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The Student Perspective: An Exploration of the Experiences and Needs of University Students with Mental Illness

Hannah Lee Gammon
Wright State University

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**THE STUDENT PERSPECTIVE: AN EXPLORATION OF THE EXPERIENCES
AND NEEDS OF UNIVERSITY STUDENTS WITH MENTAL ILLNESS**

PROFESSIONAL DISSERTATION

SUBMITTED TO THE FACULTY

OF

**THE SCHOOL OF PROFESSIONAL PSYCHOLOGY
WRIGHT STATE UNIVERSITY**

BY

HANNAH LEE GAMMON, Psy.M.

**IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE
OF
DOCTOR OF PSYCHOLOGY**

Dayton, Ohio

September, 2014

COMMITTEE CHAIR: Julie L. Williams, Psy.D., CRC, ABPP

Committee Member: Robert Rando, Ph.D., ABPP

Committee Member: Erendira Lopez-Garcia, Psy.D.

WRIGHT STATE UNIVERSITY
SCHOOL OF PROFESSIONAL PSYCHOLOGY

July 10, 2013

I HEREBY RECOMMEND THAT THE DISSERTATION PREPARED UNDER MY SUPERVISION BY **HANNAH LEE GAMMON** ENTITLED **THE STUDENT PERSPECTIVE: AN EXPLORATION OF THE EXPERIENCES AND NEEDS OF UNIVERSITY STUDENTS WITH MENTAL ILLNESS** BE ACCEPTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PSYCHOLOGY.

Julie L. Williams, Psy.D., CRC, ABPP
Dissertation Director

La Pearl Logan Winfrey, Ph.D.
Associate Dean

Abstract

There is a gap in the current literature concerning the study of university students with mental illness. Particularly, very few qualitative studies have been conducted in which interviews with university students with mental illness have yielded knowledge about the population's experiences and needs. The present study, employing a Participatory Action Research (PAR) approach, was designed to promote a more accurate perception of the lives of university students with mental illness by allowing the voices of members of this group to be heard. Eight matriculating university students who self-identified with mental illness participated in this exploratory PAR initiative. The study involved open-ended questioning of participants through mixed methods including a demographics sheet, self-administered questionnaire, and focus group interviews. Results reflected numerous salient themes based on both written and verbal interactions with participants. For instance, potential barriers to success and suggestions for ways to best serve university students with mental illness were revealed. Also, mental health stigma and disability issues were addressed. Implications for future research and action are discussed.

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Dedication

My work is dedicated to anyone who has experienced the impact of mental illness. Specifically, I am devoted to the fight against harmful mental health stigma and its associated social injustice. To all who have served or continue to serve in this movement, thank you for promoting growth among humankind through compassion and for your bravery in sharing your convictions with our world. On a related note, I would like to recognize the remarkable participants in this study who took the time and risks necessary to share their stories with me. Your voices are highly appreciated and truly important in fostering a positive perception of mental illness in our society. Finally, I would like to dedicate this work to all of the warmhearted souls who have supported me through my personal battles related to mental illness. I am proud that my life experiences have shaped me into a stronger and wiser person who is now fortunate to have an opportunity to pass along the love and positive energy that I have received over the years. To all of those who have believed in me: thank you with the utmost sincerity.

CHAPTER 1

The enrollment of students with mental illness in institutions of higher education is rising (Carter & Winseman, 2003; Hunt & Eisenberg, 2010; Kitzrow, 2009; Mowbray, Megivern, Mandiberg, et al., 2006). This increase in enrollment has been linked to several variables such as improvements in mental health treatment, landmark educational legislation, anti-discrimination laws, and self-determination movements within the disability rights community (Konur, 2006). Moreover, the onset of mental disorders ranging from mild to severe often occurs between the ages of 18 and 25, a time when many young adults pursue postsecondary education and formulate career plans (Becker, Martin, Wajeih, Ward, & Shern, 2002; Collins & Mowbray, 2005; Eisenberg, Golberstein, & Gollust, 2007; Kiuahara & Huefner, 2008). Consequently, psychiatric symptoms may disrupt the completion of expected developmental and educational tasks and may have a negative impact on academic performance, retention, and graduation rates (Becker, Martin, Wajeih, Ward, & Shern, 2002; Kitzrow, 2009; Mowbray, Megivern, Mandiberg, et al., 2006).

Despite the increased enrollment and successes of students with mental illness, high attrition rates continue among this group. Approximately 5% of all university students in the United States prematurely end their educations due to mental disorders (Kitzrow, 2009). Further, it has been estimated that up to 86% of university students who have a serious mental disorder withdraw from college prior to the completion of their

degree (Collins & Mowbray, 2005). Termination rates have been linked to persisting psychiatric symptoms, systemic and social barriers, and ineffective support networks and services (Mowbray, Megivern, Mandiberg, et al., 2006).

To complicate the aforementioned issues, studies have shown that, even when mental disorders impair functioning to the point they are considered to be psychiatric disabilities, many students do not disclose their mental illness nor do they seek support services at their universities (Brockelman, Chadsey, & Loeb, 2006; Eisenberg, Golberstein, & Gollust, 2007). Researchers have found that both the silence and lack of help-seeking behaviors amongst students with mental illness are due to stigma as well as assumptions that support services are not available to them (Eisenberg, Golberstein, & Gollust, 2007). Further, in order to receive certain support services, students with psychiatric disabilities must set themselves apart from others and face the consequence of stigmatizing themselves as being different or less able as compared to their peers (Kihara & Huefner, 2008). However, researchers have shown that when appropriate supports and treatments are in place, there are strong indications that students with psychiatric diagnoses, like students with other disabilities, can and do succeed in higher education.

Mental health problems have a profound impact on all aspects of campus life at the individual, the interpersonal, and even the institutional levels (Kitzrow, 2009). This issue represents both a growing concern and opportunity, because a large number of people could be reached during an important transitional phase of life (Hunt & Eisenberg, 2010). Universities provide a unique chance to identify, prevent, and/or treat mental disorders as campuses often encompass students' residences, social networks, and many

services (Eisenberg, Downs, Golberstein, & Zivin, 2009). Unfortunately, even when appropriate services do exist, stigma including inaccurate beliefs and harmful attitudes about mental illness may impede university students' use of available services and resources, thus limiting their capacity to be successful in their academic and personal pursuits.

The purpose of this study was to gain a more accurate perception of the experiences and needs of university students living with mental illness through an investigation of students' perspectives. Stigmatizing beliefs about mental illness, as well as societal perceptions of psychiatric disability, continue to shape the ways in which university administrators, faculty, staff, and students with and without mental illness view and interact with students affected by mental disorders. Additionally, social constructions regarding mental illness and disability may affect what services are offered at universities, the rates at which students with mental illness are utilizing these services, and even the ways in which the students themselves form their views regarding their own identities. Consequently, the investigator believed that it was crucial to gain knowledge from members of the often marginalized population of university students with mental illness in order to make a plan for future research and action.

In recent decades, there have been many studies that have investigated the needs and experiences of university students with mental illness from various perspectives. Most of these studies have involved surveying the attitudes and beliefs of university administrators, students with and without mental illness, faculty, and staff. However, after a comprehensive search, no qualitative studies involving direct contact between researchers and currently enrolled university students with mental illness via focus group

interviews could be found. Further, no known related participatory action research (PAR) studies, in which members of the community being studied are part of the research development while informing data collection, were located. Thus, this study utilized a PAR approach, involving focus groups with university students with mental illness, in order to advance a more thorough and accurate knowledge base regarding students' unique perspectives and needs.

One desired outcome for this study was to reduce, and continue in the effort to eradicate, the stigma of mental illness on college campuses by promoting awareness regarding the experiences of those diagnosed with mental disorders. Social psychologists have identified three approaches for changing stigmatizing attitudes toward mental illness: education, contact, and protest (Corrigan, River, Lunden, et al., 2001). Education involves replacing stigmatizing public attitudes with more accurate conceptions related to mental illness. The method involving contact involves challenging distorted public attitudes through direct interactions with and exposure to individuals with mental illness. Finally, protest involves taking action to suppress stigmatizing attitudes as well as the behaviors that promote such attitudes. The results of a study conducted by Corrigan et al. in 2001 found that approaches involving education and contact led to enduring attitude change whereas protest yielded no improvement. Thus, to promote an attitudinal shift regarding views toward mental illness on university campuses, this study aimed to use a method to promote education based on contact with university students with mental illness themselves.

Through direct contact and interactions with students with mental illness, the investigator gained valuable information intended for educational purposes as well as to

provide directions for future research and action. Allowing university students the opportunity to discuss their personal experiences with mental illness and higher education, proclaim their needs, express their opinions regarding campus support services, and explore their identities in relation to mental illness was, and continues to be, an essential step in gathering the information necessary to truly understand this population. The present study was conducted with hopes of using the knowledge gained to enhance the body of literature concerned with ways to best serve and design research involving students with mental illness in institutions of higher education. Further, the aim was to promote activism among stakeholders in the fight against mental health stigma.

CHAPTER 2

Literature Review

The percentage of the U.S. population with a psychiatric diagnosis is rising, especially among younger adults (Mowbray, Megivern, Mandiberg, et al., 2006). Thus, since approximately three-quarters of lifetime mental disorders have the first onset by the age of 24 and about half of American youth attend postsecondary education, the number of students with mental illness on university campuses is increasing (Eisenberg, Downs, Golberstein, & Zivin, 2009). Further, university counseling centers have reported increasing prevalence and levels of severity of student psychological problems over the past decade (Collins & Mowbray, 2005; Eisenberg, Downs, Golberstein, & Zivin, 2009). Many students with serious mental health issues are significantly impaired by their conditions, resulting in disability status.

The increase in numbers of students with mental disorders on university campuses warrants concern about the impact of society's views of mental illness and disability. Therefore, to better understand the experiences of these students, it is important to first explore issues related to both disability and mental illness. By examining the historical developments that shape general attitudes toward these oppressed groups, one can gain better insight as to current conceptualizations and social-political influences that exist regarding mental illness.

Three principal models of disability have most frequently been researched by disability theorists. First, the moral model of disability has historically viewed disability as a collection of defects or flaws that have been caused by sins, evil, or a lapse of faith (Roush & Sharby, 2011). Under this model, individuals with disabilities are encouraged to segregate and hide away from the rest of society, thereby promoting feelings of shame. Simultaneously, persons with disabilities are to be addressed with sympathy, pity, and altruism from outsiders. A shift in some of these beliefs and behaviors occurred with the emergence of a second model, the medical model of disability. This commonly held model views disability as abnormal and pathological. Similar to the moral model, disability is viewed as a flaw within the individual; however, this model posits that members of helping professions within society should attempt to “cure” an individual with disability of their imperfections and impairments so they can function similarly to able-bodied members of society. With particular regard to psychiatric disability, the medical model often holds the assumption that the “abnormality” is something that the affected individual can control. This distinction is important, because it suggests that the public generally views persons with psychiatric disabilities, in contrast with persons with physical disabilities, as personally responsible for their own impairments. A third, more recent model of disability, the social model of disability, has begun to shift the focus from the individual to issues with the external environment and society at large. When using this model, disability is conceptualized as a product of social and political forces that oppress individuals with targeted differences. Essentially, this model posits that a person with a socially defined disability, whether mental or physical in nature, is unable

to function at his or her potential if immersed in a society that is not structured for or considerate to him or her.

Though important paradigm shifts in views regarding disability have yet to produce lasting attitudinal change in our society, prominent civil rights legislation has been granted to protect the rights of individuals with disabilities (ADA, 1990). Disability activism and the emergence of the social model of disability have also begun to include issues related to mental illness in the movement. With this, views are beginning to change so that individuals with mental illness can embrace their conditions as a part of their identity and also seek services to allow for their best success in their communities (i.e., university campuses). Unfortunately, due to continued stigma and environmental barriers, members of this group often do not utilize or are not exposed to the services that would best promote their success. Thus, in order to better understand the needs of these individuals, it is important to gain awareness of their unique perspectives and challenges.

Mental Illness

‘Mental health’ may be defined as the capacity of individuals and groups to interact with one another and the environment in ways that promote subjective well-being, optimal development, and appropriate use of cognitive, affective, and relational abilities (Johnstone, 2007). Mental health problems and mental disorders, in turn, refer to the spectrum of cognitive, emotional, and behavioral disorders that interfere with the lives and productivity of people at school, work, and home and have an impact upon their interpersonal relationships. It is important to clarify, though, that the term ‘mental disorder’ is not synonymous with the term ‘mental health problem.’

The American Psychiatric Association (2000) defines the term ‘mental disorder’ as a clinically significant behavioral or psychological syndrome or pattern that occurs in an individual and is associated with present distress or disability or with a significantly increased risk of suffering death, pain, disability, or an important loss of freedom. Essentially, the term is used as a diagnostic label that is applied to a person with a mental health problem after he or she consults with a health professional for assistance in dealing with the problem and is generally taken to refer to “a clinically recognizable set of symptoms or behaviors associated in most cases with distress and interferences with personal functions” (Johnstone, 2007; World Health Organization, 1992). According to the National Institute of Mental Health (2000), one in five adults has a diagnosable mental disorder in a given year (Phelan & Basow, 2007).

‘Mental illness’ refers to the collection of all diagnosable mental disorders causing severe disturbances in thinking, feeling, relating, and functional behaviors (Souma, Rickerson, & Burgstahler, 2009). It can result in symptoms that produce a substantially diminished capacity to cope with the demands of daily life. Such symptoms may include, yet are not limited to, the following: heightened anxieties; fears, suspicions, or blaming others; marked personality change over time; confused or disorganized thinking; strange or grandiose ideas; difficulty concentrating, making decisions, or remembering things; extreme highs or lows in mood; denial of obvious problems and a strong resistance to offers to help; and thinking or talking about suicide.

For a small but significant category of people, a mental disorder is associated with severe restrictions on social, psychological, and physical well-being (Mulvany, 2001). The severity of symptoms may fluctuate, but they are chronic for many. ‘Serious mental

illness' is a term that refers to diagnosable mental disorders with durations lasting at least one year that produce impairment significant enough to be considered disabling (Mowbray, Megivern, Mandiberg, et al., 2006). Common diagnoses associated with serious mental illness typically include recurrent major depressive disorder, bipolar disorder, schizophrenia and other psychotic disorders, severe anxiety disorders (i.e., posttraumatic stress disorder, obsessive compulsive disorder), eating disorders, and personality disorders (Cook, 2000).

Not everyone with mental illness experiences disability as a result (Cook, 2000; Mowbray, Megivern, Mandiberg, et al., 2006). However, individuals with mental illness may experience symptoms that interfere with their goals and create a psychiatric disability. The term 'psychiatric disability' is associated with individuals who have been labeled with a severe mental disorder included in the Diagnostic and Statistical Manual of Mental Disorders (APA, 2000). However, a diagnosis alone is not enough to include someone as a member of this group (Cook, 2000). Individuals are considered to be disabled when the level of impairment interferes with functioning in adult roles, thus creating difficulties with living independently, maintaining employment, completing or advancing their educations, and/or relating interpersonally. Further, it is important to note that a psychiatric disability is a hidden disability; though it can be highly disruptive for the affected individual, it is rarely outwardly apparent to others.

For individuals with mental illness, regardless of the level of severity, the foremost challenge is being able to recognize, find treatment for, and successfully manage interfering psychiatric symptoms in order to maintain daily functioning and improve quality of life (Wood & Wahl, 2006). At the very least, deficits in attention,

planning and organization, memory, higher-order conceptual thinking, and output fluency are associated with most major and minor mental disorders. Despite this, the results of a recent study demonstrated that less than 40% of respondents with mental illness had received regular treatment or accommodation services in the past year (Phelan & Basow, 2007). This lack of service use is likely due, at least in part, to the belief that resources to accommodate these impairments are only available to people with other types of disabilities (i.e., physical). Further, there may be a lack of realization among those with mental illness that services beyond basic symptom management are often needed to ensure a higher quality of life in multiple facets of their existence.

Disability

In recent decades, there has been a gradual progression toward social and political equality for people with disabilities. ‘Disability,’ as defined in the Americans with Disabilities Act (ADA) of 1990, and as later amended by the United States Congress in 2008, includes a person (a) with a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (b) who has a record of such an impairment; or (c) who is regarded as having such an impairment (ADA, 1990, 42 U.S.C. § 12102 (1)). ‘Impairment’ involves limited functioning in at least one major life activity related to some defined physical or mental deficiency, usually constituting a medically classified condition (ADA, 2008, 42 U.S.C. § 12102 (4)(3); Mulvany, 2000). In general, ‘major life activities’ include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working (ADA, 2008, 42 U.S.C. § 12102 (4)(a)(2)(A)). Further, an impairment that is

episodic or in remission is considered a disability if it would substantially limit a major life activity when active (ADA, 2008, 42 U.S.C. § 12102 (4)(3)(D)). Also, mitigating measures, including assistive devices, auxiliary aids, accommodations, and medical therapies and supplies have no bearing in determining whether a disability is qualified under the law.

