well as the removal of labels that separate “us” from “them.” They also model the use of politically correct language regarding mental illness, emphasizing that a person *has* schizophrenia as opposed to labeling someone as a schizophrenic, which suggests that the diagnosis overrides all other elements of identity. This approach has been shown to be a key factor in the success of campaigns that oppose stigma and discrimination (Smith, 2002). Activists also point out that although we have

recognized descriptions for many prejudiced beliefs such as racism, ageism, religious bigotry, sexism, and homophobia, there is currently no language to describe and fight against the stigma of mental illness (Byrne, 2000).

A recent study by Clement et al., (2010) supports the *See the Person* message that is prominent in anti-stigma campaigns throughout Wales, Denmark, the Netherlands, Australia, England, Ireland, New Zealand, Scotland, and the United States. These anti-stigma programs aimed at the general public have helped to increase support for mental illness at a political and legislative level. It seems that targeting the public through mass anti-stigma interventions may lead to a virtuous cycle by disrupting the negative feedback engendered by public stigma, and thereby reducing internalized stigma amongst people with mental illness (Evans-Lacko et al., 2002). Ritterfeld and Jin (2006) expanded on this idea using an entertainment-education strategy to evaluate whether an accurate empathic media portrayal combined with an educational trailer could increase knowledge about schizophrenia and contribute to stigma reduction. Although they were able to see both an increase in knowledge and a decrease in stigma, it is important to note that the behavioral component of stigma was shown to be more difficult to change than the emotional or cognitive components.

**Community programs.** The current literature reveals that many mental health programs are now based on the 1990s recovery model emphasizing the on-going process of self-discovery, transformation, and an internal shift from feelings of helplessness and despair to feelings of competence and hopefulness (Meeson, 2012). The recovery model asserts that, with appropriate support, even the most severe and enduring mental health issues can be overcome, not by the absence of symptoms, but by having the necessary assistance to pursue self-defined goals and experience a fulfilling life (Spandler, Secker, Kent, Hacking, & Shenton 2007). Community programs

using this approach may offer a realistic and cost-effective solution to support large numbers of people who suffer from mental illness. These programs offer traditionally disempowered groups the opportunity to have a greater sense of control over their lives (Crabtree et al., 2010; Ehrlich-Ben Or et al., 2012) by fostering insight, self-esteem, confidence, empowerment, connectedness, and social engagement (Van Lith, Renner, & Schofield, 2011). Participants are no longer passive recipients of services, but are advocates for themselves and other members of their group in the fight against stigma (Ehrlich-Ben Or et al., 2012).

Some community programs incorporate the clubhouse model that was originally pioneered by Fountain House of New York City in 1948. Limited existing research shows that this model may be especially effective for young adults. Programs that use the clubhouse model refer to participants as “members” rather than “patients,” and ask them to take ownership of their group by working cooperatively with staff and contributing to the success of the program. These programs offer prevocational day programs, transitional employment programs, help with living situations, support groups, thrift shops, newsletters, psychiatric consultation, medication management, physical health programs, and a wide variety of creative art-based classes and activities. Emphasis is placed on development and support of social and recreational skills that will allow members to combat stigma and isolation and become productive members of their community (Lipe et al., 2012).

### **Use of Art to Combat the Stigma of Mental Illness**

The existing art therapy research shows that the visual arts as well as other creative endeavors can play a positive role in healing the human body, mind, and spirit by increasing hope, empowerment, and inclusion while decreasing the effects of stigmatization on an individual’s sense of self (Lipe et al., 2012; Quinn, Shulman, Knifton, & Byrne, 2011). The use of art, whether in individual

practice, group therapy, open studios, classes, or exhibits may help stigmatized populations create a sense of meaning and purpose, develop new coping mechanisms, and rebuild identity (Spandler, et al., 2007; Van Lith, Fenner & Schofield, 2011). Recent literature acknowledges the growing use of psychosocial art-based initiatives in community mental health programs, highlighting the success of the increasingly popular clubhouse model. One such organization is Towers Above, a community-based mental health program in England that offers thirteen-week art projects led by group members, culminating in a public exhibition. A study of sixty-two participants from this program reported improvement in relation to emotional disturbance, social inclusion, and empowerment (Secker et al., 2009). Two community-based clubhouse organizations in Glasgow, Trongate Studios and Art Angel, incorporate sculpture, writing, film-making, performance, and crafts in addition to visual arts in their programs for adults with mental illness. Participants report that the creative activities act as a stabilizing force that becomes a stepping stone to reconnecting with a wider social circle outside of the artistic space. They also believe that the act of creating with others provides a sense of belonging and inclusion that acts as an opposing force to stigmatization (Heenan, 2006).

Programs that follow the clubhouse model are not currently available in all parts of the country and are often not age specific. The few that offer resources specifically targeted towards young adults have had a positive response to the incorporation of art-based interventions and activities, and will hopefully serve as a model for future programs who wish to serve this vulnerable population. Although emphasis is often placed on socialization and community involvement, it is important to consider that not all members of stigmatized groups want to function within a community that has rejected them. For members who make a con-

scious choice not to try to fit in with the dominant group that has rejected and stigmatized them, community programs may provide a safe place to renew their identity without subscribing to the dominant group's social norms and to accept and value themselves exactly the way they are (Spandler et al., 2007).

In addition to the personal benefits of art-making, art therapy literature addresses the use of the public sphere to empower clients by sharing their artwork with the community. Art shows can work towards the destruction of public stigma and act as an impetus for social change (Mango, 2011; Potash, & Ho, 2011). Not only can the public display of art act as a vehicle for personal growth but it can also provide an opportunity to access previously unreachable groups within one's community (Barney, Griffiths, Christensen, & Jorm, 2009.) Art therapy literature agrees that gaining understanding of another's experience leads to greater empathy, and points to the power of art to cross cultural barriers and positively impact social issues. Specifically, art allows the viewer to symbolically interact with a marginalized group in a way that may not be otherwise possible and which may result in greater compassion and understanding. Within this context, Potash and Ho (2011) view the art therapist as a social activist who fosters the creative process in hopes of facilitating meaningful relationships. They engage Ghandi's philosophy of nonviolent resistance using art as a force designed to promote truth and create an empathic bridge between those who are oppressed and those who have the power to alleviate oppression. This is accomplished by displaying art that communicates the artist's genuine emotional experience to the viewer in hopes that it may be possible for the oppressed "out" group to maintain a persistent presence which may allow the dominant "in" group to experience increased empathy and a decreased need for social distancing. This idea is supported by a study of 951 people designed to examine the attitude of the Japanese

public towards mental illness. Participants were interviewed before and after visiting an art exhibition created by people with mental illness and results showed that art had the potential to reduce stigma, enhance community relations, and allow people to feel more comfortable discussing their views and misconceptions about mental illness (Yamauchi, et al., 2009). Further evidence of the therapeutic value of art for both the creator and the viewer was provided by Chambala's 2008 study of an eight-week art therapy group at an inpatient psychiatric unit. Patients created imagery that expressed their anxiety as well as their strategies for coping with the symptoms of mental illness. When the art was displayed in the hospital, the researcher found evidence for increased public awareness regarding anxiety, and participants reported feeling a sense of empowerment as well as pride in their new identity as artists within their community.

The Awakenings Project strives to raise public awareness and acceptance of mental illness by hosting art exhibits and publishing a literary magazine of works by adults with mental illness. Participants report that the art process has the ability to heal wounds, renew hope, and provide a new sense of purpose and identity ([www.awakeningsproject.org](http://www.awakeningsproject.org)). A similar organization, NAEMI (National Art Exhibitions of the Mentally Ill), maintains a permanent collection of over 1,000 works of art by adults with mental illness and publishes books about the art in hopes of educating the public and reducing stigma ([www.naemi.org](http://www.naemi.org)). The gallery VSA Arts provides the opportunity for artists with physical and psychiatric disabilities to display their art with the intention of reducing stigma. A traveling show called *The World Through Our Eyes* displays the art of children diagnosed with severe emotional disturbance with hopes of decreasing stigma by providing educational materials and resources for the public. The children involved report increased self-esteem and pride at being able to interact successfully with others.

In addition to art, other forms of performance, such as music, have also been successful in mental illness stigma reduction. In Scotland, the percussion group *Drumdee*, created for adults with severe mental illness, aims to promote social inclusion and create hope and meaning in members' lives. *Drumdee* participants report enhanced confidence from mastery of an activity within a social context and the group seems to be especially valuable for the most socially isolated service users. Of the participants, 96% felt a sense of achievement, 92% felt they had gained confidence and motivation, and 65% became more active outside of the group and reported better connections with family and friends. Researchers also observed a greater level of eye contact and nonverbal communication as well as improvement in personal hygiene and more interest in appearance. Along with providing the opportunity for emotional expression and self-exploration, being included and accepted within this group resulted in lower levels of internalized stigma and made members more capable of coping with public stigma (Cathro & Devine, 2012).

Although there appear to be many benefits of community-based arts organizations, it is important to also consider the potential risks. Participating in community projects designed to create a conversation about mental illness can be frightening for participants who may worry about disclosing their condition and being judged or further stigmatized. Despite this risk, most research shows that disclosure and education can have a positive impact on emotional and mental well-being, giving participants more personal empowerment and satisfaction (Meeson, 2012; Crabtree et al., 2010; Ehrlich-Ben Or et al., 2012; Van Lith, Renner & Schofield, 2011; Lipe et al., 2012; Spandler, et al., 2007; Heenan, 2006). Corrian (1999) adds that people who disclose their mental illness report lower levels of self-stigma and a higher overall quality of life.

### **Conclusion**

This literature review has examined existing research on the stigmatization of mental illness, the developmental challenges of young adults, and the use of art-making as a tool to combat both public and internalized stigma. Although more research is needed regarding the impact of art-making on young adults with mental illness, it seems likely that the integration of art into recovery-based clubhouse programs may assist young adults with identity formation and empower them to act as advocates who are able to educate the public on mental health issues.

### **Research Approach**

In order to better understand the experience of stigma and identity formation in young adults with chronic mental illness, this qualitative study utilized a semi-structured, art-based focus group intended to allow for the emergence and exploration of both verbal and visual meaning within a natural setting (Denzin & Lincoln, 1994). According to Fontana & Frey (1994), focus groups are flexible and stimulating for participants and often aid in recall as well as in elaboration, making them a rich source of diverse data. Kapitan (2010) agrees that the personal and interactive nature of this style of research lends itself to honest accounts of sensitive material that may remain hidden in a more formal survey. Using a small population provided the opportunity to capture each individual's story and conceptualize an in-depth understanding of the complexities of this nuanced subject matter. It also allowed members to engage in conversation with each other as topics emerged and unfolded. The art-making portion of the focus group corresponded to the humanistic and interactive approach of a qualitative study and gave members a non-verbal mode of expression. Art acted as stimuli for discussion (McNiff, 1998) and, by allowing metaphor, symbol, and cultural code to more fully convey meaning, proved to be a "vitally important way of acquiring and communicating information about the human experience" (Kapitan, 2010, p.165). Following French et al.'s (1993) approach, data gained from the art and discussion was categorized, coded, and analyzed, allowing themes that captured the meaning of the participants' experiences to emerge. Demographically, it was important to view the data through a multi-cultural and developmental lens when attempting to discover relationships between mental illness, stigma, and identity formation. Following an inductive, qualitative approach allowed this study to explore, describe, and interpret the subject matter but, due to the small sample size, data is not generalizable to other situations. This investigation

hopes to inform future treatment programs for this population and may bring about greater public awareness of the influence of stigma in young adults with chronic mental illness.

## **Methodology**

### **Definition of Terms**

**Stigma.** The word stigma is derived from the Greek “stig,” meaning mark (Brown & Bradley, 2002) and is defined by the American Heritage College Dictionary (2006) as a “mark of disgrace or reproach.” Influential sociologist Erving Goffman explored the concept of stigma in his book, *The Presentation of Self in Everyday Life* (1964), describing it as the process by which the reaction of others spoils normal identity. Individuals may become stigmatized when they have characteristics that differ from others and have been designated as inferior (Crabtree, Haslam, Postmes, & Haslam, 2010).

**Mental illness.** Mental Health America (formerly the National Mental Health Association) defines mental illness as “a disease that causes mild to severe disturbances in thought and/or behavior, resulting in an inability to cope with life’s ordinary demands and routines” ([www.mentalhealthamerica.net](http://www.mentalhealthamerica.net)). Mental illness may be caused by environmental stresses, genetic factors, biochemical imbalances, or a combination of these and may include physical as well as emotional and psychological symptoms. The *Diagnostic and Statistical Manual of Mental Disorders* provides a common language and standard criteria for over two hundred mental disorders and is used by mental health professionals around the world. The *DSM* was originally published in 1952 and the current version (*DSM-IV-TR*) was published in 2000. The National Institute of Mental Health reports that approximately 25% of adults in the United States experience a mental illness in a given year and approximately 6% live with a serious mental illness.

**Schizophrenia.** Schizophrenia is a chronic, severe, and often disabling brain disorder that involves a range of cognitive and emotional dysfunctions including delusions, hallucinations, disorganized speech, affective flattening, and catatonia. Schizophrenia may affect perception, inferential thinking, language and communication, behavioral monitoring, fluency and productivity of thought and speech, hedonic capacity, volition, drive, and attention. It is associated with impaired occupational or social functioning and affects approximately 1% of adults in the United States. The median age of onset is eighteen in men and twenty-five in women (4th ed., text rev.; *DSM-IV-TR*; American Psychiatric Association, 2000).

**Bipolar Disorders.** Bipolar Disorders are characterized by a combination of manic, hypomanic, depressive, dysthymic, and mixed states that negatively affect the ability to carry out day-to-day tasks due to unusual shifts in mood, energy, and activity levels. These disorder may include psychotic features and are often associated with substance abuse. It is estimated that 10-15% of people with this diagnosis will die from suicide. The median age of onset is twenty in both men and women (4th ed., text rev.; *DSM-IV-TR*; American Psychiatric Association, 2000).

**Major Depressive Disorder.** Major Depressive Disorder is a disabling illness that prevents a person from functioning normally and is characterized by feelings of hopelessness, pessimism, guilt, worthlessness, helplessness, irritability, restlessness, loss of interest in activities once pleasurable, fatigue, difficulty concentrating and making decisions, insomnia or excessive sleeping, overeating or appetite loss, and thoughts of suicide. The median age of onset is mid-twenties in both men and women (4th ed., text rev.; *DSM-IV-TR*; American Psychiatric Association, 2000).

**Posttraumatic Stress Disorder (PTSD).** PTSD is caused by exposure to an extreme traumatic stressor, often involving actual or threatened death or injury to the self or another per-

son, resulting in feelings of intense fear, helplessness, or horror. Symptoms may include reliving the event through flashbacks, avoidance of things related to the trauma, psychic numbing, feeling detached or estranged from others, difficulty sleeping, recurrent nightmares, exaggerated startle response, hyper-vigilance, irritability, angry outbursts, and difficulty concentrating. PTSD can occur at any age and can be the result of one large trauma or the accumulation of smaller traumas. The severity and duration of symptoms vary for each individual (4th ed., text rev.; *DSM-IV-TR*; American Psychiatric Association, 2000).

**Borderline Personality Disorder.** Borderline Personality Disorder generally presents by early adulthood and is characterized by a pervasive pattern of instability in interpersonal relationships, self-image, and affect as well as chronic feelings of emptiness. Individuals experience an intense fear of abandonment and often display impulsive and self-harming behaviors. Borderline personality disorder affects approximately 1.6% of adults in the United States. (4th ed., text rev.; *DSM-IV-TR*; American Psychiatric Association, 2000).

**Focus group.** A focus group collects data through group interaction on a topic determined by the researcher. Interaction is achieved by encouraging participants to ask each other questions, exchange stories, and comment on others' experiences. Data gained in the focus group cannot be taken out of the cultural, social, and emotional context in which it occurs and the results, therefore, cannot be generalized to other situations (Rothwell, 2010).

**The Painted Brain.** *The Painted Brain* is a creative arts and advocacy organization for young adults who suffer from mental illness. Through magazines, art shows, and support groups, members promote awareness of mental health issues and challenge negative assumptions about this often marginalized population. *The Painted Brain* creates a sense of community for young

adults who experience the challenges of living with a mental illness and gives them a voice with which to combat stigmatization and isolation. Members' poetry, prose, and artwork are published in a biannual magazine and can be viewed online at [www.paintedbrain.org](http://www.paintedbrain.org).

### **Design of Study**

**Sampling.** Upon receiving approval from the IRB (Appendix AA), a convenience sampling method was utilized to select six participants for this study (French, Reynolds, & Swain, 1993). Sample size was determined for the practical reasons of allowing enough time for participants to engage in an art directive and ensuring that each member of the group was able to share their opinions and experiences. For this study, I included the first three males and first three females to respond to my invitation. On the day of the focus group, one member did not show up which reduced the sample size to five: two males and three females. Participants were sampled from *The Painted Brain*, and therefore fit the criteria of being between twenty and thirty-five years old, being diagnosed with a chronic mental illness, and having experience with art-making. Participants were required to speak English and were excluded if they were judged to be unstable by Mr. Dave Leon, LCSW, founder of *The Painted Brain*. In order to avoid creating a potentially confusing and harmful dual relationship, members of *The Painted Brain* whom I had met during my first-year practicum at Daniel's Place (a community mental health organization for young adults) were also excluded from the study.

Mr. Leon offered to help coordinate this research (Appendix A) and, to insure that no one was approached in a way that might feel overwhelming, he made the initial contact with participants. I provided Mr. Leon with a flyer that gave a brief explanation of the study and the requirements for participation which he distributed to members of *The Painted Brain* (Appen-

dix F). Once referred by Mr. Leon, I met with the selected participants to explain the research in greater detail and to gain consent (Appendix B). Participants were told that they would be taking part in a focus group with the purpose of exploring stigma and identity in relation to mental illness, and that it would include an art directive. Participants were informed of their right to confidentiality and they signed consent forms using initials or a chosen pseudonym. Participants' real names were not known to me and, therefore, were never used in the research. In both the transcription and the final research paper, participants are referenced by their initials or their chosen pseudonym. Participants were informed that the group would be audiotaped, the art they created would be photographed, and the resulting data would be stored in a secure location until the research was finished in May, 2013, at which time it would be destroyed. It was made clear that participants could leave the focus group at any time if they felt uncomfortable and that they could request that any or all of their verbal contribution or artwork was not used in the final research project. Participants had the opportunity to ask questions about anything that might have been unclear regarding their involvement in the research and were again reminded of their right to withdraw at anytime. Participants were given a copy of their signed and dated consent form as well as a copy of the LMU Experimental Subjects Bill of Rights (Appendix C).

**Gathering of data.** For this research, data was gathered in the form of a qualitative, semi-structured, art-based focus group in order to allow space for participants to expand and elaborate on their own and others' experiences as they saw fit. To provide comfort and convenience for participants, the focus group took place at *The Painted Brain* headquarters in downtown Los Angeles. Mr. Leon, a licensed social worker, was in the building for the entirety of the three-hour focus group. My own experience providing individual and group therapy for young

adults with chronic mental illness, as well as my graduate training at LMU and completion of the NIH PHRP (Appendix E), enabled me to create a comfortable, nonthreatening environment where participants were supported before, during, and after the focus group.

The group began with an art directive “Use these materials to express something about your personal experience with stigma.” Participants were provided with art materials including paper, markers, oil pastels, tissue paper, collage images and phrases, plasticine, toothpicks, pipe cleaners, cotton balls, and a variety of found objects and were allowed to work on as many projects as they chose throughout the course of the three-hour group. As they engaged in the art process, the researcher opened up the discussion using a semi-structured format that included the following prompts: 1) Introduce yourself to the group in whatever way feels comfortable to you, 2) In what ways have you experienced the public or systemic stigmatization of mental illness? 3) How have you dealt with internalized or self-stigma? 4) How has your experience with mental illness influenced your identity? 5) What does being part of a creative community mean to you? Members engaged in discussion of both planned and emergent topics, sharing their own experiences and responding to the experiences of others. They acknowledging similarities and differences in the meaning attributed to the topics and offered empathic support to their fellow group members.

After the focus group, the artwork was photographed and participants were given the option to keep or dispose of their original pieces. The purpose of this research was reiterated and participants were reminded of the confidentiality clause that prevents the rest of the group from repeating anything that was shared. They were also reminded that no identifying information would be used in the research. Members were individually assessed to determine if they had experienced distress as a result of the focus group and/or required follow-up care. All participants

were given Mr. Leon's contact information as well as a list of resources available to them if they felt that they needed to talk to someone at any time after the group (Appendix D).

**Analysis of data.** The semi-structured focus group was carefully transcribed and checked several times for accuracy in order to gain an in-depth, holistic understanding of what was discussed as well as the interaction between group members. The transcription and the photographs of the artwork became qualitative data and were then interpreted following French et al.'s (1993) discussion of content analysis. The transcript and photographs were searched for recurring words, phrases, and art elements that reflected the participants' experiences of stigma and identity formation as well as their responses to the art process. Art elements were analyzed using the Expressive Therapies Continuum (ETC) which examines the art process and product on three levels: Kinesthetic/Sensory, Perceptual/Affective, and Cognitive/Symbolic (Lusebrink, 2004). These elements were organized according to shared meaning using both expected and emergent categories. The categories were displayed in a manner that allowed for each participant's data to be examined individually while also being compared and contrasted to other group members in order to illuminate common themes and patterns. After considering both manifest and latent content within the categories, three major themes were identified and expressed according to the researcher's understanding of the group's experience. Finally, these themes were connected to existing research presented in the literature review regarding stigma and identity formation as well as the meaning of art-making in relation to young adults with mental illness.

### **Presentation of Research Data**

In this section, members of the focus group are introduced and their artwork is presented. Following the introduction of participants, each identified category from the qualitative data is presented in both table and narrative form. The categories are displayed in a manner that allows for each participant's data to be examined individually while also being compared and contrasted to other group members in order to illuminate common themes and patterns.