The ADA is a federal statute developed to promote equal opportunities for people with physical, sensory, or mental disabilities that significantly impair their daily life functions (Goad & Robertson, 2000). This law protects the civil rights of persons with disabilities in access to employment, education, public services, public and private transportation, and telecommunications services. According to the ADA, physical or mental disabilities in no way diminish a person's right to fully participate in all aspects of society. Therefore, public and private institutions must provide reasonable environmental and interpersonal accommodations which afford opportunities for successful functioning and activity involvement to individuals with disabilities (ADA, 1990, 42 U.S.C. § 12101 (a)(1); Corrigan, Markowitz, & Watson, 2004).

Without proper services and accommodations, an individual with a disability is more likely to remain in a state of impairment; in turn, the individual is at higher risk to experience harmful discrimination from others. Discrimination against individuals with disabilities is often found in critical areas such as education, health services, and employment (ADA, 1990, 42 U.S.C. § 12101 (a)(3)). Individuals with disabilities encounter various forms of discrimination including the inequitable effects of overprotective rules and policies, failure to make modifications to existing practices, exclusionary qualification standards and criteria, segregation, and relegation to lesser

services, programs, activities, or opportunities (ADA, 1990, 42 U.S.C. § 12101 (a)(5)). Discrimination can also be seen as a failure to make reasonable modifications to policies, practices, or procedures, when such modifications are necessary to afford such services, privileges, advantages, or accommodations to individuals with disabilities (ADA, 1990, 42 U.S.C. § 12182 (2)(A)(ii)). Various societal structures, including educational institutions, are legally bound to abide by the statute of ADA to eliminate discrimination (ADA, 1990, 42 U.S.C. § 12181 (7)(J)). Any person whose condition meets general criteria for disability under the ADA is entitled to legal protection from discrimination as stated in the ADA legislation.

Historically, society has isolated and segregated individuals with disabilities (ADA, 1990, 42 U.S.C. § 12101 (a)(2)).

Individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society (ADA, 1990, 42 U. S. C. § 12101 (a)(7)).

Despite some structural and attitudinal improvements, such forms of discrimination against individuals with disabilities continue to be a serious and omnipresent social problem. Disability is not an individual difference that is generally acknowledged with comfort in American society (Leigh, Powers, Vash, & Nettles, 2004). In fact, though

recent statistics indicate that almost 50 million Americans (roughly 14% of the population) have disabilities, discriminatory experiences continue to be based upon pervasive societal attitudes that negatively differentiate and stereotype people with disabilities.

‘Ableism’ refers to the resulting set of assumptions and practices that systematically promote negative differential and unequal treatment of people because of apparent or assumed physical, mental, or behavioral differences which are labeled as disabilities (Onken & Slaten, 2000). Public discomfort and disapproval of people with disabilities results in diagnosing, labeling, isolating, patronizing, taunting, harassing, and abusing them. People with disabilities often experience devaluation by others, which frequently leads them to devalue themselves as a result.

In recent decades, a social model has emerged which views disability as a disadvantage or restriction of activity caused by a contemporary social organization which takes little to no account of people who have impairments and, thus, excludes them from the mainstream of social activities (Mulvany, 2000). Under this model, it is often argued that in the development of “disability,” the disorder itself is far less important than the disabling environment in which a person must function (Cook, 2000). Thus, disability is not seen as stemming from the individual’s deficits or impairments, but rather from the interactions between these and non-supportive, even hostile, environments. In essence, society limits and constrains individuals with disabilities through an environment that creates attitudinal, physical, and social barriers (Hindes & Mather, 2007).

The location of the conceptualization of disability within a social framework redirects analysis from the individual level to processes of social oppression, discrimination, and exclusion (Mulvany, 2000). Thus, disadvantage is seen as institutionalized throughout society. A social approach to disability demands an identification and analysis of social, political, and economic conditions that restrict the life opportunities of those with impairments. Central to this work is the rights of those with disabilities.

The social approach to viewing disability also has an ideological component that has the potential to give people with disabilities a feeling of self-worth that they may not attain if working under other models (Mulvany, 2000). Further, it offers individuals with disabilities a collective identity and stronger political organization. The emergence of both the social model and the disability civil rights movement has facilitated a slow cultural shift toward a social construction of disability that challenges commonly held beliefs and social stigma. Newer, more person-centered models that recognize oppression and focus on a person's strengths and capacities have offered new visions of disability as an attribute to be affirmed and celebrated (Onken & Slaten, 2000).

Psychiatric Disability

Just as disability is not often taken into account in regard to the spectrum of diversity issues, psychiatric disabilities are not often taken into account when studies are conducted regarding disability (Leigh, Powers, Vash, & Nettles, 2004). Disability theorists have rarely included psychiatric disabilities in their work (Mulvany, 2000). Further, psychiatric disabilities have traditionally been excluded from disability programs

regarding employment and training, housing and accommodation support, generic social support, recreation, and disability services. There are likely many components which contribute to the lack of inclusion of psychiatric disability in the greater disability community; one of which involves silence amongst members of the population with mental illness.

People with psychiatric disabilities are relative latecomers to disability rights activism (Cook, 2000). This is due, at least in part, to the fact that a large number of individuals with psychiatric disabilities had resided in state institutions in the previous century for significant portions of their lives. Only in recent decades, since the deinstitutionalization from public hospitals (beginning in the 1950s and 1960s), have individuals with serious mental illness been living in the community for long periods of time. A shift to outpatient models of treatment has provided persons with mental illness the capacity for social and political participation. In fact, people with psychiatric disabilities were active participants in lobbying for the passage of the ADA as they made their struggles and impairments known to society (Cook, 2000). Despite these groundbreaking changes, however, psychiatric disability largely remains invisible and unaccepted by the general public, leaving countless affected individuals living in silence to avoid painful stigma.

Psychiatric disability significantly affects an individual's ability to meet society's expectations regarding adequate participation in several major activities of daily living. Symptoms such as hallucinations, depression, or mania impair functioning in major life domains such as family, work, and education (Megivern, Pellerito, & Mowbray, 2003). Such impairments contribute to secondary impairments in social competence, work

proficiency, and ability to fulfill adult roles and responsibilities. As a result, people with psychiatric disabilities encounter assumptions by others that they are not capable of working, living independently, or attending school and oftentimes themselves accept these assumptions as fact.

Despite a lack of support from social and political groups as well as society on the whole, people with psychiatric disabilities have unique strengths. These include acceptance of the differences among others and tolerance of diverse and alternative viewpoints, self-awareness given all the feedback they have received from others throughout their lives, survivor skills (as the result of living with low income, low resources, capricious social service systems, etc.), sensitivity to oppression and a desire not to oppress others, and a tendency to challenge the “accepted reality” and envision other alternatives (Cook, 2000).

Modern theorists and psychiatric disability activists have emphasized that a focus on institutionalized oppression would extend the sociology of mental health to an examination and identification of social barriers that deny or restrict access for people with psychiatric disabilities to rights (Mulvany, 2000). Existing mental health policy is based on the assumption that the major problems and “medical symptoms” faced by people with serious psychiatric disabilities result from their illness. Broader social structural factors that affect an individual’s experiences of illness, such as poverty, inequality, discrimination, and exclusion are not targeted. Thus, a social approach to psychiatric disability may be attractive as it allows the use of theory to understand why things are the way they are and to establish a future agenda for social change. When such

an approach is employed, a paradigm shift regarding societal conceptualizations of psychiatric disability is promoted.

Mental health stigma.

People with disabilities have been largely without either a recorded or a recognized history, without a visible presence as a cultural group, and without the acknowledged language, traditions, and customs of a valued culture. In some cases they have been kept invisible and hidden, and when discovered, they have been removed, isolated, stripped of their rights, ridiculed, humiliated, and often forced to live imprisoned by silence. Breaking that silence means emerging from the closet of shame. To proclaim oneself openly as disabled and proud of one's disability is to come out of shame—to break out of the prison of silence (Onken & Slaten, 2000, p. 103).

Social structures that have developed as the result of historical, economic, and political forces create and maintain prejudice and discrimination related to disability (Corrigan & Lam, 2007). 'Public stigma' is the reaction that the general population has to people with disabilities whereas 'self-stigma' occurs when a person with a disability internalizes the stigma of his or her group and applies any stereotypes that exist to the self (Corrigan & Lam, 2007; Eisenberg, Downs, Golberstein, & Zivin, 2009). General stereotypes about people with disabilities include incompetence, character weakness, and unpredictability. In regard to mental illness, the negative stereotypes often held collectively by people in society or communities are that people with mental illness are

unattractive, dangerous, unreliable, unproductive, and unpredictable (Eisenberg, Downs, Golberstein, & Zivin, 2009; Wood & Wahl, 2006).

Though there has been a recent increase in initiatives aimed at combating stigma and discrimination against mental illness, being perceived and labeled as mentally ill continues to foster stereotyping and bias (Phelan & Basow, 2007). According to Phelan and Basow (2007), there are four components to the formation and maintenance of stigma. The first component is that a society or community focuses on a socially selected human difference that is distinguished from others and labeled. Next, the socially assigned label is associated with a stereotype (i.e., dangerous, lazy). Following this, labeling and negative stereotyping promote segregation between groups (i.e., “us” and “them”). Finally, discrimination results; those who have been identified in the stigmatized group endure status loss, rejection, and exclusion. Discrimination often occurs when the first three components to stigma are perpetuated by a group with more political, cultural, or economic power than the group being stigmatized.

It is common for assumptions about mental illness to be inaccurate or exaggerated. For instance, when people observe others and make assumptions about mental illness, they are not typically provided with a label that signifies the mental health status of those that they observe. Rather, people tend to infer illness based on the observation of deviant behavior (Phelan & Basow, 2007). Also, different mental health problems are labeled as mental illness (i.e., depression versus alcohol dependence). These labels and views about diagnosis have a tendency to influence views of dangerousness and, therefore, social distancing. In fact, researchers have found that when one’s behavior is clearly deviant and a violation of social norms, it is likely to evoke a negative response

from observing others. Such research has also found that labeling behaviors as mental illness predicts increased specific perceptions of dangerousness and, in turn, increased desire for social distance.

Attitudes toward deviant behavior and, consequentially, those with mental illness profoundly affect how society treats such individuals (Levine, 1972). Underpinning discrimination is deeply ingrained in societal attitudes of fear, ignorance, and intolerance of mental illness and mental disorders (Johnstone, 2007). This discrimination is likely perpetuated by cultural representations of “dangerousness” in relation to mental illness in the media (Cook, 2000). Further, people with mental illness are the objects of culturally-accepted humor, scorn, and humiliation. Unfortunately, it is still widely acceptable to mock people with mental health problems, make fun of their symptoms, and use stigmatizing language.

Consequences of stigma for both those with mental illness as well as their families and friends can be profoundly dehumanizing and radically alienating (Johnstone, 2002). Stigma perpetuates cruel injustice that denies to individuals with mental illness moral entitlements to things other “normal” persons may take for granted: function, a sense of place in an intersubjective world, empathic connection with reciprocating others, peace of mind, happiness, and participatory citizenship. As a result, mental illness is frequently characterized by a lonely and intense effort to “find one’s way back” to a world of meaningful human connection, intimacy, and shared identity. This journey can be torturing, punishing, and an often unnoticed struggle.

Serious mental illness is considered to be a hidden disability. The term ‘hidden disability’ refers to the fact that these disabilities are less visible than other physical, sensory, or mobility impairments and thus may not be as readily apparent to the observer (Wolf, 2001). The fact that such a disability is invisible to others may contribute to issues related to the stigma of these conditions. Though individuals with serious mental illness are eligible for protection under federal disability legislation, they may be more subject to misconceptions and stereotypes regarding the legitimacy of their disability and their need for protection due to the invisible nature of their conditions.

Attributional theorists have posited that if the cause of a particular problem or disorder is perceived as controllable, feelings of anger will be elicited by others as well as inclinations to punish or neglect those individuals (Brown, 2008). Viewing the person as in control of a situation, as is often the case with mental illness, may lead to blaming and efforts to avoid the individual (Corrigan, River, Lundin, et al., 2000). On the other hand, the more the cause of disability is perceived to be uncontrollable, the more feelings of pity will be elicited along with an inclination to help (Brown, 2008). In addition, specific disabilities may differentially influence or evoke attitudes, depending on how acceptable or unacceptable these are in the eyes of the public (Leigh, Powers, Vash, & Nettles, 2004). Research findings suggest that sensory, motor, and language disabilities are viewed more positively and are less stigmatized than psychiatric disabilities in society (Corrigan, River, Lundin, et al., 2000; Hines & Mather, 2007). Those with psychiatric disabilities are not perceived as “legitimately” disabled by large segments of society but rather as malingerers or whiners. Based on observations of the quick decompensation and

recovery that often accompanies mental illness, a perception that individuals are “faking” their problems is also common (Cook, 2000).

Advocacy groups have identified anti-stigma efforts as a necessary adjunct to clinical services for enhancing the quality of life for people with mental illness (Corrigan, River, Lundin, et al., 2000). Misunderstandings of mental illness continue as the result of limited opportunities for education and learning regarding these issues within society (Wood & Wahl, 2006). Mass media has been shown to be the public’s most common source of information about mental illness. Since media images often portray people with mental illness as violent, dangerous, unemployed, and fleeting, social distancing of this group occurs. By keeping stigmatized groups at a distance, there is limited opportunity for negative stereotypes to be dispelled. Thus, protest, advocacy, positive media advertising, and more accurate portrayals in media have been and should continue to be used to fight stigma.

Attitudes and opinions of the population with mental illness affect both utilization and success of services (Leong & Zachar, 1999). The general help-seeking attitude of those with mental illness is composed of attitudes such as fear of stigma. In recent years, prominent biomedical thinkers have argued that prejudice against mental illness is a harmful force in society that prevents people from seeking and receiving the care they need. Though some people and communities are more accepting of psychological difficulties, people with mental illness, based on their experiences, often assume that others are more judgmental, seeing their difficulties as character problems or even moral flaws. This perceived public stigma may hinder service use by individuals with mental

illness in an effort to avoid criticism and discrimination from others (Eisenberg, Downs, Golberstein, & Zivin, 2009).

Psychiatric rehabilitation. The origins of psychiatric rehabilitation are rooted in several important historical developments. Such developments include the moral therapy era, the inclusion of psychiatrically disabled individuals into public-supported vocational rehabilitation programs, the development of community health ideology, the psychosocial rehabilitation center movement, and the development of skills training techniques as an effective mental health intervention (Anthony & Liberman, 1986). The current notion of recovery dates to the 1980s, with the publication of a major study that demonstrated that the course of severe mental illness is not an inevitable deterioration in addition to several first-person accounts of emerging or recovering from mental illness (Harding, Brooks, Ashikaga, 1987; Jacobson & Greenley, 2001). As a result, mental health professionals drew on rising evidence for models of recovery. Further, during the 1990s, there was a reconfiguration of publicly funded services according to principles of managed care. These changes in the conceptualization of mental illness have altered views toward recovery.

According to Anthony & Liberman (1986), the overall goal of psychiatric rehabilitation is to assure that the individual with a psychiatric disability can perform physical, emotional, social, and intellectual skills needed to live, learn, and work in the community. The level of rehabilitation should involve the least amount of support necessary from agents of the helping professions. Rehabilitation can involve methods ranging from teaching persons specific skills needed to function effectively to developing

the community and environmental resources necessary to support and strengthen an individual's present levels of functioning.

Recovery from psychiatric disability, a multi-dimensional concept, refers to a deeply personal, unique process whereby one changes his or her attitudes, values, feelings, goals, skills, and/or roles (Bullock, Ensing, Alloy, & Weddle, 2000). Past decades have seen the construction of "recovery" as a replacement for the concept of "cure" (Cook, 2000). In recovery, one re-envision his or her life following the onset of a psychiatric disability. Thus, the focus is on controlling the symptoms as much as possible to fashion existence with dignity, maximal self-determination, and the highest level of role functioning.

Recovery is seen as involving both internal and external components. Some of the key internal conditions in the recovery process have been cited as hope, insight regarding one's disability, spirituality, healing, empowerment, the reconstruction of a positive identity, and connection (Bullock, Ensing, Alloy, & Weddle, 2000; Jacobson & Greenley, 2001). Some important external conditions include human rights, "a positive culture of healing," social support, and recovery-oriented services. Further, access to appropriate services, including education, is essential to provide consumers with knowledge, skills, and strategies that can help them relieve symptoms and control the effects of stress.

Newer models of rehabilitation promote recovery and resiliency rather than chronicity and dependency while acknowledging significant challenges faced by people with psychiatric disabilities (Onken & Slaten, 2000). These social models encourage people with psychiatric disabilities to confront and transform disability shame into

disability pride. This empowerment allows persons to take charge of their situations. Further, by progressing through the states of disability identity formation, one's emergence into the disability culture occurs, thereby providing them with a sense of unity with and connection to others.

Psychiatric Disability in Institutions of Higher Education

Over the course of the past 40 years, each generation has been generally more educated than the last (Megivern, Pellerito, & Mowbray, 2003). Advanced educational degrees are increasingly considered prerequisites for most skilled and professional occupations that also typically have higher earnings and benefits. Thus, more students are pursuing higher education than ever before. This increase in students includes individuals with psychiatric disabilities. As a result, college becomes an important setting in which to evaluate and address mental health (Zivin, Eisenberg, Gollust, & Golberstein, 2009). Preventing, detecting, and treating mental disorders among university students are promising avenues for addressing the population burden of early-onset mental illness. However, concerns have recently been brought to the forefront regarding whether campus mental health services are adequate to ensure that the needs of these students are met (Mowbray, Megivern, Mandiberg, et al., 2006). One of the current challenges in creating effective programming, then, is a lack of understanding and awareness of the needs and capabilities of students with psychiatric disabilities.

University counseling centers have indicated increasing prevalence and levels of severity of student psychological problems (Collins & Mowbray, 2005). Most university counseling centers are limited in the number of students they can treat and how much

assistance they can provide (Cook, 2007). Explanations for the increase in service need include increasing numbers of persons seeking college education as well as students who are poorly prepared for this adjustment, having parents who had previously overprotected their children, students who are entering with preexisting mental health problems exacerbated by the demands of university life, the high risk for manifestation of symptoms from ages 18-25, and the natural tendency to display symptoms during this phase of life. However, despite increasing service needs, there remain many students who could benefit from services that do not actively seek them. Even when services are available, students may be uninformed about them or reluctant to request help due to stigma, parental influences, and fear of discrimination by professors, university officials, and future employers.

Since the emergence of students with psychiatric disabilities in colleges and universities, there has been a history of institutions of higher education discouraging students by requiring or suggesting they leave school on the belief that campus life may exacerbate their symptoms (Megivern, Pellerito, & Mowbray, 2003). As recently as the late 1980s, many schools had policies of mandatory psychiatric withdrawal. Rather than working to understand the struggles that these students face, institutions had traditionally avoided the problem altogether. In fact, literature has historically emphasized students with psychiatric disabilities as perpetrators of campus disruptions rather than focusing attention to the development of accommodations for these students (Megivern, Pellerito, & Mowbray, 2003). Over time, though, researchers and administrators began to discuss barriers to success for students with psychiatric disabilities including side effects of medications, lack of coordination between service providers, lack of faculty support,

internalized perceived stigma, low self-esteem, insufficient support systems, problems with trust, cognitive skill deficits related to poor educational histories, and difficulties with attention and concentration (Becker, Martin, Wajeesh, Ward, & Shern, 2002; Megivern, Pellerito, & Mowbray, 2003). It became clear that the aforementioned barriers, when combined with the typical challenges of the college experience, can result in poor academic performance or even failure among students with psychiatric disabilities.

Title II of the ADA extends the law to public entities, including institutions of higher education, to ensure the civil rights of students with physical and mental disabilities (ADA, 1990, 42 U. S. C. § 12101; ADA, 2008, P.L. 110-325; Kiuvara & Huefner, 2007). Consequently, education must be restructured so that every educational institution can accommodate every individual irrespective of disability. Individuals with disabilities must be placed in classes and their needs must be accommodated (Hindes & Mather, 2007). Accommodation does not involve educational institutions lowering their academic standards or relieving a student of responsibility to develop essential skills and competencies expected of all students. Therefore, a major difficulty facing inclusion is that educators must determine how to promote equality and excellence simultaneously. In other words, institutions must determine the degree of modification to and accommodation in teaching and evaluation that will ensure the integrity of work for all students. Courts generally allow colleges and universities to determine what types of modifications are reasonable and what types would change essential requirements of an academic course or program (Kiuvara & Huefner, 2008).

Attitudes toward inclusion of students with disabilities in curricula are influenced by the type of disability as well as by the extent of inclusion (Hindes & Mather, 2007).

This phenomenon has been clearly indicated in research by the more negative attitudes toward psychiatric and attention disabilities as well as more negative attitudes toward providing professorial accommodations and assistance. Further, educators are more willing to include those perceived to have mild disabilities than those whose disabilities are viewed as more severe and problematic in classes. Some faculty even question the appropriateness of students with psychiatric disabilities in classrooms, sometimes concerned about issues of safety, violence, and disruption (Becker, Martin, Wajeeh, Ward, & Shern, 2002). Additionally, professors and instructors may perceive students with mental illness as trying to manipulate them or the university system (Kiuahara & Huefner, 2008).

Becker et al. (2002) conducted a study which revealed that many faculty members were not able or willing to discuss their concerns with students who show signs of issues related to mental illness. About half of the faculty involved in the study stated that they would not feel comfortable dealing with student symptoms of mental illness in most capacities. Further, approximately 5% of the faculty participants believed that students with mental illness should not be permitted in class. The results of this study also showed that the sense of fear and moral judgment among faculty increased with their sense of discomfort and feeling of insecurity around students with mental illness.

In contrast with some research findings, it has been posited that faculty generally tend to perceive students with psychiatric disabilities more positively than not (Brockelman, Chadsey, & Loeb, 2006). Researchers have also found that faculty expressed greater comfort than confidence in working with students with psychiatric disabilities. Further, it has been shown that while the majority of students and faculty

have positive expectations for success among students with mental illness, many are not uniformly positive or knowledgeable about the subject and reported that they lack information about university services and benefits available to these students (Becker et al., 2002). Generally, faculty members are willing to accommodate students with disabilities but rely on disability services for direction (Brockelman, Chadsey, & Loeb, 2006). Many members of faculty feel they do not have adequate knowledge or training to work with these students and would like to have more resources available.

Accommodations. Administrators, faculty, and students lack crucial knowledge about available resources, and needed supported education services often do not exist or are not accessed by students (Becker, Martin, Wajeeh, Ward, & Shern, 2002). Students with psychiatric disabilities may perceive that disability services offices are reserved for people with physical disabilities (Megivern, Pellerito, & Mowbray, 2003). Likewise, staff at these offices may be unfamiliar with the needs of students with psychiatric disabilities. Nonetheless, students with psychiatric disabilities constitute about 8-9% of those served in disability services offices (Mowbray, Megivern, Mandiberg, et al., 2006).

Some students with mental illness may require accommodations to allow them equal access to classes, programs, and coursework (Souma, Rickerson, & Burgstahler, 2009). An 'accommodation' is the removal of a barrier to allow full participation in learning. Curriculum accommodations refer to the format of the curriculum presented to a student (i.e., paper, sign language, audio, etc.) (Konur, 2006). Assessment accommodations are concerned with the format of the response made by the student. Timing accommodations are concerned with timing of access to curriculum (i.e., extended time). Setting accommodations involve adjustment of exams, lectures, and work

placements. Also, some have suggested the use of personal assistance services for individuals with psychiatric disabilities, particularly since the use of such services has been well-defined and successful for students with physical disabilities for over 30 years (Pita, Ellison, & Farkas, 2001).

Regarding accommodations, the emphasis is on access and not on outcome (Souma, Rickerson, & Burgstahler, 2009). This is achieved by providing the student with a disability equal access to the content and activities of a course but not necessarily assuring his or her success. Each student with a disability is encouraged to register with the office that supports students with disabilities in order to receive accommodations. Personnel from the disabilities office typically send instructors a letter documenting specific accommodations required for the student with the disability. It is the responsibility of the instructor and other support staff to provide accommodations as requested. However, it is the student's responsibility to fulfill the academic requirements of the course. The best solutions result when the instructor, student, and disability support service professionals work cooperatively.

University Students with Mental Illness

University students are often viewed as a privileged population, but they are not immune to the suffering and disability associated with mental illness (Hunt & Eisenberg, 2010). Mental disorders are as prevalent among university students as same-aged nonstudents, and disorders appear to be increasing in number and severity. Many young adults experience their first psychiatric episode during college (Mowbray, Megivern, Mandiberg, et al., 2006). The numbers of students with psychiatric disabilities are now

beginning to surpass those with learning disorders and attention-deficit/hyperactivity disorders (Kiuahara & Huefner, 2008). In the 1980s, approximately 5-12% of the university student population reported psychiatric symptoms serious enough to warrant mental health services (Megivern, Pellerito, & Mowbray, 2003). Unfortunately, studies to investigate the prevalence of mental illness on campuses have not been replicated in over 25 years (Megivern, Pellerito, & Mowbray, 2003; Mowbray, Megivern, Mandiberg, et al., 2006). However, estimates have been made that suggest that 12-18% of students on campuses have diagnosable mental illness (Mowbray, Megivern, Mandiberg, et al., 2006).

The transition from childhood to adulthood, often marked by the beginning of college, may be a particularly stressful time in life (Burriss, Brechting, Salsman, & Carlson, 2009). University students experience stressors that may contribute to the development of problems ranging from concentration difficulty, fatigue, and anxiety to alcohol and other substance abuse, suicidality, self-mutilation, eating disorders, and other self-destructive and reckless behaviors and mental health problems (Burriss, Brechting, Salsman, & Carlson, 2009; Cook, 2007). To complicate this, many students experience various situational and maturational crises while in college (Cook, 2007). Evidence suggests that, consequently, those who do not integrate well academically or socially are likely to leave the university setting (Megivern, Pellerito, & Mowbray, 2003).

Symptoms of mental illness such as depression and other mood problems, paranoia, hallucinations, anxiety, and low self-esteem all impair the self-determination and academic performance of students (Brockelman, 2002; Collins & Mowbray, 2005; Megivern, Pellerito, & Mowbray, 2003). Students coping with a serious mental illness

while attending college confront many performance barriers such as maintaining concentration, remembering important details, screening out distractions, meeting deadlines under pressure, test anxiety, executive functioning (i.e., planning, organizing, making decisions), dealing with mental health stigma, interacting within a group, making public presentations, receiving and responding to negative feedback, issues with self-esteem, expectations to act appropriately with classmates and faculty, maintaining a good attendance record (especially for early morning classes), maintaining stamina, and/or motivating oneself and others (Collins & Mowbray, 2005; Megivern, Pellerito & Mowbray, 2003; Mowbray & Megivern, 1999).

Students with psychiatric symptoms struggle with structural obstacles ranging from interpersonal discrimination (i.e., lack of awareness and understanding of mental illness by faculty and peers) to gaps in service provision (i.e., inadequate financial aid, lack of campus-based mental health services, lack of information about campus services) to difficult social relationships because of respondents' fears of being stigmatized by faculty and peers if they disclose their illness (Collins & Mowbray, 2005; Megivern, Pellerito, & Mowbray, 2003). In fact, university students report mostly negative reactions when disclosing their disabilities to instructors (Brockelman, Chadsey, & Loeb, 2006). It has also been found that negative perceptions of a student's competence often accompany knowledge of a student with mental illness' mental health history. Furthermore, there is often a sense of alienation generated through stigma-tainted campus interactions (Megivern, Pellerito, & Mowbray, 2003)

Researchers have found that students are generally unsure whether students with mental illness are eligible for civil rights protections provided by the ADA and, in turn,

services offered by offices of disability services in their colleges and universities (Becker, Martin, Wajeeh, Ward, & Shern, 2002). Students are largely unaware or unfamiliar with service options (Eisenberg, Golberstein, & Gollust, 2007). Moreover, many are unaware that they have insurance coverage for mental health services. In complication of this issue, some students are covered by their parents' insurance and are concerned that their parents will find out they are seeking services.

In order for the playing field to be somewhat equal, students with psychiatric disabilities must set themselves apart to receive proper services, treatment, and accommodations (Kiuvara & Huefner, 2008). University students who have psychiatric disabilities also have the additional burden of proving how activities such as concentrating, forming relationships with others, following schedules, regulating emotions, and managing disability symptoms are major life activities common to most people rather than specifically to a student with a psychiatric disability. Such areas are difficult to define yet are consistently areas in which students with psychiatric disabilities experience the most challenges and possibly face the most discrimination. Also, persons with psychiatric disabilities bear the burden of showing that their disabilities exist even after corrective measures have been adopted (i.e., medications).

A study by Brockelman (2009) investigated the relationship between self-determination, mental illness, and grades among university students. In this study, self-determination referred to the right of individuals to have full power over their own lives, regardless of the presence of illness or disability. The results of the study suggested that mental illness predicted the level of self-determination, and self-determination predicted academic success in terms of grades; however, mental illness itself did not appear to

predict grades. Therefore, it can be assumed that students with mental illness who are affected by negative thoughts and feelings regarding autonomy, competence, and relatedness to their environments are more likely to have difficulty succeeding in school than those who are not. Perceiving oneself as having independence, personal agency, and individual responsibility may also be more strongly correlated with achievement among students with mental illness than their peers. Additionally, it has been found that students with mental illness are often good students (Unger, Pardee, & Shafer, 2000). Moreover, research findings suggest that the type of psychiatric diagnoses carried by students with mental illness have no detectable effects on school performance.

Qualitative Research

In the field of research, the reliability, validity, and benefit of qualitative research has frequently been brought into question. Generally, quantitative research methods have been viewed as superior and preferable in comparison with qualitative research. Researchers who use quantitative methods often dismiss qualitative methods, citing that they are biased and, thus, relatively unscientific (Denzin & Lincoln, 2000). However, it has been argued that, in order to shed light on the multifaceted, conflicting, and debatably biased results that often emerge from quantitative studies, qualitative research methods should be used to uncover the experiences and truths of individuals from subject populations (Savin-Baden & Major, 2010). In essence, qualitative research provides a method for initiating the lived exploration of a topic and gathering detailed information from the source prior to the development of quantitative studies.

‘Qualitative research’ can be defined as a naturalistic, interpretive, and critical inquiry that exposes concepts, experiences, and phenomena through interactions within the environment in which they occur. Qualitative methods also acknowledge the mercurial and subjective nature of the individuals’ lived experience and thereby require research methodology that acknowledges, utilizes, and accounts for the intersection of personal beliefs, experiences, culture, and actions (Denzin & Lincoln, 2000). “In comparison with most quantitative research, qualitative research is a contact sport, requiring some degree of immersion into individuals’ lives” (Stewart, Shamdasani, & Rook, 2007, p. 12). The experiential nature of qualitative research, as well as its emphasis on meaning rather than measurement, has contributed to its characterization as “humanistic” research. It involves a general orientation that includes empathy, openness, active listening, and various types of interactions with research participants.

Participatory action research. ‘Participatory action research’ (PAR) has been defined as a collaborative process of research, education, and action explicitly oriented towards social transformation (Kindon, Pain, & Kesby, 2007). PAR researchers acknowledge that knowledge exists in a variety of institutions and locations. In particular, they assume that those who have been most systematically excluded, oppressed, or denied carry specifically revealing wisdom about the history, structure, consequences, and the breaking points in unjust social arrangements. Some authors suggest that PAR is focused on learning as a vehicle for increasing citizen voice and power in a wide range of contexts. PAR strives to embody a democratic commitment to break the monopoly on who holds knowledge and for whom social research should be undertaken by explicitly collaborating with marginalized or vulnerable others.

Some have argued that to undertake PAR, researchers must adopt a participatory perspective or worldview which asks us to both be situated and reflexive, to be explicit about the perspective from which knowledge is created, to see inquiry as a process of gaining knowledge, and to serve the democratic, political ethos of action research (Kindon, Pain, & Kesby, 2007). Thus, PAR draws on diverse forms of knowing to inform action. Such an epistemology represents a challenge to the scientific, more quantifiable approach and seeks to practice the radical, suggesting that it is not enough to understand the world but that one has to change it for the better. PAR, therefore, emphasizes that there is a socially constructed reality within which multiple interpretations of a single phenomenon are possible by both researchers and participants.

PAR is an orientation to inquiry which demands methodological innovation if it is to adapt and respond to the needs of specific contexts, research questions or problems, and the relationships between researchers and research participants (Kindon, Pain, & Kesby, 2007). PAR also values the processes of research as much as the products; its success rests not only on the quality of information generated but also on the extent to which skills, knowledge, and participants' capacities are developed through the research experience. PAR aims to change practices, social structures, and social media which maintain irrationality, injustice, and unsatisfying forms of existence. It treats participants as competent and reflexive agents capable of participating in all aspects of the research process. This type of research is context-bound and addresses real-life problems. It also integrates values and beliefs that are indigenous to the community into the central core of interventions and outcome variables; thus, it involves participants and researchers in collaborative processes for generating knowledge. PAR treats diverse experiences within

a community as an opportunity to enrich the research process. It leads to the construction of new meanings through reflections on action. Moreover, PAR measures the credibility and validity of knowledge derived from the process according to whether the resulting action solves problems for the people involved and increases community self-determination.