### **Introduction of Participants**

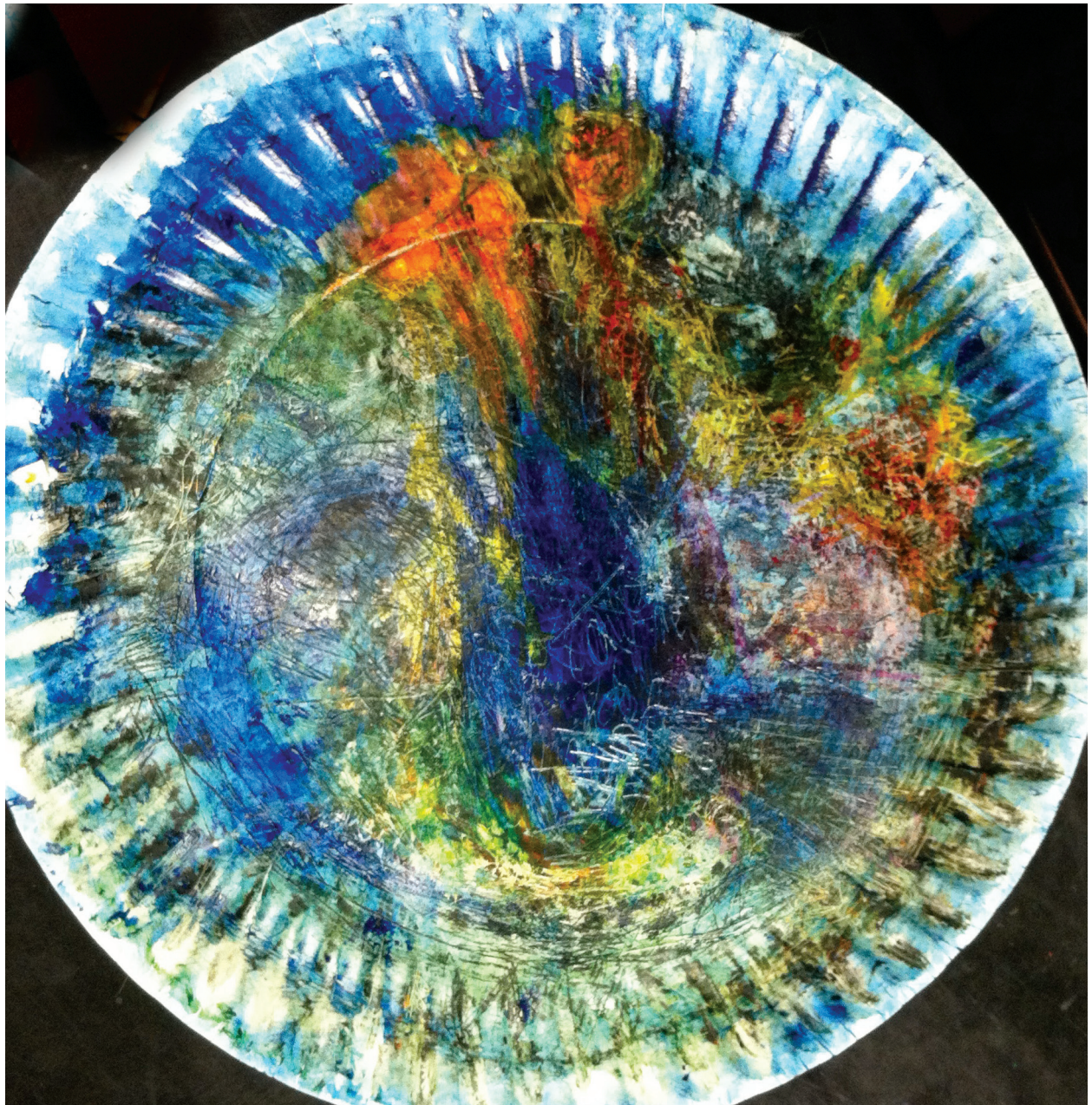
The five participants of the focus group were familiar with each other through their participation in *The Painted Brain*. All members were in their mid-twenties to mid-thirties and had been diagnosed with a chronic mental illness. They were given the option to disclose their diagnosis to the extent that they felt comfortable doing so within group. Their diagnosis and/or description of their mental illness are included in the introductions. The five participants are introduced using their own words to describe their identity, their experience with mental illness and stigma, and the art they created during the focus group. In addition to the participants' descriptions, the researcher provides observations on how the art process unfolded and the role that each member played within the culture of the group.

**BugK (32, Crazy As Fuck, Schizoaffective).** BugK presented as an outspoken, good-humored, leader of the group whose confidence and willingness to share her own experience with stigma seemed to help other members feel more comfortable to do the same. She is the only participant who spoke about being diagnosed as a young child, which may partially explain her in-your-face attitude as well as her ability to own her identity as a member of a stigmatized group. As she said, "It's all I've ever know." Bug embraced her pseudonym and playfully created

dramatic foreign accents to accompany her new identity throughout the focus group. Her attitude and style of communication suggest a spirit of rebellion that may have emerged as a defense against the dominant culture by which she has been rejected and mistreated. Through humor, sarcasm, and uncompromising honesty, Bug seems determined to be herself in all circumstances, despite the reactions of others.

After examining the art materials available, Bug chose to work with oil pastels on a paper plate (Figure 1). She was drawn to shades of blue and black which she alternately blended and scratched away, revealing brighter yellow and orange highlights. She worked on the piece throughout the three-hour group and appeared less concerned with the final product than with the soothing nature that the process provided and the unexpected designs and colors that emerged as she continued to add and remove layers. Bug's constant reworking of the pastels may have been a reflection of the social anxiety she acknowledged experiencing in groups and it's possible that the circular plate provided containment for this anxiety. The ever-changing layers in Bug's art may serve as a metaphor for the many levels of stigma that she has experienced as well as the complexities involved in identifying as a young adult with mental illness. The transformative nature of Bug's art feels similar to her own experimentation with identity as well as her openness to growth and change. Although she was very engaged in the art-making process, Bug had little attachment to her final piece and did not express a desire to keep it after the group was over. This may be representative of her ambivalence towards reliving painful memories in order to help others better understand and cope with stigma. Bug's use of the art materials as well as her ability to share the significance of her process seem to be a source of strength and an important element in her young adult identity.

In speaking about her art, Bug said, “The plate went through many transformations. I wasn’t thinking...that’s the process for me... it’s a vacation. I like to scratch layers off...I like the textures. I tried to make it less blue and wanted to give it more definition by adding some black but then it got overwhelming and really muddy. For awhile, I couldn’t get past the phase where it all looked like puke. I tried to make this into a bird and then I did this (applied rubber cement to the plate to smudge the colors) to remind myself not to make it look like a bird. It’s not about an image, but the practice of doing something. In taking away some of the layers, I get to exist inside the little nooks and crannies. There’s all these little places where the color is really nice. Its a cathexis...attention and energy and purpose that go inward rather than outward...like an implosion. Practicing in cathexis...this plate...is cathartic.”



*Figure 1.* Art exploration by BugK, created with oil pastels on a paper plate.

**FU (25, Schizoaffective Disorder, OCD, Synesthesia).** FU presented as a thoughtful, well-informed, and outspoken member of the group. He seems aware that his views are often at odds with the rest of society and that he might be judged and/or persecuted for those views, even within the safety of *The Painted Brain*. He chose to identify with the initials 'FU', and while he used this pseudonym in a humorous way, his choice may also reflect the rejection he has felt by mainstream society as a result of having a mental illness. Throughout the group, FU alternated between owning his identity as a person with mental illness and rejecting the way in which that identity is portrayed by the media and much of dominant society. His experiences with stigma seem to have taught him to proceed with caution regarding who he chooses to open up to. FU exhibits courage and strength in continuing to seek the help he needs to maintain his health and work towards his goals despite his anger and distrust of the mental health system. Although he described himself as "a hermit" and said he doesn't need much social interaction, he also expressed a desire to connect and to be understood by his peers. FU also seems to feel a responsibility to advocate for change and to expose the injustices he sees in the world. Within the group, he was supportive of other members and showed insight and sensitivity when addressing the group's reluctance to share their feelings and experiences surrounding internalized stigma.

FU worked with plasticine to create a yellow pyramid with a small face protruding from one side and a blue ball carefully balanced on top (Figure 2). He finished the piece quickly and was open to others' interpretations of what it might represent. Although the base of the structure is large and appears to be stable, the much smaller ball seems to hold the power in this relationship. As he spoke about his desire to get to the point where he can roll the ball (representing stigma) off of his head, he repeatedly put it back on top of the pyramid, making sure that it was

firmly attached. This may indicate his struggle to form an adult identity independently of the stigma of mental illness which is in conflict with his desire to reject and disprove the stereotyped portrayal by the dominant group.

As the group talked, FU took his sculpture apart, rolled the clay into balls, and put it back in the center of the table. Upon realizing that he had destroyed his art piece before it had been photographed, FU was apologetic and quickly created a new piece using pen on a paper plate (Figure 3). This second art piece depicts steps that vanish into the horizon and a man, which may be a self representation, floating in the sky. FU spoke passionately about his wish to see people with mental illness get the help they need in order to “find their nirvana.” It’s possible that the staircase represents his own uphill climb in search of a presently unknown sense of peace. The circular nature of the plates as well as the control allowed by the pen may have provided comfort and containment after creating, explaining, and destroying a piece that used a more emotionally-charged media. While FU’s possible self-portrait and his pyramid appear to be solid and strong, they also feel lonely which may be symbolic of his acknowledged isolation as a result of the public stigma perpetuated by the media as well as his own struggle to remain unaffected by the judgment of others.

In presenting his first art piece to the group, FU said “The ball is the stress and the pressure on top of my head. I guess it would be nice if that ball just rolled off like that this [demonstrates], and then I’d be free. I don’t know what the face is...it isn’t me.” He later presented his second piece, saying “On the plate is a stairway to god knows what...whatever you want it to be. Doing this [making art] is a way to learn from one another. If I’m willing to listen to others, I think they should listen to me. That’s how you grow and evolve as a person. If Neanderthals remained Neanderthals, then you and I would just be throwing stones.”



*Figure 2.* First art exploration by FU, created with plasticine and destroyed during the group. (The above image is a reconstruction created by the researcher as the original was destroyed before it could be photographed.)



*Figure 3.* Second art exploration by FU, created with pen on a paper plate.

**Allt Rue (32, All the Diagnoses).** Allt presented as a quiet, thoughtful member of the group who led by example and allowed her emotions to come out in her art. She chose her name based on the computer key but with an added 'l' which seemed to indicate her desire to be an individual while simultaneously remaining anonymous. Her choice may also be representative of her ambivalence in wanting to accept and know herself while also being aware that embracing the identity of mental illness may not always be in her best interest. Although she remained quiet and enthralled in her art process throughout most of the three hours, it was clear that the other participants had a great deal of respect for her and that she was a valued member of the group. She appeared to have a positive relationship with Bug and it's possible that, within the group, Allt's quiet leadership served as a calming and complimentary balance to Bug's more dramatic style. Allt was protective of her identity and chose to remain vague about her role in *The Painted Brain*. She was the quietest member of this group and also the one to create the most art. This may be further evidence of her choice to keep parts of her identity separate from other parts of her life.

Allt began the art process by creating a small, white figure from plasticine which remained perched on the edge of the table, facing away from the group, for much of the three hours. This figure may be a self-object that was not quite ready to face the harsh judgment of others, or perhaps of herself. Allt continued to work with the plasticine, shaping more colorful pieces that were identified as a labyrinth and an ear folded in on itself (Figure 4). It is possible that the labyrinth and the ear are metaphors for Allt's search for true identity, independent of the stigma and stereotypes of the outside world. At some point, Allt abandoned the plasticine and followed Bug's lead, working with oil pastels on a paper plate (Figure 5). Her piece went through

a series of transformations before a portrait of a man emerged from the chaos. After completing the portrait, Allt worked with another paper plate, folding it into a triangle and tying it shut with a pipe cleaner without allowing anyone to see what, if anything, was on the inside (Figure 6). Finally, Allt returned to her plasticine pieces which she combined to make one cohesive sculpture. She added colorful toothpicks and drizzled rubber cement over the entire sculpture to seal all of the parts together. By the end of the three hours, Allt felt comfortable sharing her pieces with the group and thoughtfully discussed their meaning in relation to stigma. After receiving validation from her peers, she added a heart and a chair to support the white figure and chose to turn it around to face the group. Although Allt does not identify as an artist, she was successful in using visual language to communicate the beauty and uncertainty of the search for truth amongst the overwhelming pressures of life. The power of her art was undeniable as it opened the group up to conversations about internalized stigma and family reactions to mental illness, topics which had been largely avoided until that point.

Explaining her art pieces, Allt said, “The purple clay is a labyrinth, kind of like an ear folded in on itself. This little white person is also kind of folded up as if there’s a loss of power and disowning of self that happens. A shrinking in, away from yourself, away from everybody, not really being, trying to make yourself into a ghost, not wanting to be identified, wanting to be seen as generic, nothing specific. It’s like being able to blend in. Carving the clay, it’s like what happens when you’re trying to define yourself out of mush. You have to take what’s there and piece it together. You want something to be reminiscent of what was there, but it’s not. Forming, building identity, not from the ground up but from the up ground. This is what I’ve got to work with – let’s see what I can do with it. The plate is reminiscent of an old style

of drawing that I used to do but I don't think I do anymore. It's not any person in real life.

My father once said 'all of your portraits look terrible and scary,' but I've never seen them as scary. The folded plate is internalized stigma tied with a pink bow because you've gotta look fabulous. It's repressed fabulousness."



*Figure 4.* First art exploration by Allt Rue, created with plasticine, toothpicks, and rubber cement on a paper plate.



*Figure 5.* Second art exploration by Allt Rue, created with oil pastels on a paper plate.



*Figure 6.* Third art exploration by Allt Rue, created with oil pastels, pipe cleaner, and a paper plate.

**Maximillion Diablo, Megalomaniac and Playboy Extraordinaire (Mid-thirties, Bipolar Disorder).** Max presented as a kind, friendly, well-liked member of the group who took pride in his identity as an artist and enjoyed his role in *The Painted Brain*. His experience with art seems to empower him to explore and embrace his identity and fight against both the external and internal stigma of mental illness. Max discussed the importance of having his art in shows in order to reach out to others and inspire those who may be facing similar struggles. Max showed humor in his name selection and appeared to enjoy the opportunity to assume an alternate identity that seemed in contrast to the humble persona he displayed throughout most of the group.

Max was immediately drawn to the collage box and took his time selecting words and images before gluing anything down on the paper. He arranged his words carefully and created a well-balanced piece that seems to express feelings of loneliness and confusion as well as an appreciation for the good in his life (Figure 7). Max's choice of two-dimensional media may represent a need for control that his diagnosis prevents him from having in other areas of life. Because Max appears so sweet and gentle on the outside, it was interesting to see him choose a cold, scary, iron mask as a self-image. It's possible that Max chose that image in order to reveal a part of his world that he might not always feel safe sharing.

Max described his art by saying, "For me, the iron mask represents what my world looks like from the inside...all dark and cold, silent and scary. The words represent some of the racing thoughts that pop in and out of my head on a day to day basis. Being able to create art and share it with others helps to make life less cold and scary."



Figure 7. Art exploration by Maximillion Diablo, created with collage images and phrases on construction paper.

**Laila Jane (24, Schizoaffective Disorder).** Laila presented as a cautious but open-minded group member who just recently joined *The Painted Brain*. She seemed curious to hear others' experiences and happy to have found a place to share her own. Laila used humor to describe her confusing experience with treatment but also expressed a mixture of anger and frustration at the mental health system that did not meet her needs.

At first, Laila was hesitant to engage in the art process, asking if she could just write instead of making art. She was told that she could express herself in whatever way she chose but, after exploring the art supplies, she created a piece that incorporated vellum, cotton balls, pipe cleaners, and construction paper, and did not use any words (Figure 8). It's possible that the supportive environment created by the group allowed her to explore a more emotional side of her experience with stigma through the use of three-dimensional, multi-textured materials. Laila worked quietly and deliberately and it seemed important that her piece was well-organized and that the message was clear. She appeared to be pleased with her finished piece and appreciated the positive feedback she received from other group members.

Laila's art addresses an expected developmental milestone of young adults: education and college graduation. It's possible that Laila is struggling to balance the expectations put on young adults without mental illness while simultaneously struggling with the challenges of her diagnosis. The faceless crowd staring up at her may be a metaphor for her fear of how family and friends will react if they see the chaos she keeps hidden inside. Despite efforts to cover this chaos with achievement, the red pipe cleaner refuses to be completely hidden, which may be an expression of Laila's fear of revealing and exploring the parts of herself she has not yet made peace with.

Laila kept her description brief, stating that her art spoke for itself. She told the group,

“This is me and I’m graduating and it looks normal on the outside but on the inside its mass chaos...that’s it.”



*Figure 8.* Art exploration by Laila Jane, created with plasticine, cellophane, cotton balls, pipe cleaners, construction paper, and colored pencil.

### **Categorized Data**

The data for this research was derived from the transcript of the focus group as well as the participants' artwork (Figures 1-8). Each identified category from the qualitative data is presented in the form of a table and a corresponding discussion. In addition to the categories that emerged during the discussion, it is also important to note topics that were avoided, topics that were only touched on through the art, and topics that would have been expected in a group of young adults discussing identity that did not emerge in this group. The data in the following tables is displayed in a manner that allows for each participant's contribution to be examined individually while also being compared and contrasted to other members of the group in order to illuminate common themes and patterns.

Tables 1-12 display the categories that were discussed in the focus group as well as the places that these categories can be seen in the artwork. Categories include childhood experiences with stigma, institutionalized stigma, experiences with mental health treatment, stigmatization of mental illness in the media, stigma of rhetoric, stigma of specific diagnoses, social/environmental stigma, internalized stigma, identity formation, coping mechanisms, experiences with art-making, and experiences with *The Painted Brain*. Table 13 displays each member's artwork with a corresponding description of the process and final piece(s) in the artist's words. Table 14 displays the researcher's observations of the art-making process. Table 15 uses the six categories of Lusebrink's Expressive Therapies Continuum (kinesthetic, sensory, perceptual, affective, cognitive, and symbolic) to evaluate the art process and products.

Table 1

*Childhood Experiences with Stigma*

BugK	FU
<p>in elementary school sent to a mandatory doctor/therapist - “how it was explained to me was that he’s like a doctor but for your head so I thought I was going to have brain surgery”</p> <p>lack of information led to inability to talk about mental illness with parents &amp; community - not communicating created a state of unpleasantness and fear “I grew up an information vacuum. All I had was the library and the most recent books on mental health were from 1956.”</p> <p>repeatedly called out of class, ridiculed by teachers and students, never knew the schedule or what was planned for the session, felt misinformed and didn’t want to participate because she didn’t understand, everything she or her family did became an issue - “It just became a self-perpetuating fear factory to the point where I couldn’t even turn in an assignment without worrying that it would be collected, documented, and used as evidence against me. It was terrifying.”</p> <p>referred to therapist as a “midget” and a “perve”</p> <p>parents were critical and distrustful of agencies who mandated services</p> <p>learned to say the right thing, fabricated stories to sound like a normal, healthy family for the social worker, changed clothes because they were too dark - “I learned not to disclose any info about myself and I’m still closed off because of that. I have to remember not to answer questions with misdirection and to not to be so defensive,” still difficult to trust others, especially authority figures.</p>	<p>“it’s a very sensitive subject” (in response to the group’s silence when asked about early experiences with stigma and family reactions to diagnosis of mental illness)</p> <p>turned the conversation back to the media (away from childhood and family)</p>

Allt Rue	Maximillion Diablo	Laila Jane
<p>“my father once said ‘all of your portraits look terrible and scary’ but I don’t feel like they’re scary.” - rest of the group agreed that they are not scary but that they show powerful emotions and are able to say a lot without the use of words</p>	<p>didn’t speak about specific experiences of stigma as a child but said “They always knew there was something wrong with me, they just didn’t know what.” (until diagnosed in early twenties)</p>	<p>didn’t speak about experiencing stigma as a child - artwork shows a person who is able to appear ‘normal’ to the public</p>

### **Childhood Experiences with Stigma**

Bug was the only group member to speak about her experience with school psychiatrists, teachers, classmates, and parents. Because many mental illnesses are not diagnosed until early adulthood, it is possible that the other group members didn't have childhood stories to share. It is also possible that their silence may be a reflection of the sensitive nature of this topic and an unwillingness to relive painful childhood memories within the context of this focus group. When the researcher asked if anyone besides Bug had experienced stigma as a child, Max was the only one to answer, saying "they always knew there was something wrong with me, we just didn't know what it was [until being officially diagnosed with bipolar disorder in his early twenties]." The researcher observed that Max's disclosure seemed to evoke a sense of empathy and nonverbal agreement within the group.

Because Bug was diagnosed in elementary school and received treatment within the school environment, she was forced to deal with other's perceptions about mental illness... "I had to embrace it because there wasn't another option." Although Bug now projects an image of confidence and is able to speak freely about her mental health, she remembers the fear, judgment, and isolation that she felt as a child, and acknowledges that those experiences continue to influence her behavior, especially in social situations. Bug's introduction to mental illness and treatment began when she was sent to a psychologist in elementary school and was told, "he's like a doctor, but for your head," leading her to believe that she was going to have brain surgery. Because the purpose of treatment wasn't clearly explained, she was hesitant to open up and did not form a therapeutic relationship with her psychologist, which can be seen in her references to him as a "midget" and a "perve." Bug's visits to the school psychologist caused her to be pulled out

of class without notice. She remembers being ridiculed by classmates as well as teachers which contributed to a growing sense of distrust in authority and separation from her peers. Living in a small town added to Bug's anxiety, as she felt like everything she or her family did was put on display and subject to judgment by "the rumor mill where everyone got their information." Feeling shamed for her condition and not wanting her family to have to deal with the stigma, Bug quickly learned to tell her psychologist and social worker what they wanted to hear, fabricating stories about things she thought a "normal" family would do and changing the way she dressed after being told she looked "too dark." Bug wasn't able to enjoy school because she worried that everything she said and did would be turned into a clinical issue that would lead to further stigmatization and alienation from her peers. She described this phenomenon as "a self-perpetuating fear factory to the point where I couldn't even turn in an assignment without being afraid that it would be collected, documented, and used as evidence against me. I learned not to disclose too much information about myself and I'm still closed off because of that. I still have to remember not to answer questions with misdirection...not to be so defensive." It's possible that the freedom shown in Bug's art (Figure 1) is symbolic of her current comfort with self-exploration as well as her commitment to being less defensive and allowing others to see what lies beneath the surface.

Growing up before the internet in a rural "information vacuum," Bug cites a lack of good information as one factor that kept her family and her community from having an open dialogue about mental illness. Although they didn't share specific stories, the rest of the group empathized with the lack of resources available before the internet became what it is today. They agreed that people who are diagnosed with a mental illness today have more access to information and can benefit from online support groups for themselves and their families. When asked about her fam-

ily's response to her diagnosis, Bug remembered her father voicing anger and frustration at the agencies that had mandated services, but doesn't remember (or chose not to share) her parents' emotional response, saying only that there was a "state of unpleasantness." FU was clearly attuned to the group's discomfort in discussing their family's reaction to mental illness and reminded the researcher that "it's a sensitive subject."

Although most members chose not to verbalize their early experiences with stigma, it is possible that the art process allowed them to explore and express the effect that early experiences have had in shaping their identity. Allt, Max, and Laila created art (Figures 4,6,7,8) containing elements of inside versus outside and/or public versus private. This may speak to the struggle to reconcile what they grew up being told about mental illness and the negative consequences of stigma that they may have experienced, with the desire to accept themselves and embrace all parts of their emerging adult identity.

Table 2

*Institutionalized Stigma*

<b>BugK</b>	<b>FU</b>
fear of system has decreased with better understanding of the legal system and patient rights	<p>there will always be a stigma placed on minority groups because human nature is to categorize people, things are complicated and categories and labels make it easier, stigma is created and promoted by government and media</p> <p>powerlessness of the stigmatized group, fear of being put in a database of people with mental illness and monitored by the government</p> <p>“when you say ‘mentally ill’, it changes the course of action and billing”</p>

<b>Allt Rue</b>	<b>Maximillion Diablo</b>	<b>Laila Jane</b>
powerlessness of the less dominant group		<p>long history of people with mental illness being stigmatized by the government, killed, put in hospitals naked, tortured, shock therapy</p> <p>angry about campaigns and speeches by the president to get guns out of the hands of people with mental illness because they’re “dangerous”</p>

**Institutionalized Stigma**

All five participants agreed that people who suffer from mental illness have been stigmatized throughout history and continue to be discriminated against in our society today. Laila spoke about mistreatment in hospitals and early experimentation with shock therapy as well as the torture and killing of people with mental illness by the government. She also expressed anger at politicians who speak incorrectly about mental illness and make insincere promises for the sake of promoting their own agenda, especially in relation to gun control. FU agreed that stigma is often created and promoted by the government and the media in order to further their own interests. He believes that stigma has always played a role in the experience of people with

mental illness and probably always will...“Human nature is to categorize people. Things are complicated and categories and labels make them easier.” He also fears that the government and other powerful institutions that represent the interests of the dominant culture may be able to put people with mental illness in a database where they can be monitored and controlled. Allt agreed that stigma is likely perpetuated out of fear and a need for control. She also pointed out that the less dominant group often lacks the power needed to combat the institutionalized stigma ingrained in our culture. It is possible that this powerlessness is shown in her clay sculpture (Figure 3) of a person folding in on herself, seeming to turn away from the world. Bug also empathized with FU’s fear of and disappointment in the system, saying that she has often felt that her rights have been violated and that she has had to learn to advocate for herself in order to make sure she is not taken advantage of or mistreated as a result of her diagnosis.

The issue of abuse and mistreatment by those in positions of power reemerged throughout the focus group and appeared to be a topic that all members felt strongly about. In addition to feeling the need to make sure this issue is acknowledged and exposed, the researcher became aware that this issue was one that felt comfortable for everyone to talk about, and one that was sometimes used to change the subject when the discussion became too personal. Although members shared painful memories of mistreatment and disrespect, their emphasis on the role that others played in the situation allowed them to externalize these experience and focus on the anger they felt towards the perpetrators and the injustices in the mental health system. It’s possible that with more time to establish a safe therapeutic space, members would have felt comfortable enough to open up about personal experiences with family and friends, but for the course of this focus group, it was apparent that institutionalized stigma was a place that felt safe for members to explore.

Table 3

*Experiences with Mental Health Treatments*

BugK	FU
<p>while living in the Midwest (Wisconsin), fell asleep in the dean's office and woke up in an inpatient unit, overprescribed meds, tests were scheduled against her will, leading up to electroshock therapy, was sedated but managed to get to a phone and call a friend who came and got her out because she was over 18, reluctant to seek treatment after that</p> <p>psychiatrists with delusions of grandeur</p> <p>went to police station in the middle of the night to report her car stolen and the police called the psych team, felt like she was not treated like a human being, there was no communication, no way to get help from the outside, no way to advocate for self - "They just say 'trust us' as they're slamming you against the car. Because they're superheroes." - just because a person has needed help at points in their life doesn't mean that is always the case or that they don't have a right to fair treatment by authority</p> <p>learned to avoid treatment (mental, addiction, physical) for fear of being further persecuted by the system, fear of abuse, fear of being prescribed the wrong meds and/or being given tranquilizers used to shut people up</p> <p>once you have a record with the system it effects everything in your life, you're treated differently, you have less control over your circumstances</p> <p>domestic violence treatment, counselor took history and said her impression was that almost every relationship was detrimental physically or emotionally but since diagnosed with mental illness, need to consider that it might all be in your head, always have to deal with the mental illness first before the presenting problem, the reality of the problem is always questioned - "I have to be tenacious as fuck because I demand to have the kind of treatment I need and I know I can't do it on my own. So if it turns out that the problem is all in my head, than good for me but I'm here to learn something along the way. I'm here for me"</p> <p>learned not to disclose any information and became very closed off</p>	<p>health care professionals make a lot of mistakes and don't treat patients with respect</p> <p>sexual abuse/harassment while in inpatient treatment - "a nurse had to help me go to the bathroom and she was talking about how I was lucky she was hot and I thought that was so inappropriate. If a guy said that to a girl... I felt really angry but i was strapped down...it was very degrading... dogs have value than that."</p> <p>lack of confidentiality by mental health workers, girlfriend was in hospital and went through a psychosis and a male nurse told everyone about it - "He said 'your girlfriend got naked and she was on her period. It was disgusting, man.' That's information I don't need to know. It's supposed to be confidential. That's degrading and how dare you degrade her like that. It's not right That's not human respect. That's cold and inconsiderate.</p> <p>the legal system might break more laws in prosecuting than the person who was in the psychosis</p> <p>a lot of people get misdiagnosed and are prescribed the wrong meds - "I was given the wrong meds and I gained 35lbs in one month. I was eating eight burritos a day, going nuts, losing my mind eating. I couldn't pay attention to anything. I'd fall asleep on the spot - narcolepsy. All of a sudden the things I was confident about were gone and I was so lazy, with no drive, no ambition. Why would you give someone medication to take away those things?</p> <p>its so different from being treated for a physical illness, people don't become 3rd class citizens if they go to the doctor or to the hospital because they're sick</p>

Table 3 (continued)

*Experiences with Mental Health Treatment*

BugK	FU
<p>while in rehab for drug abuse was treated at the ER for food poisoning, because of mental health diagnosis on forms the EMTs accused her of trying to escape and implied that she was not really sick, regardless of condition they always list schizophrenia as chief complaint - “more like ‘needs stomach pumped’”</p> <p>always treated differently, separated from other patients at the ER, looks of fear - “Now when I go into the ER, I don’t tell them my psychological history because it gets in the way of getting treated. I’ve gone in for liver failure and they say ‘no we can’t treat you until you see our psychiatrist first.’”</p> <p>learned not to disclose any information and became very closed off</p>	<p>treatment feels like being punished for having a medical condition but there’s never a reward for positive behavior, it leads to belief that treatment is a bad place - a punishment to be avoided, if you have mental illness and do the right thing which is to go to the hospital, get yourself away from society, prevent yourself from being a harm to self or others, that should be treated with respect but instead you get bad food, bad treatment, and no rights,</p>

Allt Rue	Maximillion Diablo	Laila Jane
<p>empathetic to others’ stories of poor treatment - did not share any personal experiences</p>	<p>positive response to medication, talk therapy, and art groups - “It helps to talk to other people who have a mental illness”</p>	<p>placed on a 51/50 hold which became longer, was told that a judge would decide how long she needed to stay for but she was there for a month and never saw a judge, no one explained what was happening, having your rights taken away is “really fucking scary”</p> <p>“the people who were there voluntarily got to go on walks so I asked if I was voluntary and they said yes. I told them if I’m voluntary then I want to leave and they said, well if you want to leave then you’re not voluntary anymore.”</p>

**Experiences with Mental Health Treatments**

Although institutionalized stigma was an original topic for the focus group, the researcher was surprised by the prevalence of stories about abuse, mistreatment, and disrespect at the hands of the people and organizations who are supposed to serve this population. Bug, FU, and Laila expressed anger and frustration when sharing their stories of mistreatment. Allt and Max did not share personal experiences but were empathetic and seemed to share a cautious attitude towards

mental health workers. It seems likely that experiencing the effects of stigma even within the institutions designed to help people with mental illness encourages young adults to embrace their own counter-culture as a way to feel a sense of control over their circumstances and to express their rejection of a system that seems to have rejected them. These experiences also seem to have contributed to the reluctance of young adults to seek treatment for mental illness in order to avoid further persecution.

All five members of the group agreed that people with mental illness are often misdiagnosed and overprescribed medication which may make their condition worse and/or causes negative side effects. FU shared, “I was given the wrong meds and I gained thirty-five pounds in one month. I was eating eight burritos a day, going nuts, losing my mind eating. I couldn’t pay attention to anything. I developed narcolepsy and would fall asleep on the spot. All of a sudden the things I was confident about were gone and I was so lazy, with no drive, no ambition. Why would you give someone medication to take away their ambition? Another time I was given pills that knocked me out for two days and I woke up not knowing where I was or who I was...it was worse than the psychosis I was being treated for. In my psychosis I could at least walk around, go to the bathroom, but what they gave me made me retarded.” Despite feelings of frustration, group members seem to accept this treatment as something they do not have the power to change. Feeling a lack of control over their treatment may be partially responsible for the fluctuation between avoidance of the mental health system and coping with it through humor and a spirit of rebellion. This rebellious attitude was shown in the pride FU took in convincing another patient to help him get out of restraints as well as Bug’s attempts to “Houdini out of those things.” Their use of humor as a coping mechanism was apparent each time a group member

used the word “medication” and another corrected them saying, “You mean sedation?” They also bonded over bad experiences with medication, renaming some of their least favorites as “shut-the-fuck-up-apine” and “disaster-zone.”

In contrast to receiving help for a physical condition, members shared that receiving treatment for a mental condition often feels like punishment and is therefore understandably avoided whenever possible. FU expressed feeling hurt and devalued saying, “It’s so different from being treated for a physical illness. You don’t become a third class citizen if you go to the doctor or the hospital because you’re sick.” The other members agreed that experiences in treatment often lead people with mental illness to believe that it is something to be avoided. FU expressed the lose/lose feeling of seeking treatment saying, “If you choose to take care of yourself and go to the hospital so that you won’t be a danger to yourself or to society, instead of being respected for taking responsibility for your illness, you’re given bad food, bad treatment, and all of your rights are taken away.” This ambiguity regarding treatment was a recurring theme throughout the focus group and seemed to be something members continue to struggle with.

FU also spoke about sexual harassment, feeling degraded, and the breach of confidentiality he experienced while hospitalized. “There was a nurse who had to help me use the rest room and she told me that I was lucky that she was so hot. Can you imagine if a guy said that to a girl?!? I thought it was so inappropriate and I was really angry but you can’t do much when you’re strapped down. It’s degrading. Dogs are given more value than that.” In addition to feeling angry about his own mistreatment, FU was sensitive to the experiences of other patients and shared a story about a girl he was hospitalized with. “The male nurse told everyone about her psychosis. He told me ‘your girlfriend got naked last night and she was on her period – it was

disgusting.’ That’s information I don’t need to know...it’s supposed to be confidential. How dare he degrade her like that...it’s not right...it’s not human respect...it’s cold and inconsiderate.”

Laila was able to relate to FU’s feelings of being treated as less than human when she was put on a 51/50 hold and not given the information she needed regarding why she was hospitalized and how long she would have to stay. In listening to the group’s supportive response to Laila’s story, it appeared to the researcher that it is not uncommon for people who are receiving treatment for mental illness to be kept in the dark and given very little say in their treatment. Laila said, “I was told that a judge would decide how long I had to stay for, but I was there for a month and I never saw a judge. No one explained what was happening. Having your rights taken away is really fucking scary.” The group agreed that sometimes feel as if they are treated like children and are expected to follow rules that haven’t been clearly explained. When Laila tried to clarify her own situation, she was given more mixed signals...“The people who were there voluntarily got to go on walks. I wanted to go on a walk so I asked if I was voluntary and they said yes. I said ok, if I’m voluntary then I want to leave, and they said well, if you want to leave then you’re not voluntary anymore.” In her art, Laila took care to portray herself as “normal,” trying to cover her internal chaos with a long graduation robe. It’s possible that experiences like the one she shared have contributed to her need to hide her mental health diagnosis as well as her need to prove to herself and to others that she is in control of her circumstances.

In addition to feeling mistreated when seeking help for their mental illness, members expressed feeling misunderstood and not believed when seeking help for other conditions. Bug shared that, while in a drug rehab program, she had an allergic reaction to food and needed to go to the hospital to have her stomach pumped. She remembers the EMTs questioning her motives,

implying that she did not really need medical attention and accusing her of trying to escape from the treatment center. When she arrived at the hospital and described her symptoms, the chief complaint recorded on the chart was schizophrenia as opposed to allergic reaction or a need to have her stomach pumped. In response to experiences like this, Bug said “Now when I go into the ER, I don’t tell them my psychological history because it gets in the way of being treated. I’ve gone in for liver failure and they say ‘no we can’t treat you until you see our psychiatrist.’” The rest of the group empathized with feeling like their words are constantly doubted and questioned because of their diagnosis and the researcher became more aware of how complicated it is for people with mental illness to seek treatment of any kind. Bug also experienced frustration when seeking help for domestic violence... “The counselor took my history and said that almost every relationship I’ve ever had was detrimental either physically or emotionally, but since I was diagnosed with a mental illness we needed to consider that it might all be in my head. I always have to deal with the mental illness first, before the presenting problem and the reality of my problem is always questioned.” When the researcher asked Bug how she deals with the doubt and disbelief, she replied “TENACIOUS AS FUCK. I have to be tenacious as fuck because I demand to have the kind of treatment I need and I know I can’t do it on my own. If it turns out the problem is all in my head then good for me but I’m here to learn something along the way. I’m here for me.”

Institutionalized stigma was also discussed in relation to law enforcement officers and other public servants. Bug recalled ending up in a psych ward against her will on more than one occasion as a result of seeking help for issues unrelated to mental illness. “I went to police station in the middle of the night to report my car stolen and for some reason the police called the

psych team. I wasn't treated like a human being. There was no communication, no way to get help or advocate for myself. They just say 'trust us' as they're slamming you against the car... because they're superheroes. Another time, I fell asleep in the dean's office of my school and woke up in an inpatient unit where I was overprescribed medication and given tests against my will. Before they were able to give me electroshock therapy, I managed to get to a phone and call a friend who got me out of there." Bug acknowledges that other people's reactions to her mental illness have caused her to avoid asking for help in the past and that the mistreatment she experienced deepened her distrust in the mental health system and authority figures in general. FU agreed that people with mental illness seem to be targeted for mistreatment by people in positions of power... "Having been treated for a mental health issue shouldn't affect how a person is treated for the rest of their life. There are people, and I've been one of them at times, who need special care until they're up and running again. I consider it a bump in the road to get to where they really want to be." Bug added, "Just because a person has needed help at some point in their life, doesn't mean that is always the case or that they don't have a right to fair treatment by authority." FU also expressed anger and frustration with the legal system saying "they broke more laws to prosecute me than I did in my psychosis." It is possible that FU was able to use the art process to cope with his feelings of helplessness and inability to change the system by shaping plasticine into a solid foundation that was strong enough to endure all of the pressure that was balanced precariously on its head (Figure 2).

Table 4

*Stigmatization of Mental Illness in the Media*

BugK	FU
<p>upset about reporting of school shootings, there needs to be more clarification and information on mental illness - "It's not enough to just say mental illness. Is it mental instability from an emotional aspect, from a neurological aspect, from a perceptual aspect, is it substance abuse?"</p> <p>when people don't know the answer, they make one up (referring to people with mental illness being blamed for violence)</p> <p>needs to be a distinction between people who know how to cope with their mental illness and take care of themselves vs people who don't, many people with mental illness take responsibility for themselves and are not dangerous, people who are untreated for mental illness can turn outward and harm themselves or others</p> <p>"Were they really mentally ill or were they just fed up?"</p>	<p>media immediately connects people who have a mental illness with something negative</p> <p>regarding school shootings the media immediately falls back on mental illness to protect their own normality, its an easy population to blame, people want to believe that only someone with mental illness could do something horrible - "They say only a mentally ill person could do something like that but normal people can get fed up and go to the school where they were bullied and shoot up the place. Could that have been it? No. They need an answer and its an easy way out. If it was a normal person, then people would question that. They'd be like wait a minute, I'm normal and I wouldn't do that, so what are you saying. But if you say the person is mentally ill, its easy for people to write it off. Yeah, he's crazy and only crazy people do that. Its easy to categorize, to put people aside...you guys are like this because you have a mental illness."</p> <p>media devalues and writes off people with mental illness</p> <p>remains geared towards the majority and the people with money and power</p> <p>media is used to shun people who try to speak the truth or who question what they are told</p> <p>need to distinguish between mental illness and people under influence of substances</p> <p>worries that people form their opinion about mental illness based on one portrayal or one incident in the media</p>

Allt Rue	Maximillion Diablo	Laila Jane
<p>agreed that media perpetuates the idea that people who have a mental illness are dangerous</p>	<p>given mixed messages from media regarding identity, conflicting messages may become internalized, words used in art piece: inner peace, blessed, make your own path, you're beautiful and smart vs rampage, dark, nothing</p>	<p>upset about how school shootings are reported, media is making things worse by blaming mentally ill people, its an easy group to blame, nobody questions the media's information</p>

### **Stigmatization of Mental Illness in the Media**

When asked about the media's portrayal of mental illness, the group immediately brought up a recent school shooting and expressed anger as well as a feeling of helplessness regarding the generalizations that are made about mental illness in the aftermath of a tragedy. All five members were allied in their criticism of the way events were reported in the Sandy Hook shooting as well as other incidents involving people who may have been suffering from mental illness. It's possible that the group's feeling of powerlessness surrounding this topic was reflected in the artwork of several members who portrayed solitary figures that appeared to be at odds with their environment. Allt's first plasticine sculpture (Figure 4) depicts a figure who appears to be shrinking away from the world... "a person trying to turn them self into a ghost... because maybe its better to be generic, nothing specific." This may reflect her fear of accepting an identity that is portrayed so negatively and her belief that sometimes it might be better not to be identified at all. In describing her process, Allt said that it was important to work only with what was already there, which may indicate her rejection of the stereotypical qualities and characteristics given to people with mental illness. It's possible that Bug's art may also address this issue as her plate may be representative of the uncovering of truth beneath layers of deception (Figure 1). Her desire to "remember not to let the bird look like a bird" may be a reflection of her own fear of being pigeon-holed by the stereotypes of mental illness. Observing the art pieces from this perspective, the researcher began to understand that, for this population, remaining a bit of a mystery is preferable to fitting into the media's preconceived image of mental illness.

FU spoke passionately about the media's attempt to shun people who speak the truth and who question what they are told. Although he would like to serve as a positive representation of

a stigmatized culture, it seems that the long reach and unlimited power of the media encourage even outspoken individuals like FU to hide their diagnosis in order to avoid being further alienated from mainstream culture. It is possible that the destruction of his original art piece was a reflection of the effort it takes to fight something so much bigger than yourself and the ultimate feeling of being overtaken by something so powerful. For young adults who are trying to come to terms with their identity, the media often creates more questions than answers and makes it difficult to identify as part of the culture of mental illness.

Members shared a common concern that the media encourages the public to form their opinion about mental illness based on stereotyped portrayals and isolated incidents that may or may not be reported accurately. Allt, Laila, and Max agreed that the stereotypes most often given to people with mental illness are instability, danger to others, and a burden on society. FU added that the media tends to be geared towards maintaining the comfort of the dominant group...“The mentally ill are an easy population to blame because people want to believe that only someone with a mental illness could do something so horrible. People need an answer and its an easy way out. If the media reported that it was a normal person who did something horrible, people would question it. They’d say, ‘Wait a minute, I’m normal and I wouldn’t do that.’ But if they say the person is mentally ill, then people can write it off –‘Yeah, he’s crazy and only crazy people do that.’ It’s easy to categorize, to put people aside and say ‘You guys are like this because you have a mental illness.’” The group agreed that the media is often guilty of devaluing people with mental illness and stressed the need for better information and greater sensitivity to these issues.

Despite their criticism of the media, group members were careful not to say that people who commit horrible crimes are not mentally ill. Instead, they discussed the need to make a

distinction between people who know how to cope with their illness and take care of themselves versus people who can't or don't. Allt and Bug suggested that there could be more clarification in the media regarding the source of a person's instability and explaining the different symptoms and treatment options for neurological, perceptual, and emotional problems. Bug also expressed a desire for the public to be aware of the fact that many people with mental illness do take responsibility for themselves and are not dangerous... "It's untreated mental illness that can cause a person to turn outward and harm others or themselves." The group also agreed that the media should distinguish between people with mental illness and people who are under the influence of drugs or alcohol, noting that the two do not always coexist.