Research design. As a research methodology that typically involves qualitative components, PAR uses data obtained from members of the subject population in order to inform future research and action (McIntyre, 2008). While a more traditional research study is externally directed by the investigator who tests a hypothesis on a given population, the ideal PAR study seeks to engage the subject population of the research so that the voice of the subject population is heard and respected (Dold & Chapman, 2012). People from the community being studied are actively involved in the research process by identifying problems, collecting and analyzing data, and using results to take action (Kramer, Kramer, Garcia-Iriarte, & Hammel, 2011). Specifically, PAR empowers members of groups that have been largely excluded or oppressed by encouraging them to use their expertise on relevant topics to guide future social justice initiatives (Kendon, Pain, & Kesby, 2007). Thus, this type of research addresses real-life problems by involving members of the population being studied in all aspects of the research process.

The fact that PAR is context-specific means that investigators usually draw on a variety of quantitative, qualitative, and creative-based methods to engage participants in the construction of knowledge (Kendon, Pain, & Kesby, 2007; McIntyre, 2008). No two PAR projects are the same; the activities, methods, participants, and objectives are all particular to the context in which the project takes place (McIntyre, 2008). Because of

this, depending on the group being studied and the goals of the project, various methods such as surveys, interviews, focus groups, or dramatization may be utilized. As a result, the diversity of methods used to collect data leads to a diversity of strategies to analyze and use such data.

According to McIntyre (2008), PAR involves a process of questioning, reflecting, dialoguing, and decision-making that resists linearity. Rather, PAR is “a recursive process that involves a spiral of adaptable steps” that include 1) questioning a particular issue; 2) reflecting upon and investigating the issue; 3) developing an action plan; and 4) implementing and refining said plan. Thus, a PAR study must often be carried out in various stages with a unique intent and purpose at each stage.

Questions about a topic relevant to the subject population typically become the point of entry into further reflection and dialogue (McIntyre, 2008). Consequently, new and different ways of perceiving the issues may surface. In other words, initial questions that frame the research often lead to other questions that emerge as the process evolves. Sometimes, the insight gained from reflection and dialogue prompts the participants to develop a plan of action. Other times, the participants reflect on a certain issue, discuss various perspectives about it, and ultimately decide that the item under consideration is not worth their time or attention. This speaks to the flexible and somewhat ambiguous nature of PAR, as it is research that is essentially driven by the community being studied.

In the questioning phase of the research, which is often the first step in implementing a PAR project, several open-ended questions may generate future discussion and/or action (McIntyre, 2008). These types of questions are often explored in

a focus group format but are not limited to such. Possible initial investigative questions include the following: What do you perceive as a problem or an issue in your community that needs to be addressed? Why do these issues/problems exist? What can we do about them? Next, further along in the PAR process, follow-up questions may be asked of participants: What do we already know? What do we need to know? What resources do we need to proceed with the project? What are common themes that have been generated in the research process? Who will control and make decisions in the research project? Will our research represent only the realities of those involved or those of other members of the community/group as well? Finally, when moving toward the stage of research dissemination, it is important to consider ways in which the group will inform others about the research that has taken place.

As was aforementioned, the research design and point of entry with PAR depends on multiple variables including the population being studied, resources (i.e., time, funding), and the context and goals of the project. Thus, it is important to consider PAR as an adaptable model that reflects the needs and experiences of each unique group.

Examples in prior research. Since the investigator involved with the present study was unsuccessful in locating existing PAR initiatives specific to university students with mental illness, it was important to consider examples of PAR used with other subject populations to assist in the construction of research design and implementation. The hope in considering various methods for implementing PAR was that insight revealed would provide suggestions for structuring and conducting such a study, regardless of the population being studied. Nonetheless, it was also crucial to consider the

differences in the groups involved in the research when applying the methodological choices from previous studies.

Teram, Schachter, and Stalker (2005) sought to inform physical therapy professionals about the ways in which survivors of childhood sexual abuse (CSA) experience physical therapy. With this, the goal was to consider sensitive and insensitive practice in the field as described by the population being studied. In the study, the investigators used a mixed-methodological approach where grounded theory was combined with PAR. The grounded theory approach aims to extract theory from data. Ideas that emerge originate with the people most knowledgeable about the subject matter; in this case, survivors of CSA. Grounded theory is an appropriate methodology for developing a conceptual understanding of a phenomenon where little prior knowledge exists (Frost, 2011). The primary aim of PAR, on the other hand, is to put such knowledge to use. Thus, the study involved different phases (Teram, Schachter, & Stalker, 2005). In the first phase, based on grounded theory, 27 survivors of CSA were interviewed. The interviews, which were audio recorded and later transcribed, involved open-ended questions that allowed participants to describe their experiences. Data collected from the interviews was used to form a theory about the subject material. Then, the investigators shared the data with participants in an effort to ensure the interpretations reflected the realities of the participants. The second phase of the study involved PAR. Participants from the first phase, as well as a group of physical therapists, met on a monthly basis for six months in order to transform a summary and analysis of the interviews into concrete suggestions and guidelines for sensitive practice in the field of physical therapy. In the third and final stage of the study, feedback from all participants

(gathered via focus groups) was used to produce a final version of a handbook for sensitive physical therapy practice.

Dold and Chapman (2012) initiated an exploratory study in order to gain an understanding of the perspectives of various stakeholders regarding the system of care for children with mental health challenges. The study used grounded theory with the goal of collecting and comparing data in order to form and reformulate questions about whether a PAR approach would be useful with children with mental health problems. The study involved distributing a survey to stakeholders (i.e., medical professionals, parents, the youth themselves) in order to track demographics and response themes. Four themes were investigated: 1) empowerment of youth; 2) investment by youth in PAR; 3) how figures of authority view youth contribution; and 4) barriers to youth in PAR success. The study unveiled promise for using PAR with this population, demonstrating that youth would likely be enthusiastic about involvement in such a model. Also, suggestions for future research were made in the process.

Kramer, Kramer, Garcia-Iriarte, and Hammel (2011) had been confronted by a community-based self-advocacy group and, thus, became involved in a two-year PAR initiative. The goal of the project was to help individuals with intellectual disabilities develop their capacity for self-advocacy. The researchers met regularly with the self-advocacy group members in order to reconcile goals the group had for their chapter. Eventually, a program was initiated in which members conducted meetings and tracked their progress. Activities such as setting an agenda, organizing materials, and preparing/running meetings were tracked so that all members could increase their capacity for advocacy. Finally, the data that was collected was presented to members

using a modified focus group approach. With this, participants were able to share their feelings and ideas in a safe environment.

Mirza, Gossett, Chan, Burford, and Hammel (2008) collaborated with two centers for independent living in a large metropolitan area. The collaboration led to a PAR project that sought to better understand how to serve people with psychiatric disabilities in a community reintegration program. The project was conducted in four phases: 1) focus groups; 2) field visits with various organizations; 3) community action planning; and 4) community resource meetings. These phases were not planned at the beginning of the project but rather emerged through reflection and action within the group of community partners and researchers. However, the content of the focus group interviews was determined beforehand by reviewing previous literature on psychiatric disability and community reintegration, as well as through conversations with community partners. In the focus groups, data regarding the experiences and needs of individuals with psychiatric disabilities was collected. Following this, themes that had emerged were analyzed in order to determine a future course of action. As a result, field visits, a discussion forum, and a community resource meeting occurred. This study laid the foundation for future bridge building between people with psychiatric disabilities and the broader disability community. Also, needs of the subject population were identified and dialogue was initiated among members of the group. The authors stated that the PAR project described was ongoing and far from complete.

McIntyre (2008) discussed an example of a PAR project whereby a group of urban youth wanted to inform their community about the effects of violence on themselves, their schools, and their community. The group met regularly to synthesize

data from transcripts of previously conducted focus group interviews. The participants divided into four separate groups that each reviewed designated sets of transcripts. Following this, all participants came together, reviewed each group's summary, and began the process of framing an agreed-upon presentation based on the themes that the young people had extracted from the data. This project involved the generation of questions, themes, and ideas that were later used to move the project forward. The result was a presentation to a university audience with regard to the "good parts" and "bad parts" of their community.

Schneider (2012) used PAR as a framework for enabling people with mental disorders to carry out research and, in doing so, to promote health equity, citizenship, and social justice for people with mental illness. In an eight-year PAR study initiated by Schneider, individuals who had been diagnosed with schizophrenia became co-researchers in every aspect of carrying out research and disseminating the results. The investigator met regularly with the participants and together the topics were chosen, research was designed and carried out, and data was analyzed and disseminated. The study involved two projects: 1) an investigation of participants' interactions with medical professionals; and 2) an investigation of participants' experiences with housing. The group met two times per month in order to brainstorm ideas with regard to research and plans for action. Eventually, the group decided to conduct interviews within the group in which good and bad experiences and relevant issues (i.e., medication, support, and diagnosis) were discussed. The information was eventually used to create and deliver presentations to inform the public about issues related to schizophrenia.

Focus groups. As a method used in qualitative research, ‘focus groups’ are carefully planned group discussions designed to obtain perceptions on a defined area of interest (Krueger & Casey, 2009). The emphasis is on interaction within a group of individuals who have experienced some “particular concrete situation” or have certain characteristics in common which relate to the topic of the interview (Krueger & Casey, 2009; Morgan, 1997; Stewart, Shamdasani, & Rook, 2007). The purpose of conducting a focus group is to listen and gather information in an attempt to better understand how people think or feel about an issue (Krueger & Casey, 2009). The interview itself is guided by questions or prompts that are supplied by the researcher who typically takes the role of a moderator (Morgan, 1997). The hallmark of focus groups is their explicit use of group interaction to produce data and insights that would be less accessible without the interaction found in a group. A second signature aspect of a focus group is the objective to better understand the group dynamics that affect individuals’ perceptions, information processing, and decision making (Stewart, Shamdasani, & Rook, 2007). The main logic for conducting the research in a group rather than an individual setting is to allow observations of how and why individuals accept or reject others’ ideas. This can provide helpful information regarding the collaboration of members of the group that can be used for determining internalized views about the topic discussed as well as future possibilities for action and research.

A researcher conducting focus group research does not just do one focus group as a part of a study (Krueger & Casey, 2009). Rather, the group discussion is conducted several times with similar types of participants so the researcher can identify trends and patterns in perceptions. The accepted rule of thumb is to plan three or four focus groups

with each type or category of individual. A focus group is a carefully planned series of discussions designed to obtain perceptions on a defined area of interest in a permissive, nonthreatening environment. Each focus group is typically conducted with 5 to 10 people led by a skilled interviewer; however, the size can range from as few as 4 to as many as 12. The discussions are relaxed, and often participants enjoy sharing their ideas and perceptions. Focus groups work when participants feel comfortable, respected, and free to give their opinion without being judged. The intent of the focus group is to promote self-disclosure among participants.

The questions in a focus group interview are carefully predetermined and sequenced (Krueger & Casey, 2009). They are phrased and ordered so they are easy to understand and logical to the participant. The moderator uses open-ended questions. These questions appear spontaneous but are carefully developed after considerable reflection and input. Questions near the beginning of the interview protocol are more general. These are meant to get the participants thinking and talking about the topic. As the group continues, the questions become more specific and focused. These questions typically yield the most useful information. There is no pressure by the moderator to have the group reach consensus. Rather, attention is placed on understanding the feelings, comments, and thought processes of participants as they discuss the issues.

Focus groups can be useful in several arenas, including program development, surveying satisfaction, understanding concerns, planning and goal setting, needs assessment, and quality improvement efforts (Krueger & Casey, 2009). Further, focus groups can be used concurrently with other research methods and can often lay the groundwork for subsequent research and action. Some researchers begin by using focus

groups to learn about concepts and factors that might be included in later research procedures or program development initiatives. With this insight, researchers can develop meaningful tools to allow for larger samples and statistical analysis. Focus groups have also been used to develop recommendations for later action or study.

Conclusion

Because of inaccurate and stigmatized views of disability, with particular emphasis on attitudes toward mental illness, university students with mental illness are often not offered or involved in services and programs that would promote success in their endeavors in higher education. Though rising numbers of students with mental illness continue to make their way into colleges and universities, the overall acceptance and integration of this population into campus environments are lacking. As a result, many students with mental illness are enduring intense struggles, both academically and personally, that often result in the termination of their educations.

Research regarding issues related to the experiences of individuals with mental illness, particularly the university student population, has traditionally been obtained via quantitative studies. Though these studies, along with civil rights legislation and anti-stigma movements, have impacted changes in views toward mental illness, little is known about the experience of university students with mental illness from the students' perspective. In order to ensure lasting structural and attitudinal change within society, it is important to first investigate the problem from the vantage point of those who experience it in their daily lives. Thus, qualitative studies that involve the members of the community being studied in the construction of research processes yield helpful

directions for further initiatives for action. With this, studies that utilize a participatory action research approach seek to empower participants from the community by actively involving them in the change process. By exploring the lived experience of university students with mental illness and discussing existing barriers to success and suggestions for change, students can define their own reality without attempting to fit into a reality that has been socially constructed for them.

CHAPTER 3

Method

Participants

Participants in this study were university students recruited from Wright State University (WSU), a public university located in Dayton, Ohio that has an enrollment of nearly 20,000 students (Wright State University, 2011). WSU is known for serving the needs of diverse populations of students with many nontraditional groups represented. Participants in this study were recruited on a volunteer basis via advertisements distributed on campus.

Inclusion criteria to participate in this study included the following: 1) student enrollment at WSU at the time of the study; 2) self-identification with regard to the diagnosis of a mental disorder not otherwise excluded. Examples of mental disorders meeting inclusion criteria based on clusters in the *Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition, Text Revision* (DSM-IV-TR; American Psychiatric Association, 2000) were: Schizophrenia and Other Psychotic Disorders, Mood Disorders, Anxiety Disorders, Somatoform Disorders, Factitious Disorders, Dissociative Disorders, Sexual and Gender Identity Disorders, Eating Disorders, Sleep Disorders, Impulse-Control Disorders Not Elsewhere Classified, and Personality Disorders. Exclusion criteria included the following: 1) no student enrollment at WSU at the time of the study;

2) no presence of a mental disorder; 3) presence of one or more of the following from DSM-IV-TR: Disorders Usually First Diagnosed in Infancy, Childhood, or Adolescence; Delirium, Dementia, and Amnesic and Other Cognitive Disorders; Mental Disorders Due to a General Medical Condition; Adjustment Disorders; Additional Codes; or 4) Substance-Related Disorders. It should be noted that exclusion criteria three and four were overlooked if a comorbid condition that met the inclusion criteria was also present. Overall, the goal was to include diagnoses in the study that were consistent with those commonly discussed in preexisting psychiatric disability literature (i.e., major depressive disorder, bipolar disorder, psychotic disorders, severe anxiety disorders, eating disorders, personality disorders) (Cook, 2000). For the scope of this particular study, diagnoses often researched separate from psychiatric disability (i.e., attention-deficit/hyperactivity disorders, autism, learning disorders, adjustment disorders) were excluded.

Materials

All materials used throughout the course of this study were approved by the Institutional Review Board (IRB) at Wright State University (WSU). The study was advertised in two ways in order to recruit participants. First, paper copies of fliers advertising the study were posted in designated areas on campus (see Appendix A). Second, the study was advertised using Campus Announcements on the WSU WINGS online communication system (see Appendix B). All data obtained for this study was collected via three methods: a demographic sheet, a questionnaire, and a focus group interview protocol.

Immediately preceding participation in the study, each participant was provided with a consent form detailing their participation in the study to review and sign (see Appendix C). Participants were also provided with a brief, anonymous demographic sheet in order to obtain information such as the participant's gender, ethnicity, student status, and diagnosis (see Appendix D). The participants were then asked to complete an anonymous self-administered questionnaire designed to collect information regarding the experiences and needs they have had while in college (see Appendix E). The questionnaire was designed to explore various issues related to academic, interpersonal, physical, and emotional functioning and experience. The questionnaire also explored issues related to each student's mental disorder(s) and symptoms as well as any related university services and/or treatment they were receiving at the time of the study or have received in the past. With this, the questionnaire was designed so that the participants could share their opinions regarding related services and/or activities they have been involved with. Further, the questionnaire prompted participants to describe any needs that had not been properly addressed since they had been enrolled at the university. In relation to this, the questionnaire was used to assess participants' opinions and experiences regarding services or programs that could address unmet needs. Opinions regarding ways current services could be improved were also assessed.