Table 5

*Stigma of Rhetoric*

<b>BugK</b>	<b>FU</b>
upset about how school shootings are reported, media is making things worse by blaming mentally ill people, its an easy group to blame, nobody questions the media's information	<p>doesn't want to identify as 'ill', would prefer discussing 'mental conditions', acknowledges and owns condition but does not think that the word ill is a fair description of a person for their entire life because they've needed help at one point or because they think differently</p> <p>repetition of the word leads to internalization of the stigma over a life-time - "Even the way people say it you know its a stigmatized group of people. Its like when people use the word Mexican and everyone knows they mean it in a derogatory way. Why use that hatred?" (also compared the use of the word ill to use of the n word during slavery)</p> <p>"What made you want to work with the crazies?"</p>

<b>Allt Rue</b>	<b>Maximillion Diablo</b>	<b>Laila Jane</b>
negative associations with words used to describe mental illness may lead a person to try to turn themselves into a ghost, would rather been seen as generic, nothing specific, than to be identified with stigmatized words	<p>the term Bipolar may be better understood because of books like 'Night Falls Fast' by Kay Redfield Jamison</p> <p>emphasized the importance of the person with the diagnosis getting more information about it in order to better understand and not be as afraid of the terminology</p>	would prefer that mental illness be called 'mental diversity'

**Stigma of Rhetoric**

From the very beginning of the focus group, the researcher sensed that the group was not entirely comfortable with the word "illness" and its implications. FU was the first to state his dislike of the word "ill," explaining that the way a word is used can perpetuate the existing stigma of the condition. When the researcher asked if there was a word the group would prefer to use, FU said "mental conditions," Bug suggested "behavioral health," and Laila preferred "mental diversity." Allt and Max agreed that any of these terms would be better than "illness" which, in

the context of mental health, implies that a person is permanently in a troubled state. This is different from physical illness in that people who are physically ill are generally allowed to recover and move on with their lives. FU added that, while he wants to own his mental illness, he doesn't feel that the word "ill" is a fair description of who he is. It was clear to the researcher that this word had a strong emotional impact on all of the group members and it makes sense that a person would be hesitant to accept a label that may cause them to experience poor treatment and negative consequences. FU compared calling people "mentally ill" with the use of racial slurs... "Just the way people say it, even if you didn't know what it meant, you'd know that it's a stigmatized group of people. It's like when people use the word "Mexican" and everyone knows they mean it in a derogatory way even though there shouldn't be anything derogatory about that word. Why would we want to use a word like that to describe people? Why use that hatred?" The researcher also noticed that, despite feeling offended when people on the outside use certain words, much like racial slurs, the words take on a different meaning when used by people with mental illness to refer to themselves or others within their cultural group. When members asked the researcher, "What made you want to work with the crazies?" it was clear that, within the safety of the group, not only was the offensive word acceptable, but it was used as a term of endearment and served to create a bond between members.

Table 6

*Stigma of Specific Diagnosis*

<b>BugK</b>	<b>FU</b>
<p>treated differently based on diagnosis: “If I said I had a mood disorder they’d be ready for the bells and whistles and a fucking drama queen.”</p> <p>specifically schizophrenia and thought disorders are misunderstood and feared, the majority of the public believes that people with mental illness are dangerous – “I could never understand why people thought I was so violent because i never put hands on anyone.”</p> <p>“I’m guilty of dismissing depression as not as serious.”</p>	<p>treated differently based on diagnosis</p> <p>feels there is a fear associated with schizophrenia</p>

<b>Allt Rue</b>	<b>Maximillion Diablo</b>	<b>Laila Jane</b>
<p>agreed that people are treated differently based on diagnosis</p>	<p>treated differently based on diagnosis, people fear schizophrenia</p>	<p>depression is seen as the tamest of the mental illnesses and not stigmatized with the danger of other groups - “They’re just like normal people who get sad. But schizophrenia...oh man.”</p> <p>the majority of the public thinks that people who have a mental illness are dangerous</p>

**Stigma of Specific Diagnosis**

All five group members agreed that different diagnoses are connected to different stigmas, and all five expressed that there is often more fear associated with thought disorders like schizophrenia. Bug spoke to her experience of this specific stigma, saying “I could never understand why people thought I was so violent because I never put hands on anyone or anything... except my art.” Max related to Bug’s experience of being seen as dangerous and noted that this perception contributes to the sense of shame and isolation that people with thought disorders often experience.

When asked if members felt that some diagnoses were not taken as seriously as others, Laila replied that depression is seen as the tamest of the mental illnesses and is not always stigmatized with the danger of other groups...“People think that those with depression are just like normal people who get sad. But schizophrenia...oh man.” Bug admitted to sometimes being dismissive of depression but acknowledged the different response that mood disorders evoke...“If I said I had a mood disorder they’d be ready for the bells and whistles and a fucking drama queen.”

Table 7

*Social/Environmental Stigma*

BugK	FU
<p>lack of information and resources in small towns especially before the internet - "I grew up in an information vacuum. All I had was library and the most recent books related to mental health were from 1956."</p> <p>lack of privacy in small communities, moved from the Bronx to a tiny village of 7,000 in New York, no confidentiality - "Nothing was sacred. Everybody was up in your shit and they built their judgments of you based on the rumor mill."</p> <p>there have been many positive changes in the last 20 years regarding the accessibility of information - "Information is power. It was limited in the 90's before the internet. Support groups now have a more informed conversation with more accurate knowledge than when internet first started."</p> <p>encounters stigma in the form of fear that people with mental illness may be dangerous, people are unable to distinguish between those who know how to cope with themselves and those who do not</p> <p>acceptance of others' fear and need for superiority, sees it as ignorance but lets people hold on to their misguided and hurtful beliefs</p>	<p>Big City: too busy, too much traffic, builds a lot of anxiety, people become detached, cold, jaded, parents don't have time for kids because they're working more, people lose their identity in large places</p> <p>small town would offer hospitality, laid back atmosphere, being part of a tight knit community allows empathy to develop something - "In the country, people develop a warmth inside. I'm 100% positive that if you have a mental illness and you're in the country, people will tend to you and have the time to hone your talents or help you reach your potential."</p> <p>acknowledges social stigma but claims to not need a lot of social validation, very self-sufficient, "a hermit"</p> <p>encounters stigma in the form of fear that people with mental illness may be dangerous</p>

Allt Rue	Maximillion Diablo	Laila Jane
<p>acknowledges social stigma and general fear and misunderstanding of people who have a mental illness but did not discuss personal experiences</p> <p>"There's a folding in on one's self... not wanting to be identified... wanting to blend in."</p>	<p>encounters stigma in the form of fear that people with mental illness may be dangerous, used to believe that he might be dangerous because of what he was told by others about mental illness</p>	<p>acknowledges social stigma and general fear and misunderstanding of people who have a mental illness but did not discuss personal experiences</p>

**Social/Environmental Stigma**

All participants agreed that there is a social stigma that accompanies a diagnosis of mental illness but only Bug and FU chose to speak about their personal experience. They disagreed about the role of community in perpetuating stigma with FU stating that being part of a tight knit community allows for the development of greater empathy and Bug speaking about the lack of information and resources in the rural area that she grew up in. In Bug's experience, moving from the Bronx to a town of 7,000 heightened her awareness of the importance of confidentiality and privacy... "Nothing was sacred. Everybody was up in your shit and they built their judgments of you based on the rumor mill." Having grown up in a large city, FU stated that it's too busy, it builds a lot of anxiety, and causes people to become detached, cold, and jaded. People lose their identity in the city whereas "in the country, people develop a warmth inside...if you have a mental illness and you're in the country, people will tend to you and have the time to hone your talents or help you reach your potential."

It was clear that members experienced the fear created by the media on an institutional level within the context of their community and on a much more personal level. Bug's approach to people who are ignorant about mental health issues is to let them hold onto their misguided beliefs and acknowledge their need to feel superior. FU says that he has become very self-sufficient and is able to live "like a hermit," needing little social validation. Max seems to have struggled on an internal level with the stigma he experienced in his community, saying that he began to fear he might be dangerous to others because of what he heard people say about mental illness.

Table 8

*Internalized Stigma*

<b>BugK</b>	<b>FU</b>
<p>diagnosed self as “crazy as fuck”</p> <p>identifies with culture of mental illness but has tried to incorporated it into identity in a positive way</p>	<p>doesn’t want identity to be that of someone who is permanently ill, differentiates between self and others with mental health diagnosis</p> <p>“I can admit that I have a mental illness. I own it but I don’t internalize it.”</p>

<b>Allt Rue</b>	<b>Maximillion Diablo</b>	<b>Laila Jane</b>
<p>art shows a labyrinth and an ear folded in on itself possibly representing internal confusion and difficulty hearing what she has been told about herself</p> <p>desire to be seen but not identified (possibly as a member of a stigmatized group)</p>	<p>feared that he might be dangerous to others because of what he had been told about mental illness</p>	<p>“The outside looks normal but the inside is chaos”</p> <p>need to hide the chaos and present a successful persona</p>

**Internalized Stigma**

Participants were reluctant to speak directly about internalized stigma but were able to do so in their art which seemed, at times, to act as a healing process. A common theme in the art was outside versus inside as well as a struggle that seems to occur as an individual decide which parts of the self to accept and which to reject. Laila’s art (Figure 8) reveals the chaos she feels on the inside and the effort made to masked it with a calm, successful exterior... “The outside looks normal but the inside is chaos.” The red, pointy pipe cleaner that she is trying to hide under a graduation robe is poking out in a way that looks painful, indicating that the internal pain may bleed into the external world, complicating her desired identity as a successful college graduate. Allt explained that the person she created was “kind of folded up in herself as if there’s a loss of power and disowning

of self that happens. A shrinking in, away from yourself, away from everybody, not really being, trying to make yourself into a ghost, not wanting to be identified, wanting to be seen as generic, nothing specific. It's like being able to blend in (Figure 4)." In addition to the shrinking person, she created a labyrinth and an ear that also appeared to fold in on itself which may speak to her internal confusion surrounding what she has been told about mental illness and what she chooses to believe and incorporate into her identity. Allt also created an art piece to represent internalized stigma (Figure 6), explaining that the folded plate was tied with a pink bow because, "You've gotta look fabulous on the outside." She did not allow the group or the researcher to see the inside of the plate. Max spoke about his internalization of other people's fear of him and used a mask in his artwork (Figure 7) that may represent his ambivalence regarding his diagnosis and which parts of himself he chooses to present to the world. FU spoke about not letting stigma become internalized and seemed determined not to give anyone that type of influence over him.

Table 9

*Identity Formation*

BugK	FU
embracing of a counter-culture as shown by pride in pseudonym and defiant attitude towards mainstream society	embraces counter-culture shown by pride in pseudonym and desire to expose injustice in government and media treatment of mental illness "The system needs to change. That's why I speak out...to end the abuse."
early diagnosis meant mental illness has always been part of identity, forced to embrace it because there wasn't another option - "The past is the map to where I am today. I have no regrets."	identified as a member of MENSA
"All of my best stories are from schizophrenia."	Mentioned being Armenian but not experiences of stigma related to ethnicity
comfort with identity of mental illness allowed her to take on a leadership role within the group	no mention of education, career, desire for marriage or children, religion, political affiliation (did express anger and distrust in politicians), culture/values of family-of-origin
identifies as an artist as a way of having a voice and as a way to avoid and/or assist with interacting with people - "too sick to attend art school" but proud of displaying art in shows	feels a loss of identity living in a big city and as part of American culture that is cold, jaded, and more connected to technology than people
no mention of career, relationships, sexuality, desire for marriage or children, religion, political affiliation, culture/values of family-of-origin	stigma of being a "stupid American"
mentioned being part Japanese but didn't discuss ethnicity in terms of identity or stigma	identifying as mentally ill can make situations more difficult - "Sometimes its better to hide it. When I go to the hospital and they ask what you are, I say 'I'm normal'."
agreed with FU's observation on "stupid Americans"	
embraces the culture of mental illness as part of public identity	

Allt Rue	Maximillion Diablo	Laila Jane
ambiguity between acceptance of self and desire to blend in with the dominant group	identifies as an artist, a way to inspire others who might have similar struggles	identified as a college graduate and a group facilitator
no mention of education, career, sexuality, relationships, desire for marriage or children, race, religion, political affiliation, culture/values of family-of-origin	embraced opportunity to create pseudonym and was playful with his temporary identity	no mention of career, relationships, sexuality, desire for marriage or children, race, religion, political affiliation (did express anger and distrust in politicians), culture/values of family-of-origin
discussed trying to define herself, forming and building identity wanting to use what is already there - work with what you have	no mention of education, career, relationships, sexuality, desire for marriage or children, race, religion, political affiliation, culture/values of family-of-origin	new to <i>The Painted Brain</i> , exploring culture of mental illness
"repressed fabulousness"		

### **Identity Formation**

The group members' choices of pseudonyms was interesting in regards to identity formation. All members embraced the chance to create a new, temporary identity and seemed to enjoy playing with what that imaginary life might look like. BugK and Allt Rue chose names that were somewhat ambiguous and could be interpreted in a number of ways. FU's choice of pseudonym seemed to convey his strong feelings about the subjects discussed within the focus group. Maximillion Diablo (Megalomaniac and Playboy Extraordinaire) adopted an identity that appeared to be the opposite of his calm and humble nature. Laila Jane did not give any clues to the origin of her name but seemed to appreciate the anonymity it allowed.

Because Bug experienced early onset schizophrenia with symptoms beginning at age three, her process of incorporating mental illness into her identity has been different from the other group members... "It's all I've ever know. This is my experience. The past is my map to where I am today. I have no regrets." Her art process, as well as her willingness to share personal experiences, felt freer than most in the group. This may be a result of having more time to learn how to cope with being part of a stigmatized population and/or having no other choice but to embrace it. She acknowledged that "All my best stories come from schizophrenia," and points to interactions with the mental health system as defining factors in her life. It is likely that these events contributed to her rebellious nature and out-spoken, unapologetic attitude towards those who are ignorant about mental health issues. Although she admits that she is sometimes hurt or angered by people's insensitive words and actions, in comparison to the rest of the group, Bug seems to be more comfortable acknowledging mental illness as part of her public identity .

All participants agreed that identifying as a person with a mental illness can create problems

and add unneeded stress to their lives. FU said, “Sometimes it’s better to hide your diagnosis. When I go to the hospital and they ask what you are, I just say I’m normal.” Despite feeling like it might be easier or safer to hide, both Bug and FU at least partially embrace a counter-cultural attitude and, in some situations, feel an obligation to expose injustices in stigmatized representations of people with mental illness with FU saying, “The system needs to change. That’s why I speak out.” In discussing identity, FU acknowledged feeling a loss of self that he believes is a result of living in a large city. He also expressed concern that American culture has become too connected to technology, causing people to act cold and jaded towards one another. Allt seemed to feel ambivalence regarding issues of identity and expressed more concern with her anonymity than other members. She also appeared conflicted in acknowledging her affiliation with *The Painted Brain* despite saying that it has played an important role in her life. This inner conflict may stem from her desire to accept herself while also being able to blend in with the dominant, more accepted group. Through the art, Allt discussed her struggle to define herself, forming and building identity and wanting to “use what is already there...I have to work with what I have.” Her final piece (Figure 6) communicated her need to keep some things wrapped up tightly. Although she told the group that there was “repressed fabulousness” inside, it was not something that she was ready or willing to show in this group.

Laila’s art (Figure 8) expressed the value she places on being identified as a well-educated, socially acceptable adult. She is new to *The Painted Brain* and seemed to use the art as a way to explore the culture of mental illness. Both Max and Bug expressed the importance of identifying as an artist. Max said that it has always been part of who he is and that it has provided him with a way to inspire others who might have similar struggles or who might not understand what it’s like to live with a mental illness.

The researcher noted that several elements of identity that would be expected to be relevant to young adults were not mentioned in this discussion. Although members of the focus group represented several different races and ethnicities, this facet of identity was only touched upon in passing. Other important elements of identity that were largely missing from the discussion include educational and career goals, relationships, sexuality, a desire for marriage or children, religion, and political affiliation. The values and culture of members' families-of-origin were also missing from the discussion which may be a result of the time limit and the discomfort caused by talking to a stranger and being recorded. It might also be indicative of the feeling of alienation from families that may not understand or embrace the challenges that this population deals with.

Table 10

*Coping Mechanisms*

BugK	FU
frequent use of humor to put the group at ease and to help facilitate conversation about difficult subjects, use of silly accent	frequent use of humor to reduce tension within the group and to discuss feelings of isolation and persecution
information is power: limited in the 90's before the internet, support groups now have more informed conversations with more accurate knowledge than when the internet first started	finding a peaceful place to live, away from city, hiking, seeing the ocean, meditating
separation from dominant group who needs to feel superior or who is fearful of what they don't understand	"It's not something you can change (stigma) so you just learn to live with it."
creating funny names for medications: 'shut-the-fuck-up-apine' and 'disaster-zone'	separates from groups that are unaccepting of differences

Allt Rue	Maximillion Diablo	Laila Jane
embracing of alternate identity offered by the opportunity to remain anonymous in the group and when sharing work in <i>The Painted Brain</i> , Conscious throughout the group of not disclosing information that could be identifiable such as length of time in with <i>The Painted Brain</i> and how she became involved	<p>spending time with friends and family, going out and exploring</p> <p>"I had trouble controlling my emotion and my anger but now I've learned to just take deep breaths."</p> <p>learn more about diagnosis, reading and better understanding the situation helped</p> <p>humor - "We all use it. We have to."</p> <p>"You have to deal with life the way it is. Medication, talking, and making art help."</p>	writing, facilitating groups at <i>The Painted Brain</i>

**Coping Mechanisms**

Participants agreed that humor was a necessary coping mechanism for dealing with the stigma of mental illness with Max contributing that, "We all use it...we have to." Throughout the focus group, members used their pseudonyms to add humor to the conversation, often laughing as they shared stories of being misunderstood or mistreated by society. Bug was especially

skilled at using her sense of humor to put the group at ease, and her ability to laugh at herself helped facilitate difficult conversations.

Participants expressed different opinions about coping with stigma through confronting it. Some try to accept it because, “It’s always going to be there,” while others feel a need to take a stand against it. Bug said, “When faced with stigma in a confrontation, I admit that the other person feels the need to feel superior and I’m ok with that...because I’m amazing and fuck you.” Member’s participation with *The Painted Brain* and the attachment they have to that group may indicate their agreement that, instead of trying to fit into the dominant culture that has rejected them, sometimes it’s healthier to distance themselves and form their own, more accepting, culture.

Other coping mechanisms that were discussed include FU’s emphasis on finding a peaceful place to live and getting away from the pressure of the city. Max spoke about finding information and learning as much as he can in order to better understand his diagnosis and Bug agreed saying that “information is power.” All members spoke about the power of art to as a coping mechanism either as a soothing process, a way to better understand the self, or a way to connect with others.

Table 11

*The Experience of Art-Making*

BugK	FU
<p>“Its not about an image, but the practice of doing something. Its a cathexis...attention and energy and purpose go inward rather than outward...like an implosion. Practicing in cathexis...this plate...is cathartic.”</p> <p>“I essentially just put all of my demons into this thing...into the surface of this and that. I remember when I started carrying around a gigantic sketchbook that I found in the trash and wherever I went I could work and people would leave me alone. People were like ‘shhh don’t bother her, she’s working.’ It was like a security cloak for me. It occupied me and gave me a rest from living in a better way than a book can because a book ends but this goes on forever.”</p> <p>being seen by just making a mark on a paper</p>	<p>tactile experience, way to let go and not have to plan things, message can be open to different interpretations by anyone who sees the art</p>

Allt Rue	Maximillion Diablo	Laila Jane
<p>“ I like that art doesn’t need words. You can plan it... you can go into an art project with a concept and figure out what works for you so its very process oriented and strategic and detailed. You can also just start and see what happens...it can be spontaneous and meditative and calming. You get sucked in and its a pleasurable experience”</p> <p>“I’m always surprised by the results. Its not about a message. For me, its a series of movements and concentration exercises. I like the patterns, the rhythm, and the tactile experience of making art.”</p>	<p>“Creating art makes life less cold and scary.”</p> <p>art acts as a way to connect and communicate with others, takes pride in art and enjoys sharing it</p>	<p>“Normally when you interact with people they present a façade, but in art people are more true to themselves.”</p>

**The Experience of Art-Making**

As members of *The Painted Brain*, all participants have experience creating art and are involved in either the magazine and/or the art shows put on by the organization. Some choose to remain anonymous and others use their real identity. Members agreed that being able to communicate or express emotions without words helps them to feel less alone, with Allt saying “I like that art doesn’t need words...you can plan it...you can go into an art project with a concept

and figure out what works for you so its very process oriented, strategic and detailed. You can also just start and see what happens...it can be spontaneous and meditative and calming. You get sucked in and it's a pleasurable experience" For Max, the experience of making art "makes life less cold and scary," and provides a way to connect and communicate with others. Bug spoke about discovering art for the first time, saying "I remember when I started carrying around a gigantic sketchbook that I found in the trash and wherever I went I could work and people would leave me alone. People were like 'shhh don't bother her, she's working.' It was like a security cloak for me. It occupied me and gave me a rest from living in a better way than a book can because a book ends but this goes on forever. I essentially just put all of my demons into this thing...into the surface of this and that." She also touched on the therapeutic value of the art process saying, "Its not about an image, but the practice of doing something. Its a cathexis – attention and energy and purpose that go inward rather than outward – like an implosion. Practicing in cathexis – this plate – is cathartic (Figure 1)." Allt agreed with the value of the process, saying "I'm always surprised by the results. It's not about a message. For me, it's a series of movements and concentration exercises. I like the patterns, the rhythm, and the tactile experience of making art (Figure 4)." FU also spoke about the value of the tactile experience, which can be seen in his plasticine sculpture (Figure 2). When sharing his art with others, FU seemed unconcerned with whether or not people understand his intention and instead encouraged others to find their own meaning in his art... "Art allows people to create a message that can be left open to different interpretations by anyone who sees it." Laila spoke about the power of art to reveal truth, saying "Normally when you interact with people they present a facade, but in art people are more true to themselves."

Table 12

*Experiences with The Painted Brain*

BugK	FU
<p>“I wouldn’t normally hang out with anybody. I’m more isolated with just with books on tape. As much as I love them, a person such as me does indeed like to be a part of a group and the only way I can enjoy myself within a group is to have an activity. I need a buffer and as long as i have an activity I’m cool.”</p> <p>“<i>The Painted Brain</i> has given me a sense of purpose and has brought me back to where i want to be. I took a vacation from my life and then I took a vacation from the vacation. It was through the magazine and through Dave constantly calling me and inviting me to stupid shit that i was able to return.”</p> <p>“I didn’t realize that I had a voice or a message or anything.”</p>	<p>“<i>The Painted Brain</i> is about coming together to share thoughts, ideas, and art. Coming together to enlighten.”</p> <p>“People come here to learn from one another, not so that they can stay the same. If I’m willing to listen to others, I think they should listen to me. That’s how you grow and evolve as a person. If Neanderthals remained Neanderthals, then you and I would just be throwing stones.”</p> <p>“To be honest, I wouldn’t say its all accepting. I sometimes feel alienated in the group. It’s not always safe and it still needs to grow. You can’t know my situation or the way my brain works...if people did, they’d probably be more sensitive.”</p> <p>“<i>The Painted Brain</i> plays a political role in my world. I’m not here to change people but I’m not here to shut up.”</p> <p>“Its a good place to share, to get things off your chest. If you don’t have any friends...I don’t have many friends...I have like one friend...I come here to share and vent and to reach out to somebody who might understand. The group is more powerful to me than being by yourself...what are you gonna do, move a mountain by yourself?”</p>

Allt Rue	Maximillion Diablo	Laila Jane
<p>“<i>The Painted Brain</i> has taken on a lot of different meanings since I’ve been involved. I really genuinely like everyone at this table and if I didn’t keep coming, I’d never see them.”</p> <p>“I don’t enjoy all of the community but there’s a lot about it that I do like.”</p>	<p>“Through <i>The Painted Brain</i>, I want to inspire people to remember that living with a mental illness is not as bad as people say it is. You can create a life around it. At first its a little scary but after awhile, through talking, taking medication, and doing art, its just a part of life.”</p> <p>“Its a great experience. As far back as i can remember wanted to make a name for myself as artist and the art shows we’ve had over the last two years have been a great start. People come out and see some of my best work. I’ve sold a few pieces.”</p> <p>able to establish identity as an artist and share work with friends, seen as creative, talented, and funny through the art</p>	<p>“Its hard for people with mental illness to form social bonds. At <i>The Painted Brain</i>, being creative and being different is appreciated and encouraged. Its nice to just be yourself and know that people will accept you for however weird or crazy you are.”</p> <p>“As a facilitator, I’m able to help people. Its super fun and mutually beneficial.”</p> <p>“I probably wouldn’t do it on my own for the most part unless I was in a really bad place.”</p> <p>basic human need for connection</p>

**Experiences with *The Painted Brain***

Three of the five group members expressed that being a part of *The Painted Brain* makes them feel less isolated and gives them a sense of community. Bug said “I wouldn’t normally hang out with anybody. I’m more isolated with just my books on tape. As much as I love books, a person such as me does indeed like to be part of a group, and the only way I can enjoy myself in a group is to have an activity. I need a buffer – as long as I have an activity, I’m cool.” FU also spoke about community and his desire to get out of his shell, saying “It’s a good place to share, to get things off your chest. If you don’t have any friends – I don’t have many friends, I have like one friend – I come here to share and vent and to reach out to somebody who might understand. The group is more powerful than being by yourself...what are you gonna do, move a mountain by yourself?” He also acknowledged that *The Painted Brain* plays a political role in his world saying, “I’m not here to change people but I’m not going to shut up either. People come here to learn from one another, not so that they can just stay the same. If I’m willing to listen to others, I think they should listen to me. That’s how you grow and evolve as a person. If Neanderthals remained Neanderthals, then you and I would just be throwing stones. It’s about coming together to share thoughts, ideas, and art. Coming together to enlighten.” Laila agreed, stressing the basic human need for connection...“It’s hard for people with mental illness to form social bonds. At *The Painted Brain*, being creative and being different is appreciated and encouraged. It’s nice to just be yourself and know that people will accept you for however weird or crazy you are.”

Participants also expressed the value of being given a place to find your voice and create an identity as an artist. Bug said, “I didn’t realize that I had a voice or a message or anything. *The Painted Brain* has given me a sense of purpose and has brought me back to where I want to

be. I took a vacation from my life and then I took a vacation from the vacation. It was through the magazine and through Dave [Leon] constantly calling me and inviting me to stupid shit that I was able to return.” Max also discussed the opportunity the organization provided him to cultivate his identity as an artist. . . . “It’s a great experience. As far back as I can remember, I wanted to make a name for myself as artist and the art shows we’ve had over the last two years have been a great start. People come out and see some of my best work. I’ve sold a few pieces.”

*The Painted Brain* also functions as a vehicle to educate and help others. Max expressed this opportunity, saying “Through *The Painted Brain*, I want to inspire people to remember that living with a mental illness is not as bad as people say it is. You can create a life around it. At first it’s a little scary but after awhile, through talking, taking medication, and doing art, it’s just a part of life.” Laila also discussed wanting to be of service, saying “As a facilitator, I’m able to help people. Its super fun and mutually beneficial.” Throughout the group, the researcher was impressed by the level of trust and comfort shown between participants as well as their ability to be honest with each other even when they differed in opinion. It is likely that this positive atmosphere is a result of the sense of community and empowerment that has been created by *The Painted Brain*.

Table 13

*Participants' Artwork and Descriptions*

BugK	FU	Allt Rue	Max Diablo	Laila Jane
				
<p>"The plate went through many transformations. I wasn't thinking. That's the process for me. It's a vacation. I like to scratch layers off... I like this texture... I tried to make it less blue and give it more definition by putting the black in there, but then it got overwhelming and really muddy. I was trying to make this bird and then I did this (applied rubber cement to plate) in order to remember not to make it look like a bird. In taking away some of the layers, I get to exist inside of the little nooks and crannies. There's all these little places where the color is really nice."</p>	<p>"The ball is the stress and the pressure on top of my head. I am the head of this triangle on top of, I guess, myself. It would be nice if the ball just rolled off like that (demonstrates), and then I'd be free. I don't know what the face is... it isn't me. I don't know if this is a tongue or a carrot... it's open to interpretation."</p> <p>"On the plate is a stairway to god knows what... whatever you want it to be."</p>	<p>"The purple clay is a labyrinth, kind of like an ear folded in on itself. The little white person is also kind of folded up as if there's a loss of power and disowning of self. A shrinking in, away from yourself, away from everybody, not really being, trying to make yourself into a ghost, not wanting to be identified, wanting to be seen as generic, nothing specific. It's about being able to blend in."</p> <p>"Carving the clay is like what happens when you're trying to define yourself out of mush. You have to take what's there and piece it together. You want it to be reminiscent of what was there, but it isn't. Forming, building identity, not from the ground up but from the up ground. This is what I've got to work with - let's see what I can do."</p>	<p>"I did a collage with a bunch of random words and an iron mask. For me, the iron mask represents what my world looks like from the inside... all dark and cold, silent and scary. The words represent all of the racing thoughts that pop in and out of my head on a day to day basis... create, inner peace, inspirations, dark, tv, old, rampage, and love, just to name a few."</p>	<p>"This is me and I'm graduating and it looks normal on the outside but on the inside its mass chaos... that's it."</p>
			<p>"The folded plate is internal stigma tied with a pink bow because you've gotta look fabulous. It's repressed fabulousness."</p> <p>"The plate is reminiscent of an old style of drawing that I used to do but I don't think I do anymore. It's not any person in real life. My father once said 'all your portraits look terrible and scary.' I don't feel like they're scary."</p>	

Table 14

*Observations of the Art Process*

<b>BugK</b>	<b>FU</b>	<b>Allt Rue</b>	<b>Max Diablo</b>	<b>Laila Jane</b>
<p>self-deprecating humor regarding her art process - "I can't seem to get past the point where it looks like puke."</p> <p>constant transformation using minimal supplies</p> <p>process seemed to provide a buffer that allowed her to be a successful part of a social group</p> <p>art seemed to be more about having something to put energy into than about the final product</p>	<p>destroyed original clay piece before it could be photographed, didn't see art as something intended to be permanent, not attached to the final product</p> <p>form and structure were important in the creation of a perfect pyramid and sphere from clay</p> <p>meaning of art pieces was left open to interpretation</p>	<p>worked silently and didn't want to discuss pieces until they were finished</p> <p>art appeared to be a meditative and calming process, she appeared to be lost in her art-making for the majority of the group</p> <p>hesitant to share meaning of art with group, it's possible that she was nervous to be on record</p> <p>each piece had a specific meaning and she choose her words carefully when describing them to the group</p> <p>after talking about her pieces, she poured rubber cement over the original clay which seemed to connect it with the other parts, stabilizing it and allowing it to be better seen by the group</p>	<p>entertained the group with jokes while working on his art</p> <p>looked at all of the collage images carefully and made thoughtful decisions about which ones to use</p> <p>drawn to words and 2D materials</p> <p>was comfortable presenting his art to the group, expressed pride in the finished piece and said he was going to laminate it</p>	<p>showed curious about materials, initially wanted to write but ultimately used a variety of materials without words</p> <p>drawn to 3D, tactile materials that could be used in a clear, organized manner</p> <p>worked silently and didn't want to discuss her piece until it was finished</p> <p>seemed to develop a plan before starting her piece and made an effort to make it neat and presentable to the group</p> <p>seemed proud of her final product and appreciated the groups' compliments</p>

Table 15

*Art Qualities According to Lusebrink's Expressive Therapies Continuum (1994)*

	<b>BugK</b>	<b>FU</b>	<b>Allt Rue</b>	<b>Maximillion Diablo</b>	<b>Laila Jane</b>
<b>Kinesthetic</b>	pressure of oil pastels on paper plate	repeated action of rolling clay ball off of sculpture, smashing clay piece	dripping rubber cement onto clay, folding and wrapping paper plate with pipe cleaner, pressure of oil pastels on paper plate	moving words around on the page, carefully pressing images down onto paper	tearing pieces of cotton, cutting construction paper and vellum into shapes
<b>Sensory</b>	blending and smudging pastels, removing color by scraping pastels away with fingernails	kneading and shaping of clay	kneading and shaping of clay, feeling sharp points of the toothpicks, blending and smudging of colors	sifting through images in the collage box	feel of cotton balls, covering of rougher 3D materials (pipe cleaners) with smooth 2D paper
<b>Perceptual</b>	found images within colors and scribbles, identified a bird but acknowledged that it could be something else	abstract representation of pressure	found a labyrinth and an ear within abstract sculpture, moving of the clay figure to face the group	imagined the mask as the stigma of mental illness, view from behind mask as well as those who encounter it	conceptualized internalized stigma as jumble of pointy materials, view from stage vs audience
<b>Affective</b>	dark colors for pain, bright spots for hope, resiliency, layers and constant motion express passion for life but overwhelmed by circumstances	chose emotional medium but exercised control over it, may have been activating so he smashed it, less emotion in 2nd piece	clay evoked feelings of apprehension and anxiety, folded plate felt like a need for control after being exposed	mask seems cold and scary, feeling isolated and misunderstood, seeking connection	red pipe cleaner for pain/chaos within, large robe for protection, feeling exposed in front of audience, shame/embarrassment
<b>Cognitive</b>	spoke of the layers in her art and the removal of surface elements to reveal hidden beauty	sculpture describes the pressure created by society's stigma of mental illness	the figure is struggling with identity and owning parts of itself	externalized and organization of racing thoughts	placement of materials to communicate relationship between outside and inside
<b>Symbolic</b>	used art process as a metaphor for self-discovery, like the plate, she is always changing and must be able to adapt	sculpture shows pressures that he wishes could "roll off of my head", steps explore an unknown path	folded plate shows repression of parts of herself, exploration of father's reaction to art vs her own reaction and reaction of peers	steel mask as metaphor for living with mental illness	internalization of stigma, living with secrets

**Art Qualities According to Lusebrink's Expressive Therapies Continuum (1994)**

**Kinesthetic.** The kinesthetic level of ETC focuses on the experience of creating art, specifically the physicality and movement involved in the process. It does not consider the artist's intention or final product. Bug and Allt began the group by making bold, pressured marks with oil pastels on paper plates which may have been an expression of their anxiety about participating in the group. FU and Allt experimented with plasticine for much of the group, using the feel of clay in their hands and the motion of rolling or crushing it as a self-soothing mechanism. Allt and Laila displayed kinesthetic energy in bending and twisting pipe cleaners while struggling to conceptualize internalized stigma. Max took his time sliding his chosen words around the page before carefully pressing them down into their permanent positions.

**Sensory.** The sensory level of ETC focuses on the tactile qualities of the art materials and the reaction that the artist has to these sensations. Like the kinesthetic level, it is not concerned with the artist's intention or final product. The blending and smudging of oil pastels seemed to be a soothing sensation for both Bug and Allt, while the kneading and shaping of plasticine seemed to be more activating, as seen in FU's destruction of his sculpture. Other sensory experiences include the softness of Laila's cotton balls and the sharpness of Allt's toothpicks, both of which were added to the art pieces after a self-representation had been created.

**Perceptual.** The perceptual level focuses on the manner in which objects are constructed and organized. As Bug added and removed layers from her piece, she identified objects that appeared within the colors and shapes, but acknowledged that they could represent different things to different people. Allt was able to identify the image of a labyrinth and an ear within an abstract clay sculpture. After keeping her clay figure perched on the edge of the table facing

herself for most of the group, she finally chose to turn it around to face the rest of the group and explored how it looked from different points of view, allowing more or less of the elements to be visible. Max's piece allows viewers to understand what it's like behind the mask while also having the experience of encountering the mask from the outside. Laila's piece also shows an inside and outside, allowing the viewer to understand the point of view of the graduate as well as the audience.

**Affective.** The affective level focuses on the emotion that the artist conveys during the art process as well as through the final product. Bug's choice of dark colors may convey her depression and the pain she has experienced as a result of being rejected or ridiculed by others. The bright colors that she revealed by scraping away layers of oil pastels with her finger nails may be an expression of her resiliency and hope that something good will come from her struggles. FU chose a media that can be emotionally activating but he exercised great control over it in his creation of a perfect sphere and pyramid. This may be a reflection of his desire to have more control over his circumstances, something he sometimes tries to accomplish by isolating himself from those who don't understand mental illness. During the group, FU crushed his sculpture and chose to create a less activating piece using pen on a paper plate. It's possible that the conversation in the group brought up emotions he didn't want to confront or share in that moment and the control of the pen allowed him to return to a less emotional state. For Allt, the clay seemed to evoke deep feelings surrounding her struggle with the stigma of mental illness and identity formation. Although her images convey fear and anxiety, she was able to combine them in a way that expresses strength and a desire to connect with others. After working with the emotional mediums of clay and oil pastels, she finished the group by folding a paper plate and tying a pipe cleaner around it.

This may have been her way of containing the emotions she had shared, and of resuming control after letting her guard down. For Max, the gray color and cold, smooth texture of the mask seem to convey feelings of sadness and isolation that he has experienced as a result of the stigma of mental illness. Laila's choice of a red pipe cleaner to represent her inner chaos may represent the anger she feels regarding a frightening loss of control over her circumstances. Her use of a large, black robe to hide the chaos within evokes feelings of shame and embarrassment, which may reflect her fear of how she might be judged if the audience saw the part of herself that she prefers to keep hidden.

**Cognitive.** The cognitive level focuses on the artist's ability to organize elements in a manner that conveys their message or story. Bug's art seems to be organized through the use of layers with the outside layers expressing difficult circumstances and the layers that are hidden beneath expressing hope. FU organized both of his pieces in a way that allows viewers to draw their own conclusions. Allt created several disconnected pieces but was able to organize them into a coherent whole, using rubber cement to solidify the piece. This may speak to her desire to bring various parts of herself together in order to create a more thoroughly integrated identity. Organization was important for Max as he carefully spaced his words on the page in order to completely surround his mask. Laila used inside/outside organization in her self-image as well as organizing the piece into "us" and "them," showing the audience's view but also the view of the graduate.

**Symbolic.** The symbolic level focuses on the artist's ability to express an idea or concept through the art piece, allowing it to have personal meaning as well as the ability to communicate that meaning with the viewer. Bug used the art process as a metaphor for self-discovery, expressing that, like the plate, she is always changing and has learned to adapt to whatever life throws at her.

FU used his sculpture as a symbol for the pressures of society and his frustration at being unable to escape from these pressures. His plate may be symbolic of traveling on an unknown path as well as his hope that he will someday be able to see things more clearly and understand the meaning of his suffering. For Allt, the white figure conveyed her experience of internal stigma and her desire to disappear or blend in. Her choice to give the figure something solid to sit on so that it could turn and face the group may be symbolic of her effort to accept the parts of herself that it might be easier to hide. Max used a steel mask as a symbol for living with mental illness with hopes that it would convey his experience to others in a way that might not be possible with words alone. Laila chose to create her graduation day, an important milestone of early adulthood, and used the art to show the difference between what people see on the outside and what is actually happening on the inside. By making the self-image so large and placing it in front of an audience, she conveys her fear of being exposed and of having her dreams destroyed by the challenges of mental illness and its accompanying stigma.

### **Emergent Overarching Themes**

After being collected and organized into categories, the data was analyzed to identify major themes central to the research exploration. Careful examination of the categories and the artwork led to the emergence of three overarching themes: 1) The challenges of coping with a stigmatizing system, 2) Internalized stigma as it relates to the formation of adult identity, and 3) The use of art to combat stigma and facilitate self-discovery. These three overarching themes are further divided into subcategories and are presented with the intention of gaining greater understanding of the lived experience of this population. The first theme (the challenges of coping with a stigmatizing system) emerged from data that identifies external sources of stigma and the impact of external stigma on the lives of young adults with mental illness. Examples of external stigma and its effects were found in every category, but were especially prominent in the categories of childhood experiences with stigma, institutionalized stigma, stigma in the media, and coping mechanisms. The second theme (internalized stigma as it relates to the formation of adult identity) emerged from data that identifies internalized stigma and the struggle of young people with mental illness to form an integrated adult identity. Categories that illuminated this theme include stigma of rhetoric, internalized stigma, and identity formation. The third theme (the use of art to combat stigma and facilitate self-discovery) emerged from data that identifies the relationship between the creative process and the ability to incorporate mental illness into participants' emerging adult identities. This data was found in the categories of experiences with art-making, experiences with *The Painted Brain*, and observations of the art-making process, as well as in Lusebrink's Expressive Therapies Continuum that was used to evaluate the art process and products. These three overarching themes are discussed using the following subcategories:

Table 16

*Emergent Themes and Subcategories*

<b>The Challenges of Coping with a Stigmatizing System</b>	<b>Internalized Stigma as it Relates to the Formation of Adult Identity</b>	<b>The Use of Art to Combat Stigma and Facilitate Self-Discovery</b>
Sources of external stigma	Internalization of stigma	The art process
Portrayals of mental illness in the media	Adult identity formation	Visual representation of a marginalized experience
Responses to external stigma	Disclosure of a mental illness	The healing potential of creative communities

**The Challenges of Coping with a Stigmatizing System**

The first overarching theme focuses on the experience of living within the boundaries of a societal system that perpetuates the stigma of mental illness. The research found that the stigmatization of mental illness is prevalent in many areas of the participants' lives including interactions with medical and mental hospitals, therapists, psychiatrists, teachers, and the police, as well as in communities, schools, and places of employment. Also important to the conversation is the anger and fear surrounding the media's inaccurate portrayals of mental illness, as it perpetuates stigma and causes those with mental illness to feel powerless, resulting in further isolation and avoidance of mental health services. The research demonstrates that, in response to being rejected by the dominant group and feeling powerless to change the system, young adults may embrace a counter-cultural community in order to find the support and acceptance they have not received from family, friends, and society as a whole. Support is shown for strength-based programs like *The Painted Brain*, that allow members of a marginalized group to find their voice in the fight against stigma.

**Sources of external stigma.** Within the focus group, it was clear that this population expects to be stigmatized by certain people and in certain situations, and that they often feel powerless to change the stigma that exists in societal systems. Bug's experiences with classmates and teachers demonstrate the prevalence of stigma within educational systems and the casual acceptance of this type of treatment. While many minority groups are protected from bullying, children and teens with mental illness are often openly ridiculed with little intervention from adults. This perpetuates the cycle of stigmatization and further isolates young people with mental illness.

Participants also expect to experience stigma within their communities, especially smaller communities and those with less access to mental health information. This was seen in Bug's description of growing up in a small town and feeling that she was being put on display and judged by "the rumor mill." It is likely that the limited information and lack of awareness about mental health issues in her community caused Bug to feel a lack of control over her circumstances, increasing her anxiety and her fear of mental health care systems. The discomfort she experienced as she witnessed her parents', teachers', and peers' reactions to her diagnosis caused her to become more defensive and to fabricate stories in hopes of sounding "normal" for authority figures that seemed to be invading her privacy. Bug acknowledged that her way of interacting with others was forever altered by her early experiences within a family and a community that was uncomfortable with mental illness and an educational system that did not provide her with adequate information or support.

While ridicule from classmates and peers may be expected, a more surprising theme that emerged revealed the prevalence of stigmatization within the mental health system, the medical system, and amongst law enforcement officials and other public servants entrusted with the job

of helping those in need. Bug's early childhood experiences with school counselors, psychiatrists, and social workers serve as an example of how confidentiality is often not respected when working with children in a school setting. It also demonstrates the importance of sensitivity and the ability to explain mental health services and medication in language that children can understand. When mental illness is portrayed as something that is the child's fault and treated in a manner that feels like punishment, school is likely to become what Bug described as, "A self-perpetuating fear factory where everything I said and did was collected, documented and used as evidence against me." Like many children who deal with social workers and mental health professionals, Bug learned to say what she thought the clinicians wanted to hear in order to avoid embarrassing her family or being treated differently by her peers. These early experiences with stigma taught Bug that, in order to be accepted, even amongst mental health workers and school officials, she needed to alter her identity... "I learned not to disclose too much information about myself and I'm still closed off because of that. I still have to remember not to answer questions with misdirection... not to be so defensive."

As young adults, all members of the group reported feeling a lack of respect from mental health workers in hospitals and treatment centers. They agreed that people who seek mental health treatment are often overprescribed medication in order to "shut them up" and make things easier for the mental health workers. FU felt like a third-class citizen while receiving treatment, saying "Even dogs are given more value." In addition to feeling looked down upon, FU discussed sexual harassment and abuse that he experienced in the psychiatric unit of the hospital. Laila expressed her fear of being held involuntarily and having her rights taken away. Bug spoke about her difficulty in domestic violence counseling and addiction treatment, reporting that her

mental illness was always treated as her chief complaint and that she was often told that what she was experiencing may not be reality. The group agreed that people with mental illness have difficulty receiving proper care for medical problems because their word is questioned and their reality is not taken seriously. FU stated that it's better not to disclose mental health history when seeking any other type of help. Laila and Allt agreed and expressed frustration with the way mental illness is treated in relation to physical illness. In their experience, when a person seeks treatment for a physical illness they're shown compassion and treated like a human being, but when someone seeks treatment for a mental illness they're seen only as their diagnosis and made to feel like they're being punished for trying to take care of themselves.

**Portrayals of mental illness in the media.** A recurring and emotionally activating topic of the focus group was the role that media plays in perpetuating the stigma of mental illness, especially in the wake of a recent school shooting. Members feel that the media's portrayal of people with mental illness as perpetually dangerous and unstable is misinformed and that incidents that are difficult to understand are too quickly written off as the result of mental illness. This may be a reflection of the more powerful, dominant group's tendency to use a marginalized, non-dominant group as a scapegoat in order to explain events that evoke an unacceptable level of fear and discomfort. Despite a desire to expose this injustice, the group seemed resigned to the fact that they don't have the power needed to compete with mainstream media. Unfortunately, as long as the media continues to stigmatize mental illness, associating it with violence and instability, it will be difficult for people to publicly acknowledge their diagnosis, and fear of judgment may prevent many from seeking treatment. Members expressed that it is challenging and sometimes dangerous to act as a leader or representative for people with mental illness. The anxiety caused

by identifying with a group that is feared and hated encourages further withdrawal from society and a lesser chance of receiving treatment.