Following completion of the consent form, demographic sheet, and questionnaire, participants were asked a series of questions in a focus group interview format (see Appendix F). Open-ended interview questions were designed to address the participants' general experiences with university life, the direct impacts of mental illness on university life, issues related to the stigmatization of mental illness, issues related to university

services, activities, and programs, as well as participants' views regarding whether their mental illness constitutes a psychiatric disability. Focus group interviews were audio recorded for transcription purposes. Once the focus group interviews were transcribed by the investigator, all audiotapes were destroyed.

Procedure

The investigator received human subjects' approval through the university Institutional Review Board (IRB) panel at Wright State University (WSU). The investigator also obtained permissions from administrators at the university, as needed. Additionally, the investigator acquired permission to post flyers and online campus announcements advertising the study. Flyers and announcements advertising the study were posted in the weeks prior to the initiation of the study for recruitment purposes. The investigator's contact information was listed on the advertisements.

Interested individuals were asked to contact the investigator via email in order to acquire follow-up information regarding the study and participate in an email screening process. The purpose of the email screening was to determine whether the individual was eligible for the study as well as to establish the individual's availability for participation. Individuals who met the eligibility requirements were encouraged to participate in the study and were provided with the study's date, time, and location.

Initially, it had been proposed that a total of three focus group interviews, consisting of approximately five to 10 participants each, would be conducted as a part of this study. However, due to scheduling difficulty and low response rate to study advertisements, only two focus group interviews were conducted with a total of eight

participants. Eligible participants who contacted the investigator were asked to attend one of the two focus group interviews, each held at a private location on campus. On the respective focus group dates, each participant was provided with a consent form detailing her or his participation in the study to review and sign (see Appendix C). The investigator reviewed the consent form with each participant and answered any questions at that time. Also, the investigator informed participants that the session would be audio recorded for the purpose of data collection; however, participants were assured that no identifying information would be used in the study (nor would the audiotape be played for anyone other than the investigator). Participants were also asked to complete a brief, anonymous demographic sheet requesting information such as gender, ethnicity, student status, and diagnosis (see Appendix D). The participants were then asked to complete an anonymous self-administered questionnaire designed to collect information regarding the experiences and needs they have had while in college (see Appendix E). The purpose of using the questionnaire was to collect information that participants may not have been comfortable sharing in a group setting. Also, the questionnaire may have prepared participants for the types of questions that would be asked as a part of the focus group interview.

Immediately following the participants' completion of the aforementioned forms, the focus groups commenced and the investigator utilized the Interview Protocol (see Appendix F). Focus group interviews were conducted in a semi-structured format, adhering to questions outlined on the Interview Protocol. At the beginning of each focus group interview, the investigator addressed issues related to confidentiality and the purpose of the study. The focus group interviews were audio recorded.

Following the focus group interviews, the sessions were transcribed and sanitized by the investigator in order to remove any identifying information. Coding and analysis of the data was conducted to uncover themes with regard to the participants' experiences as university students with mental illness. Also, the data was used to uncover participants' views regarding various related issues that might warrant attention from future researchers as well as university administrators, faculty, and staff.

Rationale

Methods for participant recruitment into this study were designed with the aim of respecting the privacy of the individuals involved, preventing exploitation of any students already utilizing mental health or student support services on campus, and extending the opportunity for involvement to any student on campus who met criteria for inclusion. As such, the investigator chose to post an internet advertisement using the campus-wide communication system as well as to distribute advertisement flyers in designated areas on campus. The decision to avoid posting advertisements near the university counseling center, disability services, or other student support services was made to ensure confidentiality, avoid exploitation of consumers, and prevent limiting the study only to individuals involved with campus services.

The participatory action research (PAR) approach selected for this study incorporated demographic sheets, questionnaires, and semi-structured focus group interviews. This mixed-methods approach has several commonalities with the examples of PAR models that were discussed in Chapter 2 – Literature Review. The approach used an exploratory design meant to engage members of the subject population, university

students with mental illness, in the initial phase of the PAR process. Similar to the studies conducted by Teram et al. (2005), Dold and Chapman (2012), Mirza et al. (2008), and McIntyre (2008), this study aimed to collect data with the intent of initiating research or action in the future. Based on studies by Mirza et al. (2008) and Schneider (2012), this study highlighted the investigator's role in questioning a subject population about what issues should be researched and/or acted upon. Finally, as was the case with the majority of the studies previously described, the approach involved a methodology with potential to elicit several distinct phases of data collection to inform future action. Therefore, the method utilized in this study emphasized the initial questioning phase of PAR. The aim was to create a foundation of information, based on written data and dialogue, that can be used for future research and action.

CHAPTER 4

Results

Participants

Seventeen eligible participants responded to this study and indicated that they were available to attend one of the three scheduled focus group sessions. Eight of the eligible participants were initially scheduled to attend the first focus group session; however, two participants withdrew prior to the study due to scheduling conflicts, and three participants did not attend the study session without prior notification. Regarding the second focus group session, seven of the eligible participants were originally scheduled; however, two participants did not attend the study session without prior notification. Two of the eligible participants were unable to participate in the study due to the investigator's inability to recruit the required number of participants for the third focus group session. All of the eight remaining eligible participants successfully completed all portions of this study.

Seven of the eight participants identified as female (87.5%), and one participant identified as male (12.5%). The participants predominantly identified as Caucasian/White/European American (87.5%), with the exception of one participant who identified as Multiracial ("Mixed European/Native American/Hispanic") (12.5%). With regard to socioeconomic status (SES), three of the participants identified as lower SES

(37.5%), four of the participants identified as middle SES (50%), and one of the participants identified as upper SES (12.5%).

Regarding student status and academic standing, the majority of participants were lowerclassmen. Three of the participants identified as freshmen (37.5%), two of the participants identified as sophomores (25%), one of the participants identified as a junior (12.5%), one of the participants identified as a senior (12.5%), and the final participant identified as a graduate student (12.5%). When asked about number of years as a college student, three of the participants stated that they had less than one full year in college (37.5%), one of the participants indicated that they had been enrolled for two years (12.5%), two of the participants stated that they had attended three years of college (25%), one of the participants endorsed seven years of enrollment (12.5%), and one participant acknowledged having attended eight years of college (12.5%). With regard to participant age at the time of the study, the range was from ages 18-31 with half of participants at age 20 or younger. Three of the participants reported that they lived in on-campus housing (i.e., dorm room, campus apartment) (37.5%) while the majority of participants endorsed living in off-campus housing (i.e., apartment, house, etc.) (62.5%). Related to these living arrangements, two participants stated that they lived alone (25%), one participant reported having a roommate or roommates (12.5%), one participant indicated living with a spouse or partner (12.5%), four participants reported living with parents (50%), three of the participants endorsed living with siblings (37.5%), and one participant acknowledged living with her children (12.5%).

Regarding mental health diagnoses, four of the participants self-identified with major depressive disorder or “depression” (50%), four of the participants identified with

generalized anxiety disorder or “anxiety” (50%), three of the participants identified with bipolar disorder (37.5%), two of the participants identified with posttraumatic stress disorder (25%), two of the participants identified with psychotic disorders (25%), one of the participants identified with panic disorder (12.5%), and one of the participants identified with narcolepsy (12.5%). Several of the participants responded with comorbid mental health diagnoses (i.e., “major depressive disorder and generalized anxiety disorder”). The age of first diagnosis ranged from ages 10 to 23 with one participant who did not respond to the demographic item. Of the respondents, four participants were diagnosed prior to the age of 18 (50%), and three of the participants were diagnosed as young adults (37.5%). Four of the participants indicated that they had been diagnosed by a family doctor or physician (50%), four of the participants endorsed having been diagnosed by a psychiatrist (50%), and five of the participants reported that they were diagnosed by a psychologist or mental health counselor (62.5%). Several respondents indicated that they had been diagnosed by various professionals.

All of the participants indicated that they were engaged in some form of mental health treatment at the time the study was conducted (100%). Four of the participants endorsed involvement in concurrent psychotherapy and medication treatments (50%). One of the participants indicated treatment involving psychotherapy only (12.5%). Three participants reported being treated with medication only (37.5%).

Only one of the participants indicated receiving academic accommodations from the university in regard to his or her mental health diagnosis (12.5%); this participant described the following accommodations: “extended time on tests in a private room.” Seven of the participants indicated that they did not receive academic accommodations

related to their mental health diagnoses (87.5%). Of the seven participants who did not receive academic accommodations, six participants provided explanations for lack of service utilization including the following: “They do not accept anxiety diagnosis;” “I don’t know of any accommodations available;” “Too late in the semester;” “They would not help me;” “I never applied for any;” and “My mental health issues do not affect my school work.” One of the participants did not provide an explanation for why he or she did not receive academic accommodations related to his or her mental health diagnosis.

Questionnaire Responses

All of the participants answered every question on the self-administered questionnaire. In the coding and analysis process, relevant responses were grouped into repeating ideas and, moreover, were evaluated by the investigator in order to uncover themes, trends, and specific examples used to highlight the participants’ experiences and needs. Since all of the questions were open-ended, results should not be interpreted in such a way that would suggest the presence of finite conclusions based on the data. Rather, the results should be examined with the intention of gaining a basic understanding of the theoretical narrative of the participants involved in this research initiative.

Question 1: What are the symptoms you experience as a part of your mental health diagnosis? Seven of the eight participants endorsed symptoms related to sleep problems or fatigue. Examples of such problems included drowsiness, exhaustion, trouble falling or staying asleep, nightmares, and night terrors. One participant acknowledged the experience of nightmares on a nightly basis. Notably, the majority of participants

discussed the presence of depressive symptoms. Included in this category of symptoms were sadness or low mood, apathy, increased or decreased appetite, and the desire to be alone or withdraw from others. One participant endorsed a history of suicidality. Another participant explicitly mentioned the experience of low self-confidence. Moreover, at least half of the participants described symptoms with regard to anxiety. Specific examples included the presence of anxiety in large groups, difficulty performing in front of others, a need for perfection, and panic attacks. Additional related symptoms included a fear of loud noises, lack of trust in other people, and intrusive troubling thoughts. At least three of the participants indicated the presence of mood swings, while another described “temporary anger problems.” Several participants alluded to difficulty concentrating or focusing. With this, symptoms of forgetfulness and organizational problems were described. One participant mentioned difficulty making decisions. Two participants indicated the experience of distracting auditory hallucinations, particularly with regard to hearing voices. Finally, several physical symptoms were listed by participants including the following: headaches, vertigo or dizziness, racing heart/palpitations, chest pain, hot flashes, muscle soreness, sensitivity to light, heart burn, and “intermittent itchy rashes.”

Question 2: In what ways does your mental health diagnosis impact your academic performance? Related to academic problems, the majority of participants described a history of difficulty attending classes. Several reasons were given for this, including the following: depression, apathy, “not feeling well enough” to attend, sleeping through classes, and not wanting to be around others. Three participants acknowledged problems with stress management or feeling overwhelmed related to academic work. Also, two participants explicitly stated that they commonly experienced test anxiety. “I

freak out on tests, and I do poorly because of this,” stated one of the participants. Several participants alluded to difficulty completing schoolwork. Various reasons were provided for problems in completing academic work such as the need for perfection, lack of motivation, lack of confidence in ability, and concentration problems. One participant described problems with delivering presentations or performing in front of others. Also, the same participant indicated difficulty speaking with instructors one on one, when needed. Finally, two of the participants alluded to problems with “absorbing” information related to a lack of sleep and/or concentration problems.

Question 3: In what ways does your mental health diagnosis impact your relationships with others? Several different themes were uncovered related to the impact of mental health diagnoses on social relationships. More than half of the participants described problems with romantic relationships. For instance, one participant stated that symptoms such as forgetfulness and concentration problems annoy her romantic partner. Another stated that he was “dumped by [his] girlfriend” related to his mental health diagnosis. One of the participants wrote, “I have a hard time finding a boyfriend, because I’m afraid it will freak [him] out if I have a bad day.” Also, one participant stated that his mental health diagnosis “confuses loved ones.” An additional theme that was found related to this prompt was difficulty in trusting other people. Specific statements related to this were needing to be careful when telling others about diagnoses, fearing being rejected by others, and avoidance of large groups of people. One participant alluded to difficulty maintaining a lifestyle similar to that of her peers. Other participants stated that people “do not understand,” and there are few people to whom they are comfortable talking. With this, one participant indicated the tendency to “push

people away.” Finally, family problems were specifically endorsed by two of the participants.

Question 4: In what ways does your mental health diagnosis impact your ability to care for yourself? Two of the participants alluded to changes in appetite or problems with eating related to their mental health diagnoses. Specifically, the participants mentioned forgetting to eat. One of the participants stated, “I sometimes get depressed enough that I lose my hunger.” Two participants stated that they are often forgetful in taking prescribed medication. Another theme that was addressed involved problems with tending to regular hygiene and appearance. One of the participants who endorsed this stated that his problems with personal hygiene were caused by drowsiness and apathy. In addition, one participant described difficulty with activities of daily living, such as doing laundry. Other specific issues raised were difficulty with relaxation, problems with sleeping, and increased alcohol use. Finally, two of the participants indicated that their ability to care for themselves was in no way impacted by their mental health diagnoses.

Question 5: In what ways does your mental health diagnosis impact your physical health? The most prominent theme that surfaced related to this question was the idea of easily becoming physically ill. One of the participants described this by saying, “stress lowers my immune system.” Another distinct theme related to a lack of exercise and physical activity. With this, the idea of weight problems was discussed by some of the participants. One participant described weight gain related to medication. Another described poor body image due to weight issues. Also, participants described unhealthy eating habits. This varied from “lack of restraint with food” to making unwholesome food

choices. As with Question 4, it was again mentioned that some participants experienced difficulty with remembering to take medications thus causing unwanted physical consequences. The experience of physical pain was represented as well, specifically with regard to muscle and joint soreness. Other physical experiences included lack of energy, increased alcohol use, and self-inflicted physical harm.

Question 6: In what ways does your mental health diagnosis impact your emotional health? Various themes that related to emotional wellbeing surfaced with this question. First, difficulty in regulating emotions was described. For instance, several participants endorsed increased emotionality as well as the presence of mood swings due to their mental health diagnoses. “My emotions feel like they are on a rollercoaster.” With regard to this theme, problems with stress management were also described. Another theme centered on the tendency to be self-critical. One participant stated that she often becomes angry with herself related to the symptoms of her mental health diagnosis. Two participants stated that they experienced guilt because of their symptoms. Related to this, one participant stated, “If I feel like I failed somebody, I will be depressed for a while.” Another participant wrote, “I am so emotional. It destroys my self-esteem.” The idea of being unsure of one’s self and constantly second-guessing decisions and actions was also described. Also, two participants indicated that they felt helpless and/or worthless most of the time. Yet another prominent theme in reference to this question regarded consistent fear (i.e., “I’m always scared of things I can’t control.”). Also, one participant stated, “There are a lot of times when I’m on my guard where maybe I don’t need to be. I expect the worst in most situations and prepare myself for it.” The idea of general anxiety was also described by several participants. Finally, one response related

to this question stated, “I have little support from peers my own age;” thereby alluding to the impact of isolation on emotional health.

Question 7: Have you been discriminated against because of your mental health diagnosis? If so, in what ways? Half of the participants stated that they had not experienced discrimination in relation to their mental health diagnosis. One of the participants who denied the experience of discrimination went on to say, “I think society is more accepting about mental disorders now.” Based on the responses from the half of participants who endorsed having experienced discrimination, however, the most prominent theme regarded negative reactions from loved ones. One of the participants explained having experienced comments from her partner such as, “I know you couldn’t handle that mentally” or “You forget stuff too much. Can’t you stop?” Another participant wrote, “I find people who claim to be friends talk about you behind your back if you tell them [about your mental health diagnosis], so I tend to tell few people anymore.” Some responses described emotional reactions from others related to the participants’ mental health diagnoses. “My dad would get mad at me, because I couldn’t keep my emotions inside,” wrote a participant. Another participant proposed that “No one wants to date you if you mention you’re mentally ill; even if you say you’ve had therapy and you take medications. So I don’t try.” Also, one of the participants recounted, “I also experience a condition where I pull out my hair...I confided in a friend and a family member, because I wanted help stopping. They sometimes ask me if I still do it and make fun of me.” Two final themes addressed by participants’ responses included physical health problems not being taken seriously by professionals and accusations of manipulation made by others. Specific examples of the latter theme included, “[My dad]

would say that I was crying to get what I wanted” and “I was accused of trying to get drugs to abuse, because I had questions regarding my medications.”