**Response to external stigma.** In discussing the effects of external, systemic stigma, it was apparent that the age of diagnosis as well as childhood experiences in the mental health system influence how members adapt to and cope with the stigma of mental illness. Within the group, there was a noticeable difference between Bug, who was diagnosed and received treatment as a child, and the other four members who were young adults when they first encountered the mental health system. It is possible that, although some elements of stigma may be more permanently ingrained in Bug's world view, she is also more comfortable working within the system when it serves her and rejecting it when it doesn't.

Group members were pessimistic about their place within their communities and expressed the need to seek out a sense of connectedness from other sources. After years of frightening and confusing encounters with treatment, it's easy to understand how members would develop a distrust in mental and medical health care systems and those who work for them. It's possible that feeling abandoned by the institutions that are designed to keep them safe has contributed to the formation of a counter-culture which allows these young adults to separate themselves from the judgment of the dominant group and maintain a sense of control over their circumstances. This was seen in members' choice of pseudonyms as well as in their humor and sarcasm which seemed to build a sense of camaraderie within the group. Although most members of the group appeared to follow Bug's lead in rejecting the society that rejected them, they did so in a less dramatic fashion. This may be a reflection of the ambiguity they feel in identifying with the culture of mental illness, wanting at times to fit in with the dominant culture and at other times acknowledging that their diagnosis sets them apart.

The group also stressed the importance of participation in *The Painted Brain* as a method of coping with external stigma. The community created by *The Painted Brain* provides members with a safe space and the opportunity to speak freely without fear of repercussions. This type of organization offers a strong support system which has been shown to be an important factor in the likelihood of people to seek treatment as opposed to becoming more isolated and marginalized. It also acts as a tool that allows members to have a voice with which to combat the negative perceptions of mental illness on both a personal and public level.

As a result of living in a stigmatizing system, it seems that the group members expect that their rights will be violated and that they will be mistreated and devalued on a regular basis. This was an obvious source of anger and frustration throughout the focus group and it felt important for members to have the opportunity to expose this mistreatment and to bring awareness to the institutionalized stigma that continues to impact their lives. Despite the uncomfortable feeling of being trapped in a system that devalues people who suffer from mental illness, group members showed an enormous amount of resiliency, insight, and creativity as they discussed their approach to coping with a stigmatizing system.

### **Internalized Stigma as it Relates to the Formation of Adult Identity**

The second overarching theme deals with the internalization of stigma and the challenges it creates for young people with mental illness as they work towards the formation of an integrated adult identity. The research suggests that when individuals internalize public stigma, they anticipate rejection due to the belief that they are not valued members of society, causing them to withdraw and/or self-sabotage, which further reinforces the dominant group's stereotype of mental illness. When public stigma is internalized, it may impact identity formation and result in the delay of im-

portant developmental milestones. Exploring participants' fluctuation between self-acceptance and the shame of their diagnosis illuminates the struggle that young adults experience when navigating their relationship with mental illness. The research also suggests that the challenge of incorporating mental illness into identity may result in less emphasis being placed on other facets of identity including race, ethnicity, sexuality, religion, and political affiliation.

**Internalization of stigma.** Identity begins within the family and for those who struggle with mental illness, the ideas and opinions of their families-of-origin regarding mental health seem to be very influential. Bug spoke of the lack of information her family had about mental illness and the avoidance of conversations concerning her treatment. Her family's inability to communicate openly about this issue led Bug to conclude that mental illness was something that should be kept secret and she learned to "act normal" to avoid embarrassing her family. She internalized the idea that something was wrong with her and that she would not be accepted unless she hid this "bad" part of herself. Bug's art shows layer upon layer of colors, each hiding the ones below, which may be a metaphor for the hidden parts of her own identity. As an adult, Bug is able to scratch away the layers and reveal hidden parts of herself when she chooses to do so. Although she now seems to have a clear understanding of who she is and acts as a leader amongst her counter-cultural peers, she acknowledges that it has been a painful and often lonely journey towards self-acceptance.

Although Max wasn't diagnosed with mental illness as a child, he related to Bug's experience of identity formation being influenced by fear and shame. Max shared that long before he was diagnosed and began treatment, his family "always knew something was wrong." His art conveys a feeling of being trapped inside a frightening mask which parallels the feelings of a

child who believes that something is wrong with him but feels powerless to make things better. Max spoke about his fear that he might be a danger to others because he had internalized the idea that people with mental illness are dangerous. Being faced with stories and images in the media that convey people with mental illness as violent caused him to question his own potential for violence with questions like “Am I dangerous?” and “Is something wrong with me?”

Allt’s art also brought up the influence of family on identity formation. She created a portrait of an unknown man and shared that her father once told her “all of your portraits look terrible and scary.” Although the portraits weren’t terrible or scary to her, it’s possible that Allt internalized the belief that a part of herself is terrible and scary, and that she should keep that part hidden. Allt didn’t talk about her current relationship with her family, but her art clearly expressed the stigma of mental illness that she has internalized and her effort to keep it hidden with “fabulousness” on the outside. Laila also chose not to speak about family, but her decision to make art that shows her graduating in front of a crowd may speak to her family’s expectations as well as their hopes and dreams for her future. The image also speaks to the internalized shame of mental illness that she carries with her as she explores her adult identity, and her desire to keep it hidden as much as possible beneath a calm and successful exterior. FU did not share any personal experiences from his childhood or family-of-origin, but he addressed everyone’s reluctance to talk about family and the internalization of stigma, saying “It’s a sensitive subject.”

**Adult identity formation.** Becoming a young adult typically means leaving behind the safety net of childhood and transitioning to a place of greater independence and responsibility. Milestones that contribute to adult identity include higher education, employment, independent living, and plans for marriage and children. When symptoms and/or diagnosis of mental illness occur

during this time, important milestones may be delayed or unfulfilled, leaving the individual to exist in a limbo between childhood and adulthood. While others are moving forward and focusing on their future, those with mental health illness are faced with other challenges including treatment, hospital stays, and the search for the right medication that demand their attention and separate them from their peers. While others at this age may feel proud of their independence and accomplishments, young adults with mental illness may feel confusion, fear, and embarrassment as they wonder if something is inherently wrong with them. The experience of not being able to step into adulthood with their peers may further contribute to the internalization of self-loathing, disappointment, and shame. Despite coming from different backgrounds, it appears that at least four of the group members' identities were influenced by their family's opinions about mental illness. Internalizing these opinions and learning to hide a piece of the self may be at the root of these young adults' struggle to accept themselves and to find their place in the world.

Although each member of the group is at a different place in their own self-discovery, the conversation and the art pieces suggest that the four members who were not diagnosed as children may experience a higher level of ambiguity regarding their adult identity. This may be a result of Bug having more time to process her situation or perhaps because, as she says, "It's all I've ever known." Being diagnosed as a young child, Bug did not have to grieve for the loss of her former self and she had no choice but to deal with her diagnosis in both her external and internal worlds. Unlike Bug, the others are faced with a reality that is probably different from their childhood image of what the future would look like. It's possible that they have been forced to let go of goals and plans they had for their future and may be disheartened to see peers and siblings moving forward when they seem to be falling behind or running in place.

At a time when many young adults are enjoying their newfound independence and taking more responsibility for themselves, those with mental illness may find themselves requiring more support and having to trust others to do what's in their best interest. Laila shared her experience of being placed on an involuntary hold and the group empathized with the fear and confusion she felt at having her rights taken away for an indefinite amount of time. Her art suggests a struggle between her independent self, shown in a cap and gown, successfully meeting a major milestone of young adulthood, and a less secure, less confident part of herself that is afraid of losing control and having to rely on others to make decisions about her health and well-being. Bug and FU also spoke about having their rights taken away, specifically citing the degrading experience of being put in restraints and not allowed to do simple things like go to the bathroom without supervision. Being repeatedly told that they are not capable of caring for themselves not only has a negative effect on self-esteem but it may also contribute to delaying the transition into adulthood.

For members of the focus group, it seems that the constant push and pull of conflicting feelings and incongruent identities takes up a great deal of space in their lives, which may partially explain the lack of conversation about other important pieces of culture and identity. Issues of race, ethnicity, gender, socioeconomic status, education, religion, political affiliation, and sexuality would typically be expected to come up in a conversation with young adults about identity but, within this group, they were barely mentioned. This suggests that the stigma of mental illness has such an overwhelming influence on members' internal sense of self as well as their external experience of the world, that they may feel a lack of connection to other parts of their identity. Unlike many cultural values that stem from the family-of-origin, young adults with mental illness may be dealing with challenges that no one else in their family has had to face.

They may deal with this sense of isolation by seeking out a community that understands their struggles, and embracing that community despite other cultural differences. Although the focus group was made up of people of different races, ethnicities, and world views, the shared identity of mental illness seemed to eclipse those cultural differences which might otherwise influence their interactions and relationships with each other. Another noticeable difference between this group and what might be heard within a group of young adults who don't suffer from mental illness was the lack of emphasis on the future. Group members were focused on coping with the present with little mention of future hopes and dreams or plans for education, career, or family. This may be representative of the limbo between childhood and adulthood that this population finds themselves stuck in, as well as the uncertainty of how mental illness may continue to impact their future. Although it was difficult for the group to talk about internal stigma and issues of identity, members acknowledged that the use of art, writing, and the community of *The Painted Brain* allow them to explore questions of identity and help them to find a sense of purpose and meaning in their lives.

**Disclosure of a mental illness.** Member of the group differed in the extent to which they were willing to incorporate the label of mental illness into their identity. They have all been faced with decisions about whether or not to disclose their diagnosis to family, friends, employers, landlords, doctors, and other community members. In having to make the choice of what to share with others, they may also be making the choice of what to accept within themselves. It seems that this inner struggle sometimes leads to withdrawal from society and other times to rebellion against it. This rebellion was seen in Bug's and Max's acceptance of their membership in a stigmatized group and their ability to embrace it as part of their public identity with Bug doing so

with a dramatic, in-your-face attitude and Max choosing a quieter style and focusing on his need to be of service to others.

Bug acknowledged that accepting all parts of herself sometimes means rejecting people who are unable or unwilling to deal with her illness. This may explain other group members' hesitation to fully embrace and disclose their identity, knowing that it could mean pushing away family and friends as well as the comfort and safety provided by the ability to fit in. Laila, Allt, and FU fluctuated between wanting to be positive representatives of mental illness in some situations and preferring to keep that part of their identity private in order to fit in with the dominant culture in others. Allt's sculpture of a white figure who wants to disappear beautifully illustrates her need to be "generic, nothing specific, like a ghost" in order to blend in and avoid judgment. The consequences of belonging to the culture of mental illness were apparent in FU's sculpture which he described as "having to balance all of the pressure on top of your head and wishing that it would just roll off and set you free." He acknowledged that, although he accepts his condition as a part of himself, he is not always comfortable sharing it with others saying, "Why would you want to be part of a group that's feared and hated?" When the pressure becomes too much, he withdraws and "becomes a hermit" who is able to live with little human interaction. It's possible that the struggle of having to monitor when, where, and with whom it's ok to share their true lived experience leaves this population with an inconsistent sense of self. It also seems to create a pervasive feeling of loneliness as a result of only allowing people to see the "good" parts of their identity.

The research found that some of the groups' hesitation to incorporate mental illness into their adult identity is due to language. The rhetoric surrounding mental illness stirred up strong emotions for all group members who passionately rejected the word "ill." They expressed anger at

being permanently labeled by a word that is associated with weakness. They also pointed out the need to differentiate between people who take care of themselves and seek the treatment they need (and therefore are not currently “ill”) and those who do not. Although there are many inspirational people who suffer from mental illness and also live full and successfully lives, the words “mentally ill” tend to be associated with most tragic, frightening, and heartbreaking individuals and their behaviors. It makes sense that this population is reluctant to identify with the culture of mental illness when the public is rarely exposed to the inspiring stories of Elyn Saks and Kay Redfield Jamison and are instead bombarded with images of school shootings and horrific crimes. Members suggested that, instead of being labeled with a word that suggests something is wrong and needs to be fixed, it would be more productive to talk about mental health, mental diversity, or behavioral conditions.

### **The Use of Art to Combat Stigma and Facilitate Self-Discovery**

The third overarching theme that emerged from the data focuses on the role that art can play in the lives of young adults with mental illness. The research provides evidence that engaging in the creative process with others facilitates a sense of inclusion that may act as an opposing force to stigmatization. Participants were able to use the art to work through issues both emotionally and physically and to give visual representation to marginalized experiences. The art process as well as the product proved to be useful tools for self-examination and discovery. This may speak to the ability of organizations like *The Painted Brain* to foster insight, self-esteem, confidence, empowerment, connectedness, and social engagement. Although the act of creating and sometimes destroying art seemed to serve a different purpose for each member of the group, it was apparent that all five participants were able to express themselves through the art in ways that would not have been possible with words alone.

**The art process.** Members' choice of materials and their tactile sensations felt significant to the experience, as some materials provided structure and containment while others allowed for more freedom and uncertainty. Regardless of what media was used, the art found a way to act as a reflection of the participant's identity and to speak about the influence of external and internal stigma. Although participants were told at the beginning of the focus group that they would only spend fifteen minutes working on their art, they chose to work for the entire three hours. This allowed their art to go through many transformations and resulted in pieces that truly capture the experience of stigma and its influence on each individual's identity.

The choice of media varied within the group which may speak to different stages members are at in their own personal development and in their understanding of their relationship to stigma. Their choices may also reflect past experiences with art-making as well as ideas about the role that the creative process can play in their lives. It was interesting that, although a wide variety of materials were presented, three members chose to draw on paper plates, which the researcher only included to provide a base for sculptural pieces. This media choice may demonstrate the resourcefulness of this population that has learned to make the most of what they have and to look for potential in unexpected places. Oil pastels and plasticine were the most popular media choices (used by Bug, Allt, and FU), allowing the participants the freedom to be vulnerable and to dig deeper into feelings they were hesitant to share in words. These mediums offered a tactile experience to the artists as they kneaded and formed the clay and blended the pastels. Both Bug and Allt used their fingers to blend and smudge oil pastels on a plate, adding and removing layers with movements that revealed hidden beauty and also appeared to relieve anxiety. FU and Allt both worked with plasticine but used it in different ways. FU chose to create structurally

sound, geometric shapes that allowed him to maintain a sense of control over what he presented, while Allt used the material in a more experimental way, allowing her forms to move around and interact throughout the group. She explained her process saying, “I like the patterns, the rhythm, and the tactile experience of making art. Using the materials creates a meditative state.” While FU smashed his piece and returned the clay to the center of the table, Allt chose to drip rubber cement over her pieces in order to bind them together in a way that felt permanent and stable. It’s possible that sharing the art caused FU and Allt to reveal parts of themselves they don’t fully understand or aren’t comfortable with, which might explain their different but equally strong actions regarding the fate of their creation. For Bug, Allt, and FU the choice of media lent itself to more abstract pieces with colors, shapes, and images often left open to interpretation. In contrast to these exploratory pieces, Max and Laila chose to work with media that allowed for more organization and control. Both began working with two-dimensional materials, starting with a large piece of paper and formulating a plan that allowed them to use the space in a way that best conveyed their message. Max was drawn to the collage box and carefully sifted through all of the images and words, cutting things into shapes that fit together to form a well balanced image on the page. Laila walked around the table and looked at everything available, eventually choosing to incorporate three-dimensional materials (pipe cleaners and cotton balls) into her piece. She worked conscientiously, saying that she usually did more writing than art, but remained open to the process and created a scene that depicts an important moment in her life.

In addition to the soothing and meditative qualities of the tactile experience, members discussed using art materials and the art process as a buffer that allows them to feel more comfortable in social situations. This may explain their desire to work with the art materials for the entire three

hours of the focus group instead of the originally planned fifteen minutes. Bug described this buffer, sharing one of her first experiences with art...“I found a giant sketchbook in the trash and started carrying it around. Wherever I went, I could work and as long as I was doing something with that sketchbook, people would leave me alone. They were like ‘shhhhhh, don’t bother her – she’s working, she’s an artist.’ It was like a security cloak that protected me from the world.”

Regardless of the media used, the art-making process seemed to function as a self-soothing technique as well as a vehicle towards self-discovery. Bug described the art process as “a rest from living in a better way than a book can provide because a book ends but art can go on forever.” The constant transformation of her piece may be a metaphor for the way she lives her life. Although she appreciated colors and images as they emerged, she accepted them as temporary and was not afraid to destroy them in search of the next discovery. Within her life, Bug has had to let go of people, places, and plans she has made but she seems to have found a way to acknowledge the past without letting it take away the potential enjoyment of the present. The group agreed that the art process was cathartic and helped them get difficult emotions out in the open and see them in a new light. Bug spoke about “putting all of my demons into the art” which may be her way of processing the less confident parts of herself in a way that feels safe. Regarding the value of the process, she said “It’s not about an image, but the practice of doing something. Its a cathexis – attention and energy and purpose go inward rather than outward – like an implosion. Practicing in cathexis...this plate...is cathartic.” Like Bug, FU’s art seemed to be more about having something to put his energy into than about the final product. He seemed unconcerned with the permanence of his art and, after explaining its meaning to the group, he destroyed his first piece before it could be photographed. It’s possible that the act of putting the clay back into

its original form was his way of repressing unexpected feelings that came up within the group. It may have been cathartic for him to have the opportunity to take control over the pressure that was depicted in his sculpture by smashing it and returning it to the pile of art materials.

Unlike Bug and FU, the other group members seemed invested in their finished art piece, especially Max who planned on laminating his collage and showing it to friends and family. For him, an important part of the art process is sharing with others, giving them a window to better understand what it's like to live with mental illness, and "making life a little less cold and scary." Laila and Allt worked quietly throughout the group, often appearing to be lost in the process and unaware of the group around them. Both chose not to speak about their pieces or show them to the group until they were completely finished. Allt spoke about the process as being an exploration saying, "I'm always surprised by the results. Its not about a message. I like that art doesn't need words. You can also just start and see what happens...it can be spontaneous and meditative and calming. You get sucked in and its a pleasurable experience." Laila shared Allt's appreciation for visual language, saying "Art can exist without words, and sometimes words are too difficult."

**Visual representation of a marginalized experience.** Although each member was unique in their choice of materials as well as their art process, all of the pieces supported and expanded the narrative of the group, often touching upon topics that were verbally avoided. As Laila said, "Art provides a way to communicate without a facade – people are more true to themselves in art." The process as well as the final pieces seem to reflect each member's sense of self as well as their experience with both external and internal stigma and its influence on their identity. Although Allt spoke very little during the group, she was able to convey a great deal about her experience

with stigma through her art. Her use of a paper plate that is folded and tied with a pipe cleaner to represent internalized stigma allowed her to acknowledge the parts of herself that she may be uncomfortable looking at and revealing to others. She also created a labyrinth which may be her way of representing her struggle to choose a path or her hesitation to move forward without a better understanding of her own identity and place in the world. After destroying his plasticine sculpture, FU used a pen on a paper plate to create a second piece depicting a path that leads to an unknown destination. Laila's art continued to explore the relationship between outside and inside as well as the internalization of stigma and the discomfort of living with secrets. The placement of imagery and the way the materials interact with each other allowed her to clearly convey her struggle as well as her attempt to contain it.

**The healing potential of creative communities.** From the conversation of the focus group, it's clear that *The Painted Brain* plays an important role in the lives of these five participants. In addition to *The Painted Brain* they also recognized the importance of strength-based mental health programs like Daniel's Place that empower individuals to be responsible for their health and contribute to their community. The community created by *The Painted Brain* seems to serve as a base from which members can explore their identity as artists while examining the role that mental illness plays in their lives. In addition to providing an avenue for awareness and advocacy regarding the stigma of mental illness, it also provides a safe space in a world that may otherwise feel dangerous and overwhelming. Members expressed that *The Painted Brain* has served different purposes at different times in their lives, acting as a fluid element that meets people where they are at. For some, it provides the opportunity to become an advocate in their community and help others who face the stigma of mental illness. For others, it's a place to laugh,

relax, and let down their guard, knowing they're surrounded by people who accept them and can relate to their challenges. Members agree that belonging to *The Painted Brain* has increased their sense of empowerment, hope, and meaning, and reduced their feelings of isolation. It acts as a place to learn, grow, and evolve, as well as a place to teach and inspire others. FU shared that "Without *The Painted Brain* I might not socialize or get outside of myself. It's a place where you can reach out to someone who might understand – a place to get things off your chest." For a population that is often misunderstood and rejected by the dominant group, *The Painted Brain* provides a somewhat counter-cultural alternative where members don't have to hide parts of their identity in order to fit in. Instead, they are able to be themselves and take pride in their unique lived experience. FU summed up the importance of having a place of support and belonging, saying "The group is more powerful than any individual. What are you gonna do – move a mountain by yourself?"

## **Conclusion**

This analysis of data resulted in three emergent themes: 1) The challenges of coping with a stigmatizing system, 2) Internalized stigma as it relates to the formation of adult identity, and 3) The use of art to combat stigma and facilitate self-discovery. An in-depth exploration of these three themes was provided in order to allow the research to be compared and contrasted to existing literature on stigma and identity formation in young adults with chronic mental illness.

### **Discussion of Findings and Meaning**

This research explored the impact of stigma on identity formation in young adults with mental illness, as well as the role that the creative process can play in self-discovery. A focus group was used to gather data which was then categorized and organized into themes. Careful examination of the categories led to three emergent themes: 1) The challenges of coping with a stigmatizing system, 2) Internalized stigma as it relates to the formation of adult identity, and 3) The use of art to combat stigma and facilitate self-discovery. In this section, the three emergent themes are integrated with both the general literature and the art therapy literature. Clinical implications and research limitations are also presented.

#### **The Challenges of Coping with a Stigmatizing System**

Members' descriptions of their social lives as well as the lack of conversation regarding employment and relationships may point to the impact of the stigma of mental illness on all areas of a person's life including personal relationships, social functioning, employment, living situations, medication compliance, treatment success, participation in community activities, and self-esteem (Bathje & Pryor, 2011; Byrne, 2001). Findings from the research reinforce Crabtree et al.'s (2010) report revealing that people with mental illness are generally thought to be less competent and fundamentally different from "normal" people and are often disliked, derogated, and discriminated against. This unchallenged fear, mistrust, anger, and avoidance of those with mental illness (Brown & Bradley, 2002) can be seen in Bug's recollections of being singled out as a child within her school and her community. It is also seen in members' choice to keep their diagnosis private in situations where they feel it could be harmful to identify as part of a stigmatized group. Livingston and Boyd's (2010) observation that members of a stigmatized group are discredited, undesired, and reduced from whole

and usual to tainted and discounted can be seen in FU's description of his experiences in treatment...

"It's like being a third class citizen...even dogs are given more value." Laila and Bug's experiences of being placed on an involuntary hold also speaks to the feeling of being less than others. Laila felt that she was treated like a child and was not given the opportunity to advocate for herself... "I was told that a judge would decide how long I had to stay for, but I was there for a month and I never saw a judge. No one explained what was happening...having your rights taken away is really fucking scary." Bug also felt she was unable to advocate for herself reporting that she was overprescribed medication and given tests against her will. This, along with FU's description of sexual harassment and lack of confidentiality in treatment supports Link and Phelan's (2002) report that, "at its most extreme, a group is reduced entirely to its label and is no longer seen as fully human, allowing for the justification of horrific treatment." Bug's experiences in addiction treatment and in domestic violence counseling as well as her visits to the ER for physical problems supports current literature regarding instances of "diagnostic overshadowing," in which the physical and medical needs of people with mental illness are overlooked because the person's mental illness is always seen as the primary factor (Jones, Howard, & Thornicroft, 2008). It seems clear that the experience of being marginalized, disenfranchised, excluded, and denied the human rights and social entitlements that others take for granted (Arboleda-Florez & Stuart, 2012) is a common and expected part of living with mental illness for the young adults included in this research.

Allt, Laila, and Max agreed that the stereotypes most often given to people with mental illness are instability, danger to others, and a burden on society. This is discussed in current literature which shows that this population continues to be portrayed in the news as violent, murderous, disheveled, unpredictable, weak, and self-involved which leads to feelings of fear, mistrust,

and anger, as well as avoidance and discrimination by members of the dominant group at the personal, professional, and institutional level (Eisenhauer, 2008; Quinn, Shulman, Knifton, & Byrne, 2011; Bathje & Pryor, 2011). Members' opinions regarding the portrayal of mental illness in the media provide support for Kadri and Satorius' (2005) use of social dominance theory to discuss stigma which hypothesizes that threatened identity and self-esteem motivate discrimination and that it's beneficial for the dominant group to justify the systems that work to their advantage in order to maintain their perceived superiority. FU discussed this benefit to the mainstream, saying "The mentally ill are an easy population to blame because people want to believe that only someone with a mental illness could do something so horrible. People need an answer and it's an easy way out. If the media reported that it was a normal person who did something horrible, people would question it...But if they say the person is mentally ill, then people can write it off... 'Yeah, he's crazy and only crazy people do that.' It's easy to categorize, to put people aside and say 'You guys are like this because you have a mental illness.'" This speaks to the need of those in power to maintain their position by widening the distance between the dominant (in) group and the stigmatized (out) group, and stresses the imbalance of power that must occur for stigmatization to exist (Link & Phelan, 2001).

The imbalance of power discussed in current literature seemed to be a factor in Allt, FU, and Laila's ambiguity regarding their desire to advocate for themselves and others with mental illness, with all three expressing that they sometimes felt overwhelmed by the power of the media and their own lack of power to change it. Although Max and Bug were more comfortable identifying with the culture of mental illness, they agreed that the media's stigmatizing portrayal can make it challenging and sometimes dangerous to act as a leader or representative for people

with mental illness. The effort it takes to fight something so much bigger than yourself and the feeling of being overtaken by something so powerful may be reflected in FU's destruction of his original art piece that spoke to the pressures of his world. The group's feeling of powerlessness may also be seen in the artwork of several members depicting solitary figures that appear to be at odds with their environment.

It seemed important to the group to recognize the difference between people with mental illness who take care of themselves and those who do not as well as those who are under the influence of drugs or alcohol. The lack of awareness of these issues by the media does not seem to be addressed in current literature regarding the stigmatization of mental illness. This may reflect the dominant group's desire to categorize the non-dominant group in a way that is easy to understand and to control.

Regarding the response of young adults to external sources of stigma, the research supports existing literature that cites stigma as a major obstacle to accessing care (Jenkins & Carpenter-Song, 2009; Link et al., 2004; Kadri & Sartorius, 2005). All members acknowledged the possibility of experiencing negative social consequences in connection with seeking treatment for mental illness and agreed that the stigmatization they experience may encourage them to find other ways of dealing with their condition. Members spoke about their tendency to deal with stigma by either withdrawing from or rebelling against the society that has rejected them. Withdrawal can be seen in Allt's sculpture of a white figure, folded in on herself, trying to "disappear, become generic, nothing specific, like a ghost" in order to avoid judgment, as well as in FU's description of learning how to live without human interaction, "like a hermit." A spirit of rebellion can be seen in Bug's choice to embrace mental illness as part of her public identity with a dramatic, in-your-face attitude as well

as in FU's choice of pseudonym. Pepper and Ryclewicz's (2000) study addresses the rebellion of young adults with mental illness but, instead of seeing it as a response to rejection, they discuss it in relation to the developmental characteristics of young adulthood and cite age as the primary reason for this group's resistant to treatment.

Existing literature discusses the potential of community programs to empower this marginalized population but rarely addresses the counter-cultural attitude that exists within them. In addition to their own personal sense of rebellion, a larger rebellious attitude was apparent within the group as a whole as seen in their sense of humor and renaming of medications to "shut-the-fuck-up-apine" and "disaster-zone." The research suggests that feeling continually rejected and abandoned by the institutions that are designed to keep them safe has contributed to the formation of a counter-culture which allows these young adults to separate themselves from the judgment of the dominant group and maintain a sense of control over their circumstances.

### **Internalized Stigma as it Relates to the Formation of Adult Identity**

Existing literature discusses internal stigma through labeling theory, which proposes that a person who is labeled as deviant or different will conclude that they are, in fact, deviant or different and will therefore label them self with that stereotype or stigma (Thoits, 2011). Similarly, social constructionist theory asserts that a person's self-esteem is formed socially on the basis of others' views and that, when others appraisal is negative, this becomes internalized and results in low self-esteem (Crabtree et al., 2010). This research shows that group members' early experiences with family as well as community members, teachers, and mental health professionals acted as an impetus for their internalization the stigma surrounding mental illness. Bug, the only group member diagnosed as a child, spoke about the lack of information her

family had about mental illness and the avoidance of conversations concerning her treatment. Her family's inability to communicate openly about this issue led Bug to conclude that mental illness was something that should be kept secret and she learned to "act normal" to avoid embarrassing her family. Her negative perceptions of mental illness were reinforced by her teachers, peers, and the mental health professionals she interacted with in elementary school, causing her to internalize the idea that something was wrong with her and that she would not be accepted unless she hid this "bad" part of herself. This supports modified labeling theory which says that young children develop negative conceptions of stigmatized groups as part of the process of socialization, and that members of stigmatized groups will continue to apply the learned expectation of rejection and devaluation to themselves as adults (Link & Phelan, 2001). Although she has worked to overcome the shame surrounding her diagnosis, Bug's art shows layer upon layer of color, each hiding the one below, which may be a metaphor for the hidden parts of her own identity. Max was also influenced by his family's perceptions of mental illness, sharing that even before he was diagnosed, "they always knew something was wrong." His art conveys the feeling of being trapped inside of a frightening mask which may parallel Max's experience as a child being told that something was wrong with him but feeling powerless to make things better. Allt expressed similar childhood experiences, sharing that her father thought that portraits were "terrible and scary." Although her art wasn't terrible or scary to her, it's likely that Allt internalized the belief that a part of herself is terrible and scary, and that she should keep that part hidden from the world. This is seen in Allt's final art piece which uses a folded paper plate, tied with a pipe cleaner, to beautifully express her efforts to keep part of herself hidden by disguising it with "fabulousness" on the outside.

Smith (2002) discusses the need to remove the labels that separates “us” from “them” in order to reduce the likelihood that people will internalize the idea that something is inherently wrong with them. For example, instead of being called schizophrenic, Smith stresses the importance of saying that a person *has* schizophrenia. FU’s comparison of the label “mentally ill” to the use of racial slurs furthers Smith’s ideas about the impact of rhetoric... “Just the way people say it, even if you didn’t know what it meant, you’d know that it’s a stigmatized group of people. It’s like when people use the word “Mexican” and everyone knows they mean it in a derogatory way even though there shouldn’t be anything derogatory about that word. Why would we want to use a word like that to describe people? Why use that hatred?” The anger that was provoked by the group’s discussion of rhetoric also speaks to the alienation they feel as a result of internalizing what they have been told about mental illness. Several authors provide evidence for alienation along with poor self-esteem, lack of empowerment, and low self-efficacy as common manifestations of internalized stigma in people with mental illness (Bathje & Pryor, 2011; Quinn et al., 2011; Ehrlich-Ben Or, et al., 2012).

Current literature discusses the formation of a coherent and cohesive personal identity is an important developmental milestone for young adults (Tesch & Cameron, 1987; Cote, 2006; Erikson, 1980) and cites the gradual transition to adult roles and responsibilities as well as the weakening of the safety net supporting adolescents as characteristic of this time (Park, Mulye, Adams, Claire, & Charles, 2006). Although much of the art created in the focus group spoke to issues of identity, there appeared to be more ambiguity regarding the transition to adulthood than might be expected. This supports Pepper and Ryglewicz’s (2000) findings that mental illness often delays the milestones of young adulthood or leaves them unfulfilled, resulting in chronic

stress, impatience, frustration, and a weaker sense of personal control over one's life. This frustration and lack of control may be seen in FU's use of his sculpture to demonstrate how the pressure he feels continues to be placed on top of his head no matter how many times he rolls it off, ultimately resulting in the destruction of both the pressure and himself.

Mossakowski (2001) describes this frustration, saying that young adults with mental illness may feel permanently stuck between the parental support of childhood and the adult autonomy they desire. This research supports Mossakowski's hypothesis that the limbo this population finds themselves in may result in a troubling incongruence between the ideal self and the actual self, and that the disappointment of unfulfilled expectations may be internalized as depression. Laila's decision to make art that shows her graduating in front of a crowd may speak to her hopes and dreams for her future which have been made more complicated by having to cope with mental illness. Her image also speaks to the internalized shame she carries with her as she explores her adult identity, and her desire to keep it hidden as much as possible beneath a calm and successful exterior. Her art suggests a struggle between her independent self shown in a cap and gown, successfully meeting a major milestone of young adulthood, and a less secure, less confident part of herself that is afraid of losing control and having to rely on others to make decisions about her health and well-being.

While members were reluctant to speak directly about internalized stigma, the loneliness, fear, and shame portrayed in their artwork reinforces Biddle, Donovan, Sharp and Gunnel's (2007) study demonstrating that being stigmatized at this critical time in life is likely to decrease the rate of recovery, lead to greater social and familial problems, and increase levels of anxiety. A common theme in the art was that of outside versus inside as well as a struggle that seems

to occur as an individual decides which parts of the self to accept and which to reject. It's possible that the struggle of having to monitor when, where, and with whom it's ok to share their true lived experience leaves this population with an inconsistent sense of self. As FU said, "Why would you want to be part of a group that's feared and hated?" The solitary nature of many of the figures seen in the art also conveys a pervasive feeling of loneliness as a result of only allowing others to see the "good" parts of their identity.

Not addressed in current literature is the lack of emphasis on other parts of identity in this population. This research suggests that the constant push and pull of conflicting feelings and incongruent identities that result from the internalization of stigma take up a great deal of space in their lives of young adults with mental illness. Although the group was made up of members of different races, ethnicities, and world views, the shared identity of mental illness seemed to eclipse cultural differences which might otherwise influence their interactions and relationships with each other. The group's lack of conversation about other important parts of culture such as race, ethnicity, gender, socioeconomic status, education, religion, political affiliation, and sexuality may speak to the overwhelming influence that internalized stigma has on members' internal sense of self as well as their external experience of the world, resulting in a disconnect with other parts of their identity. Another noticeable difference between this group and the conversation that might be expected within a group of young adults was the lack of emphasis on the future. Group members' focus was on coping with the present with little mention of future hopes and dreams or plans for education, career, or family. This may be representative of the limbo between childhood and adulthood that this population finds themselves stuck in as well as the uncertainty of how mental illness may continue to impact their future.

### **The Use of Art to Combat Stigma and Facilitate Self-Discovery**

Researchers agree that the visual arts and other creative endeavors play a positive role in healing the human body, mind, and spirit by increasing hope, empowerment, and inclusion while decreasing the effects of stigmatization on an individual's sense of self (Lipe et al., 2012; Spandler, et al., 2007; Van Lith, Fenner & Schofield, 2011). This research supports the use of the creative process to facilitate self-discovery as participants were able to work through issues both emotionally and physically while giving visual representation to marginalized experiences. The use of oil pastels and plasticine provided the freedom to explore vulnerabilities and to dig deeper into feelings that participants were hesitant to put into words and allowed the art to act as a reflection of identity and the influence of stigma. This is seen in Bug's description of being able to put all of her "demons" into the art as well as Laila and Allt emphasized the need for visual language. Laila shared that, "Art can exist without words when words might be too difficult," and Allt added, "I like that art doesn't need words. You can also just start and see what happens...it can be spontaneous and meditative and calming." The participant's final pieces were able to reflect their sense of identity as well as their experiences with both external and internal stigma in a way that may not have been possible with words. It is clear that the addition of an art directive to the focus group supported and expanded the narrative, often touching upon topics that were otherwise avoided.

The research also provides support for art therapy literature which addresses the value of the tactile experience of art-making as well as the use of both public and private art as a vehicle for personal growth as well as a step towards the destruction of cultural stigma (Mango, 2011; Potash & Ho, 2011). Bug and Allt both used the blending of oil pastels as a soothing process and Allt and FU used the kneading and rolling of clay to calm anxieties and express frustrations. Allt

described the value of the kinesthetic experience saying, “I like the rhythm, and the tactile experience of making art. Using the materials creates a meditative state.”

The majority of literature regarding the treatment of mental illness from the past twenty years focuses on holistic, recovery-based interventions that emphasize personal growth and the development of purpose beyond the symptoms and stigma of mental illness (Heenan, 2007). The group’s commitment to *The Painted Brain* and their ability to use it to find a voice with which to combat stigma speaks to the value of having a safe space to explore identity without fear of repercussions. Members also emphasized *The Painted Brain*’s ability to foster insight, self-esteem, confidence, empowerment, connectedness, and social engagement. The power of the group to reduce isolation was shown by FU who shared that “without *The Painted Brain* I might not socialize or get outside of myself. This supports Thoits’ (2011) study that discusses the value of connecting with others who share similar concerns and challenges in order to establish a support system and be a valued part of a group.

The members’ acceptance and support of each other provides evidence for Branscombe’s (1999) use of social identity theory to explain the benefits of group membership and the key role it plays in determining an individual’s self-esteem. *The Painted Brain* seems to serve as a base from which members can explore their identity as artists as the role that mental illness plays in their lives. In addition to providing an avenue for awareness and advocacy regarding the stigma of mental illness, it also provides a safe space in a world that may otherwise feel dangerous and overwhelming. The group expressed that being part of a creative community gave them the opportunity to advocate for themselves and to reach out to others who face the stigma of mental illness. They also stressed the importance of having a place to laugh, relax, and let down their

guard, knowing that they're surrounded by people who can relate to their challenges.

Art therapy literature asserts that the act of creating with others provides a sense of belonging and inclusion that acts as an opposing force to stigmatization, with emphasis on the clubhouse model of treatment in which participants are no longer passive recipients of services, but advocates for themselves and other members (Ehrlich-Ben Or et al., 2012). This identity as advocate is shown by Bug who shared, "I didn't realize that I had a voice or a message or anything. *The Painted Brain* has given me a sense of purpose and has brought me back to where I want to be." Max also discussed the opportunity the organization provided him to cultivate his identity saying, "It's a great experience. As far back as I can remember, I wanted to make a name for myself as artist. I want to inspire people to remember that living with a mental illness is not as bad as people say it is. You can create a life around it."

### **Clinical Applications**

This research suggests that the ability of art to empower young adults with chronic mental illness may be especially beneficial when used within a healing community. The study shows that the creative process offers an alternate method of expression that may allow this vulnerable population to confront and process challenging emotions regarding stigma and identity that are often difficult to articulate in words. The use of visual metaphor allows the artist to examine his/her relationship with stigma and mental illness from a safe distance and the art materials provide kinesthetic and sensory experiences that may act as self-soothing mechanisms. The opportunity for the creation and destruction of art gives a voice to marginalized experiences while assisting in self-exploration and discovery as this population attempts to reconcile opposing aspects of their identity in order to form a coherent adult self.

Evidence for the use of the clubhouse model of community-based treatment suggests that the counter-cultural atmosphere and promotion of self-responsibility are positive qualities that may increase the likelihood of this population to seek treatment and take responsibility for their health and well-being. Organizations such as *The Painted Brain* which offer the option of remaining anonymous or publicly identifying as a member of the culture of mental illness are able to meet members where they are at in their own journey towards self-acceptance and identity formation.

### **Study Limitations and Implications for Future Research**

This research has a limited sample of only five participants. Perspectives may vary for different diagnosis, different age of diagnoses, and different cultural experiences. This sample is also tied to a specific geographical area and other parts of the country and/or world may provide a different experience. It is also important to note that the five participants in this research are members of an art-based mental health organization and have experience using the art process as a coping mechanism and a means of communication.

### **Conclusion**

This research used both personal narrative and an art-based exploration to examine the impact of stigma on identity formation in young adults with chronic mental illness and to provide a deeper understanding of the lived experience of this population as they strive to move beyond adolescence towards the formation of adult identity. Data gathered from a semi-structured focus group and a careful analysis of artwork resulted in the emergence of three overarching themes:

1) The challenges of coping with a stigmatizing system, 2) The formation of adult identity within the context of having a mental illness, and 3) The use of art to combat stigma and facilitate self-discovery. The available literature discussing the effects of external and internal stigma on those with mental illness offer support for this study but often fail to address the specific challenges facing young adults as they struggle to incorporate their mental illness into their formation of a coherent adult identity. Art therapy literature has begun to provide evidence for the benefit of incorporating art in the context of healing communities created specifically for this age cohort with the goal of creating a sense of meaning and purpose, developing new coping mechanisms, fostering hope, and rebuilding identities

The narrative and art-based results of this research strive to provide a better understanding of the pervasive nature of stigmatization and the direct effect it has on identity formation within the developmental phase of young adulthood. The unique perspective and insight offered by participants in this study aims to inspire new ways of conceptualizing the treatment of mental illness while bringing about awareness of the harmful consequences of stigmatization.

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IRB Letter of Approval

Paterson, Julie <Julianne.Paterson@lmu.edu>

Jan 7

to me, Einat, David, John

Dear Ms. Blackstone,

Thank you for submitting your IRB application titled An Exploration of Stigma and Art-Making in Relation to Young Adults with Chronic Mental Illness. All documents have been received and reviewed, and I am pleased to inform you that your project has been approved.

The effective date of your approval is January 7, 2013 – January 6, 2014. If you wish to continue your project beyond the effective period, you must submit a renewal application to the IRB prior to December 1, 2013. In addition, if there are any changes to your protocol, you are required to submit an addendum application.

For any further communication regarding your approved study, please reference your new protocol number: LMU IRB 2012 FA 40.

Best wishes for a successful research project.

Sincerely,

Julie Paterson

Julie Paterson I IRB Coordinator I Loyola Marymount University I 1 LMU Drive I U-Hall  
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## LOYOLA MARYMOUNT UNIVERSITY

## IRB Application Questionnaire

**1. RESEARCH BACKGROUND**

Please describe the purpose of your research. Provide relevant background information and briefly state your research question(s). You may provide relevant citations as necessary. (300 Word Max)

The purpose of this qualitative inquiry is to gain an understanding of the experience of stigma and the experience of art-making in young adults with chronic mental illness. I hope to explore the influence that both external and internal stigma have on this population by looking at how it manifests in young adults who are transitioning out of adolescence and forming an adult identity. I will attempt to explore what the experience of creating and sharing art may mean for members of a stigmatized group and how their relationship with art may affect their relationship with stigma.

Despite significant advances in our understanding of mental illness, this population continues to be portrayed in a negative manner, which may lead to both external and internal stigmatization (Quinn, Shulman, Knifton, & Byrne, 2011; Link & Phelan, 2001; Eisenhauer, 2008–). Literature supports the assertion that many areas of a person's life may be effected by stigma, including personal relationships, social functioning, employment, living situations, medication compliance, treatment success, participation in community activities, and self-esteem (Jenkins & Sajatovic, 2007; Brown & Bradley, 2002). Because it often prevents people from seeking treatment, reduction of stigma is now considered central to the promotion of mental health (Crabtree, Haslam, Postmes, & Haslam, 2010).

Art therapy literature addresses the use of the public sphere to empower clients with mental illness by sharing their artwork with their community. Art shows can work towards the destruction of cultural stigma and act as an impetus for social change (Mango, 2011). Not only can public display of art act as a vehicle for personal growth but it can serve as a bridge to access previously unreached groups within one's community (Griffiths, 2008.)

The literature on these topics fails to address issues specific to the developmental challenges of young adults. As this is the time that a person moves beyond adolescence and works towards the creation an adult identity, more research is needed to understand how those who suffer from chronic mental experiences stigma and art-making in relation to identity formation. Since The Painted Brain is an organization created specifically for people in their twenties, it provides an opportunity to gain insight into the experience of stigma, art-making, and identity formation in young adults with mental illness.

**2. SUBJECT RECRUITMENT**

How will subjects be selected? What is the sex and age range of the subjects? Approximately how many subjects will be studied? How will subjects be contacted? Who will make initial contact with subjects? Specifically, what will subjects be told in initial contact? If subjects will be screened, describe criteria and procedures.