Question 8: Do you currently participate or have you participated in any university services, activities, programs, or treatment related to your mental health diagnosis? If so, please describe and indicate your overall level of satisfaction with these services below. If not, please describe why you are not involved in services.

Three of the participants indicated that they had utilized counseling and/or psychiatry services at the university they were attending. One of the participants described the psychiatry and individual counseling services that she received as excellent. The same participant also indicated that she was involved with group psychotherapy on campus and described it as “good.” Another participant who utilized campus counseling services stated that he was referred to another agency for continued care related to his mental illness following his initial intake assessment. Moreover, one of the participants stated that she was informed by a financial aid counselor that mental health services existed on campus; however, she stated that she was unaware of the counseling center’s location and was unsuccessful in her attempt locate it via an internet search. Another participant stated that she had utilized counseling services at a previous university but had not done so at Wright State University. Four of the participants stated that they utilized services at the disability services office on campus; however, only two reported that they received services in relation to mental health diagnoses (i.e., narcolepsy, depression). Finally, one participant stated that she had not been involved with any mental health or student support services at the university, because she was not aware of existing services.

Question 9: Do you have any suggestions for the development or improvement of services, activities, and/or programs to better serve the needs of university students with mental illness? Participants gave varied responses related to suggestions for the development or improvement of university services for students with mental illness. Three participants stated that they would like increased accessibility to and awareness of services. With this, it was suggested that service providers better advertise their services to the university community. “Make it easier to find out where counseling services are and how to make an appointment.” One of the participants stated that she had no awareness of any existing programs to serve students with mental illness aside from counseling. Two of the participants addressed academic accommodations in their responses to this question. First, one of the participants stated that she was denied accommodations for anxiety and was told that the office of disability services did not provide such accommodations. The second participant who addressed accommodations stated that he desired a program to help students complete schoolwork with extra time. One participant suggested that general support groups for students with mental illness be introduced on university campuses. Finally, one participant stated that she did not have any suggestions or ideas related to this question, because she had not utilized university services aside from academic accommodations for her sleep disorder.

Question 10: Do you feel you have any unmet needs in relation to your mental health diagnosis? If so, please describe below. Participants raised a range of concerns related to their unmet needs. First, one participant stated that she needed more social support (i.e., “Finding people I can relate to and get support from.”). Other participants described problems related to accessibility of mental health services. For

instance, one participant stated that she would like more therapy sessions but reported that the number of sessions is limited by insurance coverage. Another participant stated, “Make it easier to talk to someone when you need to.” Also, a need for mental health services at one’s place of residence was mentioned with regard to accessibility (i.e., case management services). Further, needs related to medication were described. For instance, one participant implied difficulty determining the appropriate dosage of medication. Another participant wrote, “I wish medications were better explained instead of just handing a prescription over.” In addition, one of the participants stated that she was in need of a trustworthy counselor. “All of the psychologists I have seen have told my parents everything, so I stop telling them anything, and I act like life is fine.” Another participant indicated the presence of unmet needs but stated that she has not sought help due to other barriers in her life. Finally, one participant indicated that she did not have any unmet needs related to her mental health diagnosis.

Focus Group Interview Responses

All participants engaged in one of two focus group interviews. The first focus group interview consisted of three participants while the second focus group was comprised of five participants. Participants were asked a series of 10 questions in a semi-structured interview format. The intent of the questions was to provide prompts for dialogue among group members. The investigator often asked follow-up questions and added commentary in order to elicit clarification and to prompt further discussion. The focus group interviews were audio taped, and the investigator took notes throughout to track the conversations.

Following the focus group interviews, the investigator transcribed the focus group dialogues via audio tape recordings. The coding process selected in order to analyze the data was a method outlined by Auerbach and Silverstein (2003). This method utilizes six steps for constructing a theoretical narrative from text derived from focus group interviews: 1) Explicitly stating research concerns and theoretical framework; 2) Selecting the relevant text for further analysis; 3) Recording repeating ideas by grouping together related passages of relevant text; 4) Organizing themes by grouping repeating ideas into coherent categories; 5) Developing theoretical constructs by grouping themes into more abstract concepts consistent with theoretical framework; and 6) Creating a theoretical narrative by telling the participants' story in terms of the theoretical constructs. The data analysis process as applied to this study, conducted solely by the investigator, yielded five overarching theoretical constructs (i.e., The Essence of Mental Illness, Personal Impact, Interpersonal Interactions, Systemic Barriers, and Social Paradigm) which were comprised of 14 distinct themes.

The essence of mental illness. The first theoretical construct that was revealed following data analysis concerned issues related to the general presentation of mental illness. When telling their stories in the focus group interviews, participants were direct and open in discussing their symptoms, history with diagnosis and treatment, as well as the nature of mental illness broadly. Though participants entered the discussions with different diagnoses and backgrounds, there were many commonalities in their experiences.

Background of onset, diagnosis, and treatment/services. This theme involved accounts related to diagnosis and duration of mental health problems, onset of symptoms,

campus services utilized, and services utilized elsewhere. One noteworthy finding was the great range in length of time for which participants had been diagnosed. For instance, one participant stated she had been diagnosed for over 13 years while another indicated a period of only four months. One of the participants went on to describe the onset of his mental illness, which had occurred soon after beginning college in his freshman year: “The first two weeks [were] fine for me. [I] went to a friend’s house; no drugs, of course. Something would twinge in my brain, and I suddenly had schizophrenia. I heard full blown voices, thoughts that weren’t mine. Before that, classes were fine, everything was fine. Then, something went wrong.” In reference to services utilized, four students acknowledged the use of disability services on campus. Two of the participants indicated they accessed disability services and accommodations related to physical disabilities only. One of the participants acknowledged using such services related to an attention-deficit/hyperactivity disorder. The final of the four participants who utilized disability services and academic accommodations did so for a diagnosis of narcolepsy. Further, a few of the participants acknowledged using counseling and/or psychiatry services on campus; however, there were multiple members who had not engaged in these services due to lack of awareness of availability or receipt of services elsewhere. Finally, one participant described having previously dropped out of college due to the seriousness of her mental illness several years ago; she reported that a “Fresh Start” program erased her previous grades upon return after the years she took off from school to recover.

General nature and pattern of symptoms. The next theme unveiled in this study involved issues related to the consistent yet often unpredictable nature of mental illness and its accompanying symptoms. With this, participants discussed ways with which they

have coped and/or remained concerned about their mental health diagnoses. For instance, ways in which participants self-accommodate were discussed. In the discussion, various statements were made such as, “I’ve always dealt with it...I’ve always had it, ever since I can remember...If something’s happening...I know how to deal with it in the situation.” Moreover, one participant described the consistent nature of her mental illness: “It’s not something you can turn on and off. It’s always there with you...I think there are better days than others...but, in general, it’s an ongoing thing.” On the other hand, several participants discussed the symptoms of their mental health disorders as often unpredictable. “You don’t even know when it’s going to happen, how it’s going to happen, what it’s going to affect, and what [it’s] not.” Additionally, a lack of control related to symptoms was discussed. For instance, when speaking of her auditory hallucinations, one participant noted, “You don’t want to do what they say, but it’s really hard. When a voice says something...you can’t not do what it says.” Another participant described symptoms of her mood disorder: “It’s like uncontrollable crying. It’s like you should stop crying, there’s nothing to be sad about, and you’re still crying. It’s stupid.”

Personal impact. The second theoretical construct yielded from this study concerned the various ways in which participants were personally affected by the specific symptoms of their mental health diagnoses. It appeared important for participants to convey the experience of everyday barriers and impact of symptoms related to functioning in various areas of their lives.

Common everyday fears. This theme captured a variety of commonalities regarding the burdening presence of fear in everyday life for individuals with mental illness. For instance, an intense fear of failure was described. “When you have mental

illnesses, you're afraid of falling back into how it was before." Also, participants described the tendency to relentlessly second-guess oneself (i.e., "Am I doing this right? Am I doing this okay?"). For some participants, safety concerns were at the forefront of their daily experiences. "I'm always checking the exit. I keep something close to me that I can use as a weapon." A final idea discussed was the fear of losing control, particularly related to symptoms of mental health diagnoses. "It was a fear that I'd wake up one morning and not be able to function and start hallucinating and not know what to do...I have no warning of it." In general, these fears were described as interferences in ability to function in daily activities of functioning.

Social barriers, isolation, and loneliness. Some participants described symptoms of their mental health diagnoses in relation to social concerns. For instance, one participant stated, "I just can't be in crowds anymore." As a result of social barriers, some participants described the occurrence of isolation and resulting feelings of loneliness. One participant even discussed feelings of alienation even when in the presence of others: "You feel lonely, even though the other person's in the room." Another stated that she does not "really have a social life" due to the symptoms of her mental health disorder.

Medication, side effects, and physical health. Several of the participants involved in this study described problems related to medication, side effects of treatment, and issues with their physical health. Some participants discussed personal attitudes related to taking medication (i.e., "Having to take medication to function is really not good."). Others described side effects of medications and other treatment (i.e., psychotherapy) as a barrier to their success. For example, with regard to trying new medications, one participant admitted, "I have to plan to miss school, because I know I'm going to have

side effects.” Another described her experience with medications: “The side effects of medications are absolutely the worst. And then, when one doesn’t work, you have to switch to something different. I think the scary part about medication [is] that in the first few weeks, months, whatever, you don’t even know what you’re going to do...It’s like you can’t trust yourself.” Further, participants shared their experiences regarding the impact of mental illness on physical health (i.e., “Our immune systems are crap!”).

Barriers to academic and occupational success. There were many repeating ideas captured by the theme related to barriers to academic and occupational success. First, several members recounted ways in which their symptoms have directly impacted their academic performance. An example of this was the collective difficulty among participants in meeting course attendance requirements. One of the participants recalled a time when she was emotionally activated for hours by a sad song on the radio: “I just sat there, and missed two classes, because I couldn’t stop crying.” Another participant stated, “I wouldn’t know what day of the week it was. ‘I have class today? Really?’” when describing her personal barriers of classroom attendance. A suggestion made by one participant to ameliorate the attendance problem was, “Don’t have a set limit on how many classes you can miss. Let us talk to you about it, based on our situations.” One student described his difficulty with completing academic work: “I take meds to get rid of voices, but it’s still a little stressful when you can’t focus and you have work to do...even if you have a completely dark room, and the computer’s off...and you’re just sitting there with a piece of paper in front of you...It was basically having something constantly yelling at me in my head, which it’s kind of hard to focus with.” Several students described a “balancing act” that made managing symptoms of mental health diagnoses

challenging. Multiple students indicated that balancing demands from school and home increased psychological distress. Some of the participants involved in the study discussed issues related to giving up, leaving, or quitting academic or occupational endeavors. One participant recalled the first time she had attempted college: “I failed. I did so badly, and so I dropped out.” Another participant recalled a time when she experienced significant problems at a work setting that she eventually chose to leave: “I would get complaints from my supervisor saying that ‘They’re saying to me that they feel like you just don’t care and that you don’t want to be there.’” This particular participant went on to describe symptoms such as moodiness which contributed to others’ negative perceptions of her as well as to her legitimate difficulty in completing the necessary tasks at the job.

Interpersonal interactions. A third theoretical construct, related to interpersonal issues, elicited apparent emotion from participants. Here, individuals described their personal experiences with harmful statements from others related to their identification with or presentation of mental illness. Conversely, participants also discussed ways in which they have received empathy from others, particularly those who understand based on their own identification with mental illness.

Negative or unwanted reactions from others. The participants involved in this study described many different negative reactions that they have experienced from others in relation to their mental health diagnoses. For instance, some participants described overreactions or overprotection from family members or friends. One participant stated that her mother had once overheard her telling her psychologist that she was hearing voices. The participant recalled her mother’s reaction: “WHAT?! You’re hearing voices?! We have to get you to a hospital immediately!” She explained that her mother’s

reaction had been stressful for her because she felt misunderstood. Another idea captured within the context of this theme was that others without mental illness do not understand the experience. One participant stated, “I’ve lost friends, because people just don’t get it who don’t have disabilities.” Related to this, participants acknowledged that others, even loved ones, do not know how to help and cannot “handle” mental illness. One participant acknowledged, “I just won’t even go to people [for help] sometimes, because I know they’re going to throw advice at me.” Another participant, when discussing her interactions with others, stated that “They just don’t know how to deal with me.” Moreover, some of the participants recounted feeling judged or rejected by others. When talking about a recent romantic relationship, for example, one participant stated, “In a single text, she dumped me; saying that she didn’t understand [my mental illness].”

Questioning credibility or seriousness of mental illness. This theme encapsulated various assumptions or attitudes from others related to judgments about the participants’ mental health diagnoses. In this category, minimization or denial from others was discussed. Examples of this were, “Oh, [your mental health problems are] temporary. You’ll get over it” and “Oh, you can deal with it. You’re fine. It’s just a little depression.” Also discussed within this theme was others’ attitudes toward treatment. One of the participants explained that she had been reluctant to tell her mother that she was involved with psychiatric treatment due to her mother’s personal beliefs about mental health treatment. She stated that her mother would say things like, “Oh, I don’t think you need it” when the topic of treatment was discussed. Another issue that was important for participants was accusations of manipulation made by others. For instance, a few of the participants had heard phrases like, “Oh, you’re just doing this to get

attention.” Another participant recalled how she had been accused of manipulating a mental health agency in order to abuse medications. Finally, participants discussed the idea of being ignored related to their mental health concerns. One participant recalled painful experiences with her father’s reactions to her symptoms: “...and I was crying, and he just ignored me. He just walked by.”

Empathy and positive social experiences. Participants recalled several ways in which they have interacted positively with others in relation to their experiences with mental illness. Within the context of this theme, participants described the benefits of social support and recounted instances in which friends and loved ones had made a constructive impact on their mental health. “I would lose the ability to walk, and they would help me out,” recalled one of the participants. One participant recalled ways in which a referral to mental health services had made a significant difference in her life: “I’d always thought [my mental illness] was a part of me...finally, a university personnel was like, ‘Have you ever thought about going to see a psychiatrist?’” Some participants also described the power of humor when addressing mental illness in interpersonal relationships. One participant recalled a comical nickname that he was given by his friends due to his mental illness; he stated the nickname made him feel accepted by his peer group. Additionally, participants described the importance of normalizing experiences in which they realized they were “not alone.” For instance, the idea of learning about the prevalence of mental illness was described as beneficial. Also, participants stated that meeting others who identify with mental illness has had a positive influence on their own mental health. Finally, participants discussed the positive impact of receiving empathy and comfort from others with mental illness. One participant

described this in detail, acknowledging “I would rather talk to a bunch of people who have mental disorders than a counselor.”

Systemic barriers. The fourth overarching theoretical construct revealed in this study was concerned with problems within the mental health profession as well as with general institutional structures that made adequate service utilization problematic for the participants. The concept identified under this construct dissects systemic concerns from the vantage point of the individuals who engage in various mental health services. It is noteworthy that some of the concerns addressed by the participants were broader than the university level and suggested the presence of problems within the mental health field on the whole.

Barriers to mental health treatment and service utilization. Participants discussed their concerns about university students’ accessibility to mental health and student support services. A major topic of discussion within this context involved participants’ general lack of knowledge of existing mental health services on campus. Related to this, one of the participants stated, “I don’t feel like I have access to anything.” Some of the participants mentioned that, even when they had known services existed, they were unsure as to where appropriate offices were located or procedural concerns regarding access. Next, several of the participants alluded to financial concerns throughout the focus group interviews. Though many of these comments did not directly pertain to ability to access services, the topic of economic concerns was raised enough times throughout discussion to be considered a repeating idea in its own right. With this, many participants acknowledged that university students experience difficulty in managing their finances in order to pay for day to day needs let alone additional costs of

mental health services. Moreover, students discussed a general lack of personal resources, whether financial or otherwise, as interfering with ability to access services. One of the participants illuminated this point by purporting, “I feel like due to a lack of transportation or resources, some people may just forgo seeing a psychiatrist.”

Problems within the mental health profession. Several of the participants had complaints with regard to the mental health profession at large. One of the topics of concern related to problems with getting diagnosed. One of the participants appeared to feel very strongly about this topic and suggested that mental health agencies “really let people down [because of] the pain and the struggle that [individuals with mental health problems] have to go through in order to even get diagnosed with something...places don’t even take it seriously until you’ve been officially diagnosed with something.” The participant went on to describe that the process of getting an accurate diagnosis can take extended periods of time and often makes it difficult to get the help or treatment that is needed in the meantime.

A second concern within the context of this theme was in regard to communication problems within mental health systems. A participant who had been involved with several different mental health agencies throughout her life suggested that various institutions (i.e., mental health agencies, legal system, educational institutions) increase communication with one another. She expressed frustration that individuals with mental illness may be “lost between the cracks” if various services and organizations are not adequately communicating with one another.

Further, many of the participants in this study addressed a lack of empathy or personal experiences with mental illness by mental health service providers and researchers. Participants recounted experiences where they felt as though their mental health providers were judging them, lacked emotional attunement, did not care about them, or were generally uninformed about and inexperienced with mental illness. Several members suggested that therapists or other professionals should know what it is like to be in the seat of the client. One participant asked, “How are you going to be a therapist if you’ve never been to therapy yourself?” With regard to mental health research, comments were made suggesting that much of the research that is conducted within the field of psychology does not address the real life concerns of the populations being studied. “If you don’t go through something and then you try to study it...you might have an interest... [but] at least talk to somebody with a mental illness who’s gone through it...Stuff you get off the internet is really not valid or helpful. You don’t really know what it’s going to do...Even if...you’re trying to learn Chinese and you’ve never been to China, you don’t go on the internet and look up a bunch of stuff about China and then it’s like you went to China...It’s like, talk to a Chinese person!” Another participant stated, “I find that a lot of people who study mental illness don’t have a mental illness. And that’s not the problem; but it’s hard for you to connect with somebody when you don’t really know what they’re going through.”

Social paradigm. The final theoretical construct derived from this study described the effects of societal attitudes and assumptions about mental illness and disability on those who are impacted by mental health problems on a daily basis. The participants in this study described their own attitudes and identity as related to mental

health and disability but also discussed the impact that the beliefs of others have had on their own experiences and self-identities.

Stigma of and discrimination against mental illness. The participants described various experiences and attitudes related to the stigma of mental illness and disability. One of the topics discussed involved broad discussions of stigma and the idea of labeling. “The world’s always trying to attach a label or a stigma or a name to something like ‘disability,’” said one of the participants. The course of the interviews also led participants to consider the idea that certain labels within the context of mental illness have more stigma than others. For instance, one of the participants discussed her fear of her bipolar disorder diagnosis being discovered at some point in time throughout her career in education. Specifically, she feared that she would not be hired due to negative assumptions about the disorder based on stereotypes. In addition, participants engaged in discussion that suggested that labels tend to follow an individual once he or she has been diagnosed or has utilized mental health services: “Once you have a diagnosis, it’s there. They can’t just take it off your chart. I’ve been hospitalized, but am I going to kill myself? No. Was I going to kill myself then? No. But whoa, we can’t give her life insurance because she might kill herself. Or she’s depressed so she might die earlier, because she’s putting stress on her body. I just think that’s really sad.” The idea of stigma related to a history of mental health treatment was discussed in greater detail. One of the participants stated that she feared applying to graduate school due to her mental health history, believing that others may see her as inconsistent or incapable of managing the workload.

In a powerful statement, one of the participants described her dissatisfaction with harmful assumptions about mental illness as applied to the context of the focus group: “I want the negative stigma to be erased, because I’m sitting here with a bunch of intelligent, nice people who don’t look like they’re going to kill me. So it seems weird that people think that all these people...in these hospitals and in these places are...out to kill you and they all hear voices...It’s just so negative, and I don’t like it, because these people are real people...It’s just a characteristic or a disability. And [the stigma is] really, really, really, really frustrating.”

Some of the participants indicated the belief that they had been discriminated against at one point or another in their lives due to their mental health status. For instance, one participant told the focus group that she had been denied life insurance due to a previous hospitalization related to panic attacks. “It felt like a lot of discrimination, because you could have certain other diseases, but you couldn’t have psychiatric diseases, history, and hospitalizations to get life insurance...This really hurts my future plans.” Another participant recalled being turned away from academic accommodations for an anxiety disorder. Also, denial of appropriate medical care related to physical health problems was discussed. One participant recalled that it had taken a long time to get the proper testing and care she needed for a heart condition because health professionals had minimized her problems due to her mental health diagnostic label.

Finally, when analyzing the data, the investigator noticed the casual use of stigmatizing language among participants at points during the interviews. This was noteworthy as some of the participants used phrases such as “that’s really crazy” or “that drives me insane” when describing difficult or frustrating topics.

Attitudes toward and experiences with disability. When participants were asked about the concept of disability as related to mental illness during the focus group interviews, several general attitudes toward disability were reflected. Many of the participants appeared to initially reject the disability label on the basis of societal assumptions related to disability; however, it was notable that many of these same participants also felt an identification with disability based on impairment caused by their psychiatric symptoms. For instance, one participant stated, “I don’t want to view [my mental health diagnosis] as a disability. I’ve learned how to deal with it for as long as I know,” despite also alluding to impairment in functioning in various areas of her life. Another explained, “I think it is a disability...[but] I wouldn’t want to think of it as a disability, because ‘disability’ is such a negative word...I’ve heard it used my whole life not just because of my mental health but because of my physical challenges...I don’t really like to attach the word disability to it, but that’s what the rest of the world considers it, so I guess it is. I like to consider it more of a characteristic.” Other participants made a point to say that someone with mental illness can still live a lifestyle typical of someone without mental illness. Other issues that arose related to this topic were attitudes about severity impairment needed to warrant disability status and abusing disability status and making “a bad reputation for people who actually have it.”

Throughout the focus group interviews, participants questioned and discussed the legitimacy of psychiatric disabilities in contrast with other types of disabilities. Some of the participants implied that psychiatric disability is not often considered “on the same level” or taken “as seriously” as other types of disabilities, despite their beliefs that it should be. For instance, one participant emphasized, “[The disability services office does

not] accept people with anxiety or depression. They don't. Which I think is just as bad as people with ADHD or anything like that. I think it's very prejudiced in a way. I don't want to say it like that, but it's kind of like they don't see it as that bad of a problem."

One of the participants recalled a time when she had worked in a disability services agency. She indicated that, despite the agency servicing a disabled population, she feared discussing the impairments of her own mental health disorder with her supervisor as she assumed they would not understand or would not make efforts to accommodate her impairment. She and others explained that they felt as though their mental illness would not have been recognized or taken seriously because "it's not as obvious" and is a hidden disability. "I would kind of compare it to having migraines or something like that. It's constant, all day long, and even though it's unseen, it's still there and impairs your functionality."

When participants were asked by the investigator as to whether they considered their own mental health diagnoses to be disabling, the general response was that they, indeed, did. One of the participants described feeling frozen by the symptoms of her mental health diagnosis, indicating that she "can't move" when she experiences them. Another participant recalled being unable to perform at the expected level in her original major due to the presentation of her symptoms. Moreover, one of the participants described a period in her life when she needed to drop out of college due to the severe nature of her disorder: "There was a time...shortly after I was diagnosed with posttraumatic stress disorder and it was really, really bad...I was in the hospital. I could not function at all. I was suicidal...there was nothing left in my being...That went on maybe two or three years before I had successful therapy for that. And, during that time, I

would consider myself disabled, because there was just no functioning.” A few of the participants expressed feeling as though mental illness impacts “everything you do” and acknowledged that it is extremely difficult, if not impossible at times, to carry out everyday tasks.

Also within the context of this theme, the idea of Ableism was touched upon. Some of the participants discussed the experience of others having high expectations for them based upon what others were able to accomplish or what they themselves had accomplished prior to the emergence of their mental illness. For instance, one of the participants discussed pressure from his mother: “She is very much a doer, and I was perfectly up with that...[but] she’s going off what I was able to do before [my mental illness] popped up...She pushes me...[and] most of the time it just makes me feel like I can’t be right. I can’t do things correctly.” Another participant explained this principle of Ableism in a simple statement: “The attitude is that everyone has perfect health” and can engage in the same expected activities.

Silence and internalized oppression. During the course of the focus group interviews, the idea of silence related to issues of mental illness was heavily discussed. Many participants expressed the feeling that most people have a tendency to “tiptoe” around the topic of mental illness. Because of this, the participants discussed the need for the silence to be broken. Multiple members stated that they would prefer for others to ask questions or talk to them directly about their mental illness rather than making assumptions or talking behind their backs. One of the participants even indicated that his friends joking with him by using a potentially pejorative nickname to describe his mental illness was preferred to the avoidance of talking about his condition. Further, it was

mentioned that individuals with mental illness do not tend to disclose their mental health status to others. Related to the process of the focus group interviews, where multiple individuals who identified with mental illness came together to share ideas, one of the participants said the following: “Just talking makes me feel like I’m not hiding something. I feel so much better, because you go day in and day out and you feel this way, but you don’t talk to anybody about it. You just kind of push it to the back of your head and think (pause). You deal with it. You don’t really get a chance to talk about it, which is like, what, once in a blue moon?” Some of the participants even indicated that they had not known what they would say at the outset of the focus group interview because of their previous experiences with the silence. However, by the end of one of the interviews, one participant projected, “I think we could probably go on [talking about the topic of mental illness] for hours.”

Several of the participants in this study alluded to maintaining silence for fear of stigma. For example, one of the participants stated that she was afraid of searching for a new romantic partner: “I don’t want to go out to find a different person, because I don’t want to sit there and explain everything and him...think, ‘Oh my God; she’s crazy. She’s going to kill me one day.’” Another participant described her hesitancy in talking to her professors about her mental health diagnosis for fear of their reactions: “I wasn’t in class the other day because I just wasn’t. I don’t dare tell [professors] I was crying in my car for hours because there was a song on the radio. They’d be like, ‘Oh, you’re crazy.’ So...I don’t say anything to them aside from I wasn’t feeling well.” Yet another participant reported, “I find that if I tell people, they start freaking out and wondering if I’m going to go psychotic right that second. And so I don’t tell.” One of the students even

stated that, though she considered her mental illness to be disabling, she had not sought disability services because of the fear of stigma.

Another idea related to silence and internalize oppression that was discussed was that participants felt the need to “hide” their mental illness, thereby resulting in the feeling of living two lives. One of the participants described this in detail: “I know that just from me having [mental illness] for so long that I have become really good at putting a fake mask on. And I feel like I’m never myself because I always have a fake mask on to be that happy-everybody-likes girl. And I’m really not. I’m the complete opposite actually. I’m [a]...hide-in-a-hole type person, but I’m really good at putting off that really happy...preppy nice person thing that I’m not really. I’m more of a like gothic emo person.” She went on to say that the “mask” serves as a means to cope so others do not think of her as a “weird person.” This phenomenon was also described as similar to having two separate personalities. Another participant indicated that she hides her diagnosis from others because it “scares a lot of people.” A few of the participants alluded to viewing their mental health diagnoses as embarrassing or shameful. Finally, revealing one’s mental illness was discussed as a “coming out” process. One of the participants suggested that “there should be more support groups for students who have mental illness, because a lot of people are hiding their diagnoses from other people...I think that if they had [support groups] in place, [individuals with mental illness] would be more comfortable in coming out.”

Some of the topics of discussion in the focus group interviews also led to projections about awareness and acceptance of mental illness. For instance, one participant explained, “I don’t think [mental health stigma is] as bad as it

[was]...probably a couple years ago, because more and more people have [mental illness]. It's more...accepted. That's really not the right word...It's understood more.”

Others implied a general lack of awareness in society and suggested mental health awareness days to promote a societal shift in understanding.

CHAPTER 5

Discussion

Demographics

The participants involved in this study were predominantly Caucasian females with the exception of one male participant who identified as Multiracial. This finding was consistent with existing literature that suggested that women tend to disclose mental illness and seek mental health services more so than men (Rhodes, Goering, To, & Williams, 2002; Rhodes & Goering, 1994). Further, the presence of a predominantly Caucasian sample may support previous research findings that individuals from minority ethnic and racial groups are less likely to disclose mental illness or utilize treatment and support services (Broman, 2012; Ojeda & McGuire, 2006; Garland et al., 2005). There was somewhat more diversity in the sample with regard to socioeconomic status (SES), with the largest portion of participants identifying as middle SES and the second largest in the lower SES bracket. Findings with regard to SES may have been somewhat representative of the student body population at Wright State University (Wright State University, 2011).

Most of the participants in this study were lowerclassmen with the exception of two upperclassmen and a graduate student. Despite the fact that the median number of years spent in college was about 2.5 years, at least three of the participants endorsed

attending college for more years than would typically be expected given their student status. For instance, an individual who identified as a senior endorsed having attended seven years of college. Though the reason for the disparity was not explored directly, the finding may be suggestive of some academic struggles for such individuals. For example, some of the participants later discussed the need to transfer schools or take time away from college due to the severity of their mental health problems. This may coincide with previous literature that suggests that students with mental illness who are affected by negative thoughts and feelings regarding autonomy, competence, and relatedness to their environments are more likely to have difficulty succeeding in school (Brockelman, 2009). In regard to age, the sample was relatively young with half of the participants age 20 or younger. Though it is not possible to make a clear projection as to why this may have occurred, it is possible that older students with serious mental illness were less likely to become involved in the study due to significant academic struggles or potential issues with retention. This potentially supports previous research findings that those who do not integrate well academically or socially are likely to leave the university setting (Megivern, Pellerito, & Mowbray, 2003).

Three of the participants, two freshmen and one senior, indicated that they lived in on-campus housing arrangements; the remaining participants lived off-campus. The majority of participants endorsed living in the company of at least one other person, giving the indication of some degree of social support. Of the participants who disclosed that they lived with at least one other person, the majority stated that they lived with a parent or parents. Since Wright State University is often considered a commuter university, this finding may be representative of the student body population (Wright

State University, 2011). On the other hand, it may also suggest the possibility that some of the participants were somewhat dependent on parents for support and/or may have had parents who were unwilling to allow the participants to establish independence. This may be important to consider further as literature indicates that students with mental illness who perceive themselves as having independence, personal agency, and individual responsibility tend to make stronger academic achievements (Brockelman, 2009). It was noteworthy that only two of the eight participants acknowledged living alone.

With regard to diagnostic identification, the most commonly represented diagnoses in the sample of participants were major depressive disorder or “depression” and generalized anxiety disorder or “anxiety.” This finding is consistent with university counseling center data suggesting that the majority of individuals seeking services in university counseling centers present with problems centered on depressive symptoms and/or general anxiety (Mistler et al., 2012). It is also important to note that most of the participants had been given comorbid mental health diagnoses. This finding corresponds with literature that suggests the complexity and severity of mental illness and symptom presentation for university students with mental illness is increasing (Hunt & Eisenberg, 2010; Barr et al., 2011; Mistler et al., 2012).

The age of first diagnosis ranged greatly among participants, with the youngest age of diagnosis being 10 and the oldest age 23. About half of the participants indicated that they had been diagnosed as a child or adolescent. Such a finding suggested that many individuals with mental illness entered university life with preexisting knowledge of their diagnoses and had been already seeking treatment for their conditions. Previous experience with diagnosis and help-seeking may have increased the likelihood that these

particular individuals would engage in the present study. On the other hand, three of the participants indicated being diagnosed as young adults. For these individuals, consistent with research findings that suggest mental health problems often emerge after the age of 18, it is very possible that their mental health problems had not surfaced until entering college or that these students did not have access to mental health treatment prior to that time (Becker, Martin, Wajeeh, Ward, & Shern, 2002; Collins & Mowbray, 2005; Eisenberg, Golberstein, & Gollust, 2007; Kiyuhara & Huefner, 2008). For example, it is possible that parent attitudes toward mental illness and mental health treatment could have been a barrier to treatment access for some students. Regardless of age of first diagnosis, however, it was noteworthy that several participants had been diagnosed by more than one mental health provider. This suggested that participants had been involved with multiple types of treatment and/or in multiple treatment settings.

It was remarkable that all of the participants were engaged in some form of mental health treatment at the time of the study. This finding differed significantly from a previous research study that found less than 40% of respondents with mental illness to have received regular treatment or accommodations in the previous year (Phelan & Basow, 2007). The results from the present study suggested that this particular sample was somewhat experienced with regard to mental health treatment and, likely, had begun to develop their own identities as related to mental illness. With regard to academic accommodations, on the other hand, only one participant acknowledged receiving services from the disability services office on campus for a mental health diagnosis. Some of the participants stated that they had been unsure that disability services existed for their diagnoses or alluded to problems receiving such accommodations. This finding

was consistent with previous literature that suggested that individuals with mental illness often make assumptions that resources to accommodate impairments are only available to people with non-psychiatric disabilities (Phelan & Basow, 2007).

Questionnaire

The ten open-ended items on the self-administered questionnaire were designed with the intent of learning about various areas of the experiences and functioning of participants. First, participants were asked to describe the symptoms of their mental illness. Participants listed a wide range of symptoms from low mood and sadness to various physical concerns. Many of the symptoms described appeared to cause distraction or difficulty concentrating for the participants. Further, nearly all of the participants endorsed problems related to sleep or fatigue. Thus, it appeared that problematic sleep patterns could be a potential barrier for these students regardless of the diagnostic classification of their mental illness. Moreover, students discussed the negative impact of symptoms on academic performance. Some of the most prominent concerns with regard to this were problems with attending classes, experiencing test anxiety, and difficulty completing schoolwork. Such complaints were generally consistent with previous literature related to barriers to academic success for students with mental illness (Collins & Mowbray, 2005; Megivern, Pellerito & Mowbray, 2003; Mowbray & Megivern, 1999).