Members of *The Painted Brain*, a media and outreach campaign created by young adults with mental illness, will be invited to participate in a focus group that will explore stigma and

art-making in relation to mental illness. I had the opportunity to meet Dave Leon, founder of *The Painted Brain*, during my first year practicum and he has offered to help coordinate this research (Appendix A). To insure that no one is approached in a way that might feel overwhelming, Mr. Leon will make the initial contact with members of *The Painted Brain* who may be interested in taking part in the focus group. He will assess the ability and emotional stability of members prior to inviting them to participate in the study. Members who show any signs of suicidality and/or psychotic behaviors that would interfere with participation will not be included in the study. For this research, I will include the first three males and first three females between the ages of twenty and thirty who respond to my invitation. Participants must speak English. In order to avoid a potentially harmful or confusing dual relationship, anyone who has worked with me in the past will not be allowed to participate in this research. After being referred by Mr. Leon, I will meet the participants, explain the purpose of the research in greater detail, and gain the consent of all participants (Appendix B). Participants will be told that they will be taking part in a focus group that will explore stigma and art-making in relation to mental illness and that they will be doing a simple art directive during the group. Participants will be informed of their right to confidentiality and it will be made clear that they can withdraw from the study at anytime if they feel uncomfortable and no longer wish to participate. They will be informed that the group will be audiotaped and that their art will be photographed. I will make sure everyone understands that they have the right to request at anytime during the research that what they've said or made is not used. I will assure participants that the audiotape and the photographs will be stored in a password-protected drive until this research is finished in May, 2013. At that point the audiotape and photographs will be destroyed. Participants will have the opportunity to ask questions about anything that might be unclear regarding their involvement in the research and will again be reminded that they have the right to withdraw at anytime.

*The Painted Brain* is an organization that attempts to change attitudes and challenge assumptions about mental illness through outreach, education, gallery shows, fashion shoots, and art, music, and writing groups. Members' poetry, prose, and artwork are published in a magazine and featured online ([www.paintedbrain.org](http://www.paintedbrain.org)). This organization has created a community of young adults who deal with the challenges of mental illness and stigma and provides them with a vehicle to break down the isolation of mental illness and have their voice heard in the public media.

### 3. PROCEDURES

Summarize fully all procedures to be conducted with human subjects.

This project will involve gathering data in the form of a focus group and an art directive from young adults with chronic mental illness. I will arrange to meet the participants referred by The Painted Brain at their main office building in Los Angeles and explain that the purpose of my study is to better understand their experiences regarding stigma and art-making in relation to mental illness. I will distribute consent forms and give participants time to read them and ask any questions they may have before signing. The consent form will explain that, for the purpose of this study, stigmatization is defined as "the process by which a dominant group designates characteristics of a non-dominant group as inferior, problematic, or shameful; to be stigmatized is to be discredited, undesired, and reduced from whole and usual to tainted and discarded." Participants will be given a copy of their signed and dated consent forms as well as a copy of the LMU Experi-

mental Subjects Bill of Rights (Appendix C). In order to protect confidentiality, participants will write their chosen pseudonym on the consent form and will sign only with their initials. Mr. Leon will keep a record of the initials and full names of participants in a secure location in case any concerns arise that would necessitate the recovery of full names. I will remind participants that the focus group will be audiotaped and transcribed and that, at any time, they can withdraw from the study and/or request that something they said will not be used in the research. Mr. Leon, who is a licensed social worker, will be in the building during the focus group. The focus group will follow a qualitative, semi-structured format and will allow all members to share their experiences and respond to the experiences of others.

I will begin the group by providing members with art materials (paper, markers, oil pastels, tissue paper, clay) and asking them to complete the following art directive: “Use these materials to express something about your personal experience with stigma.” Participants will be given approximately fifteen minutes to complete this directive. After finishing the art directive, I will open the group up to discussion using a semi-structured format. Focus group topics/questions may include:

- 1) Introduce yourself to the group and tell us about your art.
- 2) Tell me about your experience with stigma.
- 3) How have you dealt with internal or external stigma in relation to mental illness?
- 4) What does being part of a creative community mean to you?
- 5) How has mental illness, stigma, and/or art influenced your identity?

I anticipate that the focus group will last approximately three hours. I will monitor the time to make sure all participants are able to share their experiences and receive feedback from others. If, at anytime during the focus group, a participant demonstrates behavior or makes statements that suggest instability, I will ask Mr. Leon to take the participant out of the group before proceeding, and make sure he/she receives appropriate care. In this situation the participant will be removed from the data and will not be included in the study. At the end of the focus group, participant’s art pieces will be photographed and they will be able to keep or dispose of the originals as they choose.

Following the focus group, I will reiterate the purpose of the research and remind participants of the confidentiality clause that prevents the rest of the group from repeating anything that was shared and prevents me from using any form of identifying information in the research. I will remind each participant individually that they have the option to withdraw their participation and that, if they do so, nothing they said or did will be used in the research. Participants will be asked specifically about the inclusion of their narrative and/or artwork in the research as well as in possible future publications. They will also be asked if they are willing to allow The Painted Brain to use this research. I will check in with each member of the group individually in order to assess if they are experiencing distress and require follow up care. All participants will be given Mr. Leon’s contact information as well as a list of resources available to them if they feel that they need to talk to someone at any time after the group (Appendix D). Participant chosen pseudonyms will be used when referencing specific stories and art in the research.

#### **4. RISKS / BENEFITS**

What are the potential benefits to subjects and/or to others? What are the reasonably foreseeable risks to the subjects? (Risks may include discomfort, embarrassment, nervousness, invasion of privacy, etc.) If there are potential risks to subjects, how will they

be minimized in advance? How will problems be handled if they occur?

Benefits of this research for participants may include having their voice heard in a safe and supportive environment, connecting with others who may have had similar experiences, and the possibility of better understanding their own relationship with stigma. Sharing their stories without fear of judgment may be therapeutic and may help them feel less isolated. The focus group and the art directive may lead to new insights for members and may provide them with new coping mechanisms to combat the effects of stigma. Participants may feel empowered by taking an active role in combating the stigma surrounding mental illness through helping the public better understand an issue that is important to them. This research may benefit others by providing information and insight about stigma and the challenges of living with mental illness to the general public and to families and friends of people with mental illness. It will give others the opportunity to see the benefits of art for this population and may inspire future research and/or programs aimed at combating the stigma of mental illness.

Risks of this research include the possibility that topics discussed in the focus group will cause anxiety or discomfort for participants. Discussing stigma and the challenges of mental illness may cause members to feel fear, pain, anger, frustration, and/or sadness. They may be uncomfortable sharing their experiences with the group and knowing that what they say is being audiotaped. Participants may also feel anxiety regarding their artwork and may not be comfortable sharing it with the group or having it used in research. Participants also risk other members of the group breaking the confidentiality clause.

To minimize these risks, participants will be reminded before the group starts that if at any point during the conversation they feel uncomfortable, they have the right to terminate their participation and I have the obligation to destroy all recordings and records I have made of their participation. I will inform the group that they can request any comment to be excluded at anytime and that I will stop recording while they speak or exclude their comments if they change their mind at anytime after the group. I will assure them that their identities will be kept confidential and that any reference to their participation or artwork will be done with their chosen pseudonym. I will remind that the photographs of their art and the audio recording will be kept on a password protected drive and will be destroyed after the completion of the research in May, 2013. In the event that a participant experiences distress due to the emotionally challenging issues being discussed, they will be asked if they would like to leave the group and not be included in the research. After the focus group, I will check in with each member of the group individually in order to assess if they are experiencing distress and require follow up care. All participants will be given Mr. Leon's contact information as well as a list of resources available to them if they feel that they need to talk to someone at any time after the group (Appendix D).

## **5. CONFIDENTIALITY**

Will subjects be identifiable by name or other means? If subjects will be identifiable, explain the procedures that will be used for collecting, processing, and storing data. Who will have access to data? What will be done with the data when the study is completed? If you are collecting visual images of your subjects please justify this.

Participants will sign consent forms with their initials and will have the option of being identified by those initials or by a pseudonym of their choosing, which they will indicate on their

consent form. Participant's real names will not be known to me and, therefore, will never be used in this research. Participants will be referred to by their initials or chosen pseudonym in both the transcription of the focus group and the final research paper. I will keep the audiotape from the focus group and the photographs of the art on a password protected drive and I will be the only one with access to the data. When the research is complete, I will destroy the audiotape and photographs of the art. No visual images of the participants will be used. It is likely that members of the focus group will know each other and may be involved in other projects together so confidentiality amongst members will be discussed and agreed on by all. Depending on the results, it is possible that The Painted Brain will cite this research in future fundraising efforts. All participants will be informed that this is a possibility and assured that no identifying information will be used.

## **6. INFORMED CONSENT**

Attach an informed consent form or a written request for waiver of an informed consent form. Include waiver of written consent if appropriate. If your research is being conducted in another language, please include copies of the translated "Informed Consent" or "Waiver of Written Consent" forms.

Appendix B

## **7. STUDENT RESEARCH**

When a student acts as principal investigator, a faculty sponsor signature is required on the application form.

Dr. Einat Metzl is my faculty sponsor.

## **8. RENEWAL APPLICATIONS**

When the submission is a Renewal Application, include a summary of the research activities during the previous granting period specifically addressing: number of subjects studied and any adverse reactions encountered, benefits which have been derived, any difficulty in obtaining subjects or in obtaining informed consent, and approximate number of subjects required to complete the study.

n/a

## **9. PAYMENTS**

If subjects are to be paid in cash, services, or benefits, include the specific amount, degree, and basis of remuneration.

Participants will not receive payment for participation in this research.

## **10. PSYCHOLOGY SUBJECT POOL**

When students from the Psychology Subject Pool (PSP) are to be involved as subjects, permission must be obtained from the PSP prior to running subjects. Forms are available from the Psychology Office in 4700 University Hall. It is not necessary to inform the IRB of approval from the PSP, however the PSP requires IRB approval prior to permission for using the pool being granted.

n/a

## **11. QUALIFICATIONS AND TRAINING**

Describe the qualifications of, or method of training and supervision afforded student experimenters. This includes past experience, type and frequency of student/sponsor interactions during the experiment, and Human Subjects Protections Training.

I have completed MFTH 691, a graduate level research methods course at LMU, and have reviewed the literature that currently exists on this subject. I have also completed the NIH PHRP online course (Appendix E). I did my first year practicum at Daniel's Place in Santa Monica where I provided individual and group therapy for young adults with chronic mental illness. My time there helped me better understand the challenges that this population faces. I will be working with Dave Leon, a licensed social worker and publisher of The Painted Brain, to make sure that the focus group is conducted in a comfortable, unthreatening atmosphere and that members are supported before, during, and after the group.

## **12. RANDOMIZATION**

Describe criteria for assigning subjects to sub-groups such as "control" and "experimental."

There will not be a control group for this research.

## **13. USE OF DECEPTION**

If the project involves deception, describe the debriefing procedures that will be used. Include, verbatim, the following statement in the consent form: "Some of the information with which I will be provided may be ambiguous or inaccurate. The investigator will, however, inform me of any inaccuracies following my participation in this study."

The purpose of this research will be transparent to participants.

## **14. QUESTIONNAIRES AND SURVEYS**

Include copies of questionnaires or survey instruments with the application (draft form is acceptable). If not yet developed, please so indicate and provide the Committee with an outline of the general topics that will be covered. Also, when the questionnaire or interview schedule has been compiled, it must be submitted to the Committee for separate review and approval. These instruments must be submitted for approval prior to their use. Consider your population. If they are foreign speakers, please include copies in the foreign language.

Art directive: Use these materials to express something about your personal experience with stigma. (Materials will include paper, markers, oil pastels, tissue paper, and clay.)

Focus group topics/questions:

- 1) Introduce yourself to the group and tell us about your art.
- 2) Tell me about your experience with stigma.
- 3) How have you dealt with internal or external stigma in relation to mental illness?
- 4) What does being part of a creative community mean to you?
- 5) How has mental illness, stigma, and/or art influenced your identity?

### 15. PHYSICIAN INTERACTIONS

To ensure that all patients receive coordinated care, the principal investigator is obligated to inform the primary physician (when not the principal investigator) of all studies on his/her patients.

n/a

### 16. SUBJECT SAFETY

Describe provisions, if appropriate, to monitor the research data collected, to ensure continued safety to subjects.

Data collected from the focus group will be on a password protected drive and will be destroyed when the research is completed in May, 2013.

### 17. REDUNDANCY

To minimize risks to subjects, whenever appropriate, use procedures already being performed on the subjects for diagnostic or treatment purposes. Describe provisions.

n/a

### 18. COUNSELING

In projects dealing with sensitive topics (e.g., depression, abortion, intimate relationships, etc.) appropriate follow-up counseling services must be made available to which subjects might be referred. The IRB should be notified of these services and how they will be made available to subjects.

All participants will be given Mr. Leon's contact information as well as a list of resources available to them if they feel that they need to talk to someone at any time after the group (Appendix D).

### 19. SAFEGUARDING IDENTITY

When a research project involves the study of behaviors that are considered criminal or socially deviant (i.e., alcohol or drug use) special care should be taken to protect the identities of participating subjects. In certain instances, principal investigators may apply for "Confidentiality Certificates" from the Department of Health and Human Services or for "Grants of Confidentiality" from the Department of Justice.

n/a

### 20. ADVERTISEMENTS

If advertisements for subjects are to be used, attach a copy and identify the medium of display.

A flyer will be handed out by Dave Leon to inform members of *The Painted Brain* about this research (Appendix F).

### 21. FOREIGN RESEARCH

When research takes place in a foreign culture, the investigator must consider the ethical principles of that culture in addition to the principles listed above.

n/a

## **22. EXEMPTION CATEGORIES (45 CFR 46.101(b) 1-6)**

If you believe your study falls into any of the Exemption Categories listed below, please explain which category(ies) you believe it falls into and why.

1) Research conducted in established or commonly accepted educational settings, involving normal educational practices, such as (i) research on regular and special instructional strategies, or (ii) research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods.

2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), if information taken from these sources is recorded in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects.

3) Research involving survey or interview procedures, except where all of the following conditions exist: (i) responses are recorded in such a manner that the human subjects can be identified, directly or through identifiers linked to the subjects, (ii) the subject's responses, if they became known outside the research, could reasonably place the subject at risk of criminal or civil liability, or be damaging to the subject's financial standing, employability, or reputation, and (iii) the research deals with sensitive aspects of the subject's own behavior, such as illegal conduct, drug use, sexual behavior, or use of alcohol. All research involving survey or interview procedures is exempt, without exception, when the respondents are elected or appointed public officials, or candidates for public office.

4) Research involving the observation (including observation by participants) of public behavior, except where all of the following conditions exist: (i) observations are recorded in such a manner that the human subjects can be identified, directly or through the identifiers linked to the subjects, (ii) the observations recorded about the individual, if they became known outside the research, could reasonably place the subject at risk of criminal or civil liability, or be damaging to the subject's financial standing, employability, or reputation, and (iii) the research deals with sensitive aspects of the subject's own behavior such as illegal conduct, drug use, sexual behavior, or use of alcohol.

5) Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available or if the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects.

6) Unless specifically required by statute (and except to the extent specified in paragraph (1)), research and demonstration projects which are conducted by or subject to the approval of the Department of Health and Human Services, and which are designed to study, evaluate, or otherwise examine: (i) programs under the Social Security Act or other public benefit or service programs, (ii) procedures for obtaining benefits or services under those programs, (iii) possible changes in or alternatives to those programs or procedures, or (iv) possible changes in methods or levels of payment for benefits or services under those programs.

n/a

# THE Painted BRAIN

a project of special service for groups

Dear Kerri,

This is a letter to support you in your efforts towards doing research into the impact of stigma in young adults living with mental health disorders. I am writing to let you know that I am a licensed clinical social worker and I am making the commitment to be on site during your proposed focus group with our peers and young adults. In the selection process for the focus group I will assure that participants are stable, open to participation and that such a process will not be detrimental to their stability or mental health needs. I look forward to working with you in this process.

Sincerely,



Dave Leon, LCSW  
License #: LCS 24285  
[www.thepaintedbrain.org](http://www.thepaintedbrain.org)  
626-354-1584



THE Painted BRAIN

## LOYOLA MARYMOUNT UNIVERSITY

## Informed Consent Form

Date of Preparation: November 21, 2012

**Loyola Marymount University**

An exploration of stigma and the art-making process in young adults with mental illness.

- 1) I hereby authorize Kerri Blackstone, MFT trainee to include me in the following research study: An exploration of stigma and the art-making process in young adults with mental illness.
- 2) I have been asked to participate on a research project which is designed to better understand the influence that the stigma of mental illness has on the external and internal lives of young adults who have been diagnosed with mental illness as well as the effects that art-making can have on this population. For the purpose of this study, stigmatization is defined as the process by which a dominant group designates characteristics of a non-dominant group as inferior, problematic, or shameful. To be stigmatized is to be discredited, undesired, and reduced from whole and usual to tainted and discarded. This will be done through a focus group and which will last for approximately three hours.
- 3) It has been explained to me that the reason for my inclusion in this project is that I am between the ages of twenty and thirty-five, have been diagnosed with a mental illness, and have participated in *The Painted Brain*.
- 4) I understand that if I am a subject, I will participate in a three-hour focus group that will be audio-recorded and will include a simple art directive. The investigator will lead the focus group, audiotape the session, and photograph the artwork that is done during the group. These procedures have been explained to me by Kerri Blackstone, MFT trainee.
- 5) I understand that I will be audiotaped and that my artwork will be photographed in the process of these research procedures. It has been explained to me that these tapes will be used for teaching and/or research purposes only and that my identity will not be disclosed. I have been assured that the tapes will be destroyed after their use in this research project is completed and that, during the course of this project, the data will be stored on a password-protected drive. I understand that I have the right to review the tapes made as part of the study to determine whether they should be edited or erased in whole or in part.
- 6) I understand that the study described above may involve the following risks and/or discomforts: discussion of sensitive subjects, being audiotaped, and creating artwork may provoke anxiety and/or emotional distress.
- 7) I also understand that the possible benefits of the study include having the opportunity to be

heard in a safe, supportive environment, connecting with others who may have similar experiences, discovering new insights and coping mechanisms, helping the public better understand the stigma of mental illness, possibly inspiring future studies and programs aimed at combating the stigma of mental illness.

- 8) I understand that Kerri Blackstone, who can be reached at 310-968-4963, will answer any questions I may have at any time concerning details of the procedures performed as part of this study.
- 9) If the study design or the use of the information is to be changed, I will be so informed and my consent re-obtained.
- 10) I understand that I have the right to refuse to participate in, or to withdraw from this research at any time without prejudice to (e.g., my future medical care at LMU.)
- 11) I understand that circumstances may arise which might cause the investigator to terminate my participation before the completion of the study.
- 12) I understand that no information that identifies me will be released without my separate consent except as specifically required by law.
- 13) I understand that I have the right to refuse to answer any question that I may not wish to answer.
- 14) I understand that this research may be referenced by *The Painted Brain* for fundraising purposes.
- 15) I understand that in the event of research related injury, compensation and medical treatment are not provided by Loyola Marymount University.
- 16) I understand that if I have any further questions, comments, or concerns about the study or the informed consent process, I may contact David Hardy, Ph.D. Chair, Institutional Review Board, 1 LMU Drive, Suite 3000, Loyola Marymount University, Los Angeles CA 90045-2659 (310) 258-5465, david.hardy@lmu.edu.
- 17) In signing this consent form, I acknowledge receipt of a copy of the form, and a copy of the "Subject's Bill of Rights".

Subject's Name or Chosen Pseudonym: \_\_\_\_\_

Age: \_\_\_\_\_ Diagnosis: \_\_\_\_\_

Subject's Signature (Initials Only) \_\_\_\_\_ Date \_\_\_\_\_

The Painted Brain is allowed to use this research \_\_\_\_\_

Witness \_\_\_\_\_ Date \_\_\_\_\_

## LOYOLA MARYMOUNT UNIVERSITY

## Experimental Subject's Bill of Rights

Pursuant to California Health and Safety Code §24172, I understand that I have the following rights as a participant in a research study:

1. I will be informed of the nature and purpose of the experiment.
2. I will be given an explanation of the procedures to be followed in the medical experiment, and any drug or device to be utilized.
3. I will be given a description of any attendant discomforts and risks to be reasonably expected from the study.
4. I will be given an explanation of any benefits to be expected from the study, if applicable.
5. I will be given a disclosure of any appropriate alternative procedures, drugs or devices that might be advantageous and their relative risks and benefits.
6. I will be informed of the avenues of medical treatment, if any, available after the study is completed if complications should arise.
7. I will be given an opportunity to ask any questions concerning the study or the procedures involved.
8. I will be instructed that consent to participate in the research study may be withdrawn at any time and that I may discontinue participation in the study without prejudice to me.
9. I will be given a copy of the signed and dated written consent form.
10. I will be given the opportunity to decide to consent or not to consent to the study without the intervention of any element of force, fraud, deceit, duress, coercion, or undue influence on my decision.

**Mental Health Resources**

**Suicide Hotlines:**

National: 1.800.273.TALK  
Los Angeles: 1.800.854.7771

**Mental Health Emergency and Urgent Care Centers (UCC)**

Westside / Exodus Urgent Care Center  
3828 Delmas Terrace  
Culver City, CA  
310.253.9494

**Downtown Mental Health Center FSP Program**

619 E. 5<sup>th</sup> Street  
Los Angeles, CA 90013  
213.633.2903

**Telecare Mental Health UCC**

6060 Paramount Boulevard  
Long Beach, CA 90805  
562.790.1860

**Olive View Urgent Care Center**

14445 Olive View Drive  
Sylmar, CA 91342  
818.364.4340

**Eastside / Exodus Urgent Care Center**

1920 Marengo Street  
Los Angeles, CA  
323.221.2591

**Agustus F. Hawkins Mental Health Center (South LA)**

1720 East 120<sup>th</sup> Street  
Los Angeles, CA 90059  
310.668.4271

**LAC Emergency Outreach Bureau (EOB Crisis & Homeless)**

10605 Balboa Blvd. Suite 100  
Granada Hills, CA 91405  
818.832.2410

**PET**

1.800.854.7771

**Dave Leon**

626-354-1584  
thepaintedbrain@gmail.com



## **Opportunity to Participate in a Graduate Art Therapy Research Project**

Looking for men and women  
age 20-35 who have been  
diagnosed with a mental illness.

If selected, you will be participating  
in a focus group that will explore  
the experience of stigma and  
the experience of art-making  
in relation to mental illness.

Participation will be anonymous.  
No names or identifying information will be used  
in the final research project.

The focus group will last approximately three hours and  
will take place at The Painted Brain headquarters  
at a time that is convenient for all participants.

The first 3 men and first 3 women to respond  
will be invited to participate.