All of the participants discussed problems with interpersonal relationships related to their mental health diagnoses. The majority of participants discussed the experience of difficulty in romantic relationships for various reasons (i.e., symptoms annoy or confuse

loved ones). In addition, participants noted that trusting others was a significant barrier to maintaining positive relationships. It appeared that, at least in part, the trust issues were based on negative previous experiences of rejection and fear of stigma related to their diagnoses. This finding confirmed previous literature that suggested that university students with mental illness often experience difficult social relationships due to fears of being stigmatized by others (Collins & Mowbray, 2005).

The participants' mental health diagnoses also appeared to affect areas such as self-care and physical health. Several participants openly discussed deficits related to activities of daily living that impacted other facets of living such as academic performance, relationships, and physical health. With regard to health concerns, some of the participants noted that their immune systems were compromised due to stress. Thus, it is important to consider that the scope of mental illness is not limited to psychological concerns; often individuals with mental illness are impacted by physical pain and malaise as well. Further, the emotional impact of mental illness was described by participants. It appeared that not only was emotion regulation difficult for participants, but the impact of enduring such affective experiences led several participants to become disappointed, angry, or embarrassed with themselves. Frustration with oneself concerning the presence of symptoms is likely, at least in part, perpetuated by forces of internalized oppression related to mental health status and the belief that one should be able to control his or her mental illness (Corrigan, River, Lundin, et al., 2000).

When asked about previous experiences of discrimination by others based on mental health diagnoses, about half of the participants denied any such experiences. Many of these individuals indicated that they had not told others about their mental health

problems and, therefore, had not been discriminated against. Some of the participants, however, felt as though others made inaccurate assumptions about the nature of their mental illness, which coincided with existing literature that indicated that discriminatory experience continue to be based upon pervasive societal attitudes that negatively differentiate and stereotype people with disabilities (Leigh, Powers, Vash, & Nettles, 2004; Onken & Slaten, 2000). Other participants described the occurrence of social distancing from others based on knowledge of their mental illness. Additionally, the participants described experiences in which they had not been taken seriously or had been accused of manipulation by others. Experiences such as those described likely contribute to silence among this group in an effort to avoid painful intolerance of their mental illness from others.

Regarding university services designed to support students with mental illness, the most prominently utilized service was campus counseling and/or psychiatry services. Nonetheless, students who utilized university counseling and psychiatric services were among the minority of participants as most participants attended mental health services elsewhere. Though some participants appeared to be satisfied by the mental health services they received at the university, others complained about limited access to such services. These findings were consistent with literature that describes counseling and psychiatry services as central in assisting students with mental illness despite the limitations of such services (Cook, 2007). Additionally, only one of the participants in the sample received academic accommodations related to her mental health diagnosis. Several students indicated a lack of accessibility to or knowledge of such services. Thus, despite impairments in functioning described in other parts of the questionnaire, the

majority of participants were not receiving accommodations to decrease barriers to their academic success.

Participants recommended that accessibility and awareness of student support services available on campus be increased. Also, one participant suggested the introduction of mental illness support groups on university campuses so that students with mental illness can come together to make connections with regard to their experiences. It appeared that this suggestion was made in an effort to decrease isolation and increase normalization experiences for students. Participants described several unmet needs including social support, appropriate mental health services, and successful medication treatment. Thus, service providers and mental health researchers should be attentive to such issues when looking to improve the experience of this population.

Focus Group Interviews

The focus group interviews were guided by questions and prompts supplied and moderated by the investigator. As such, the focus groups were not only used as a methodology but also as a means to help frame themes and issues for later use (Montoya & Kent, 2011). Participants in the study were prompted with open-ended questions to unveil important themes (i.e., “If you had an opportunity to give advice to university administrators and mental health researchers regarding the experience of university students with mental illness, what advice would you give?”). Analysis of the transcripts of the focus group interviews yielded five theoretical constructs that helped to tell the narrative of the participants involved.

The participants were very open in telling their stories throughout the focus group interviews. Overall, the general experience of mental illness was described as consistent yet unpredictable. In other words, it was suggested that someone with mental illness carries it with him or her in all that he or she does; however, the presentation of symptoms tends to wax and wane in various contexts. While some of the participants were able to identify specific triggers for their symptoms, several others described a lack of warning in the emergence of symptoms. Also, issues related to impairment and the lack of control over mental illness were addressed. Overall, the general discussion about the presentation of mental illness uncovered the sense of distress experiences by those who endure it.

Focus group interviews also yielded information with regard to the personal impact of mental illness. Notably, many of the participants revealed consistent feelings of fear due to their mental illness that caused them to be consistently cautious in their daily experiences. Along with this, the participants in the study alluded to common feelings of isolation and loneliness. Since many of the participants had difficulty trusting others, a tendency to withdraw from social supports was acknowledged. Also, some of the participants described feeling alienated from those without mental illness, a phenomenon that has been previously described in the literature (Johnstone, 2007).

A few of the participants described negative consequences or side effects of taking medication or attending psychotherapy that affected other areas of their lives (i.e., academics). Some of the participants indicated the need to “plan ahead” for the side effects in their treatment; for example, taking time away from school if they were trying a new medication or were exploring a difficult topic in psychotherapy. Mental health

researchers have addressed this finding, describing side effects of medications as a barrier to academic success for this population (Becker, Martin, Wajeeh, Ward, & Shern, 2002; Megivern, Pellerito, & Mowbray, 2003). Related to this, participants in the study described several academic struggles that were consistent with various other themes in preexisting literature on the topic. For instance, the participants confirmed problems with attending classes, difficulty completing academic work, and concentration problems in the classroom as typical struggles for university students with mental illness.

Regarding unwanted reactions in discussing their mental illness with others, the participants described various themes including the following: overreaction, overprotection, inability to “handle” knowledge of mental illness, lack of ability to help or lend support, negative judgment, and rejection. Also, participants described ways in which their mental health diagnoses had been deemed illegitimate by others. This experience correlated with previous research findings which suggest that the impairments caused by mental illness are not perceived as reasonable by large segments of society and that those with mental illness are often viewed as malingerers or whiners (Corrigan, River, Lundin, et al., 2000).

In contrast with negative experiences from others, participants discussed positive experiences of disclosing their mental illness. The benefits of receiving empathy from others who have also experienced mental illness or disability were described. In addition, participants explained the power of using humor at times when others who do not have mental illness attempt to relate to their experiences. Overall, it appeared very important to the participants of the study to be able to openly discuss their mental illness in a context in which they felt safe and accepted.

Similar to themes revealed in the questionnaire responses, participants complained of problems within university systems related to availability and accessibility of services throughout the focus group interviews. For instance, some of the participants were concerned that services to meet their needs (i.e., disability services, support groups) were not available to them. Others stated that even when specific services or programs are available, such as counseling services, there may be barriers to access such as lack of knowledge or resources (i.e., financial, transportation, etc.). The participants also addressed problems within the broad context of the mental health profession including difficulty getting diagnosed, communication problems among various agencies and systems, biases in mental health research, and a general lack of empathy among service providers.

Another major concept discussed in the focus group interviews centered on the impact of stigmatized views of mental illness in society. For instance, some participants recalled feeling discriminated against due to their mental health diagnoses and/or histories. Examples of discrimination included denial of life insurance and rejection of appropriate health care services. Some of the participants expressed concerns about applying for graduate school or jobs for fear of stigma and/or discrimination. This fear appeared to be consistent with an existing research finding that indicated negative perceptions of a student's competence often accompany knowledge of the student's mental health history (Brockelman, Chadsey, & Loeb, 2006). In addition, the participants in the present study discussed assumptions and stereotyping in society based on labels. For instance, it was discussed that those with mental illness are often seen as incapable or inconsistent, traits that are often cited in the literature in reference to

stereotyping (Eisenberg, Downs, Golberstein, & Zivin, 2009; Wood & Wahl, 2006).

Though participants seemed to be very frustrated and hurt by existing stigma, they did not appear to know the best ways in which to navigate it. Because of this, the participants discussed the silence of mental illness. Some of the participants reported feeling as though they were living two lives due to hiding their mental illness from others for fear of stigma and negative reactions. This phenomenon can be related to previous literature that describes mental illness as invisible and unaccepted by the general public, leaving numerous affected individuals living in silence to avoid painful stigma (Cook, 2000).

The participants in the present study discussed mental illness within the context of disability. There appeared to be some reluctance among participants in identification with disability despite the fact that most, if not all, of the participants recognized various ways in which they were impaired by the symptoms of their mental disorders. The rejection of the disability label may, at least in part, relate to a lack of inclusion of psychiatric disabilities within the greater disability community (Leigh, Powers, Vash, & Nettles, 2004). Also, the aversive reaction may be suggestive of negative attitudes toward disability (Onken & Slaten, 2000). Nonetheless, participants expressed the belief that psychiatric disabilities were not taken seriously in comparison to other types of disabilities. Thus, many of the participants displayed a somewhat pessimistic view in embracing a disability label.

It was stated by several participants that, throughout the course of the focus group interviews, connecting with one another in regard to their experiences with mental illness was relieving and empowering. The participants suggested that meeting with other

individuals who self-identify with mental illness allowed them to feel both supported and understood in a world in which they often feel neither. Such a phenomenon supports the work of disability activists that has suggested that by progressing through the states of disability identity formation, one's emergence into the disability (i.e., mental illness) culture occurs, providing him or her with a sense of unity and connection to others (Onken & Slaten). Thus, it was recommended by participants that university administrators and organizations consider the implementation of mental illness support groups for students to address relevant topics with the intent of increasing social support. Also, the benefit of engaging in plans for action and social justice initiatives in campus communities was mentioned.

Conclusion and Implications

Research related to the experiences of individuals with mental illness, particularly the university student population, has largely been conducted via quantitative studies. Therefore, this study contributed to the literature by enhancing an understanding of the unique perspectives of members of this population via a qualitative Participatory Action Research (PAR) approach. Despite its unique methodology, the results from this study upheld previous research findings that suggested that university students with mental illness often experience symptoms that significantly interfere with functioning at the collegiate level.

The sample of participants involved with the present study cited sleep problems, depressive symptoms, anxiety, mood swings, problems with executive functioning, and psychosis among leading symptoms that interfered with daily functioning. Participants

acknowledged that their mental health diagnoses impacted the following areas: academic performance, interpersonal relationships, self-care, physical health, and emotional wellbeing. Some of the participants endorsed having had experienced discrimination related to their mental health diagnoses while others did not. Moreover, a few of the participants had accessed university counseling services; however, most of the participants had not. Reasons provided for not utilizing university counseling services were lack of knowledge of or accessibility to such services. It was noteworthy that only one individual had received academic accommodations related to a psychiatric disability. This finding supported previous literature suggesting that many students make assumptions that support services are not available to them (Eisenberg, Golberstein, & Gollust, 2007). Throughout the course of the focus group interviews, five major theoretical concepts were discussed related to mental illness including the general nature of symptoms and treatment, everyday personal impact of mental illness, positive and negative social experiences, systemic barriers to success, and societal views of mental illness and disability.

Conducting a PAR study with university students with mental illness yielded numerous positive implications. Foremost, members from an often marginalized population were provided an opportunity designed to promote empowerment. A social model such as the one employed in this study encourages people with mental illness to confront and transform their shame into pride, thereby allowing them to take charge of their situations (Onken & Slaten, 2000). Working in an atmosphere fueled by the common interest of social justice, participants were able to construct and clarify knowledge relevant to their population by engaging in the initial stage of a potentially

long-term research initiative. Further, this study helped to uncover issues important in the fight against the mental health stigma that contribute to the way in which university administrators, faculty, staff, and students (both with and without mental illness) view and interact with this population. If this research were to be continued, the outcome may result in stakeholders advocating for important systemic changes, thereby positively enhancing their experiences as university students.

Limitations and Strengths

The limitations of this study must be considered in examining the results and future directions. First, no preexisting PAR studies involving university students with mental illness from which to derive research methodology were located; thus, such an initiative was unprecedented. In a proactive attempt to counter potential downfalls that may have resulted from this, the investigator found previous studies that used similar methods with different subject populations to integrate findings into the research design. However, the fact remains that this was an exploratory study whereby data gathered did not result in clear conclusions or the implementation of a concrete project. Because of this, the study should be approached as a pilot for future research and action initiatives. Next, a true PAR model involves recursive elements of questioning, reflecting, dialoguing, and decision-making. This study was only to be considered as the initial phase of a PAR project that could be reinitiated at a later date with proper time and resources. Thus, all of the phases of a PAR project were not completed as a part of this study. Rather, it involved the initial phase whereby stakeholders helped to formulate ideas for future research proposals. Essentially, this study was meant to set the stage so that future researchers can readily become involved in a long-term PAR project.

Another limitation relates to the number of participants that completed the study. It should be noted that the investigator received many initial responses to the internet-based advertisements for this study, and dozens of students expressed interest in participation. Despite this, only eight participants attended and completed the present study. Many of the initial respondents were ineligible for participation based on inclusion and exclusion criteria, and others discussed scheduling conflicts. However, several potential participants did not provide a reason for not attending the study while a few of the respondents cited issues such as symptoms of their mental illness as reasons preventing participation. Thus, the perspectives of these individuals were not taken into account and could have added to the overall results obtained by this study. Further, only hypothetical projections as to the reasons such individuals did not participate can be made.

With regard to the specific methods used in this study, it is important to acknowledge that the demographic sheet, questionnaire, and focus group interview protocol were all designed by the investigator. Thus, biases regarding the constructs investigated may have existed throughout all stages of the process. In order to counter this, this researcher attempted to use an open-ended format in order to collect data and track the emergence of themes. Regardless, focus groups are susceptible to a priori assumptions that can constrain or limit community drives and designers of health research and activity (Montoya & Kent, 2011). For example, participants in the focus groups may have simply responded with what they thought the investigator wanted to hear. The investigator attempted to ameliorate this in the research design by asking vague questions and eliciting feedback from the perspective of the participants (i.e., “Is there

anything you came wanting to say that you didn't get a chance to say?"). Further, the questionnaire was used complementary to the focus group interviews in order to capture any data points that participants may not otherwise have felt comfortable sharing in the focus group interviews.

Another limitation was that individuals with mental illness who attended but did not complete college were not included in the study. The inclusion of such individuals in this type of research could likely provide more pointed suggestions toward prevention of dismissal from and/or quitting school. Despite this, there were participants involved in the study who described issues related to the need to transfer schools because of poor academic performance. Also, one of the participants described the need to take several years off from college for recovery purposes due to the severity of her mental illness. Thus, some of the participants in this study were able to provide insight as to issues that may lead to problems with retention among this population.

As discussed in Chapter 2 – Literature Review, mental illness has yet to be clearly defined by our society. Thus, selecting inclusion and exclusion criteria related to diagnoses proved to be difficult when establishing this study. As mental illness refers to the vast collection of all diagnosable mental disorders causing severe disturbances in thinking, feeling, relating, and functional behaviors (Souma, Rickerson, & Burgstahler, 2009), it encompasses a wide array of disorders. In order to maintain a specific focus on psychiatric disability, the disorders that were chosen for inclusion were those consistently discussed in the literature reviewed. Thus, common diagnoses that are often associated with mental illness were included, such as major depressive disorder, bipolar disorder, schizophrenia and other psychotic disorders, anxiety disorders, eating disorders, and

personality disorders (Cook, 2000). Diagnoses (i.e., autism, attention-deficit/hyperactivity disorders) that are often not grouped with psychiatric disabilities in the literature were excluded. It should be noted, however, that making such a determination creates a slippery slope whereby some individuals are included in the psychiatric disability movement while others, perhaps even somewhat arbitrarily, are not. This could further promote stigma within the disability community and, specifically, with those with mental illness. Thus, it is important to recognize this in and of itself as a limitation in the present study.

Despite any existing limitations of the proposed study, several strengths and potential benefits exist. First, the model used stands on the premise that the community being studied is already powerful and armed with activists and agents of change. The PAR model provided a space and force in which key players came together in order to engage. In this case, university students with mental illness were able to gather in an effort to construct knowledge about issues relevant to them and, ideally, were benefitted in the process. The PAR model incorporated was designed to allow the participants' voices to be heard and respected. In addition, the study was created so that it can be used for future initiatives at institutions of higher education where there is potential buy-in from stakeholders. Further, the mixed-methodology (i.e., demographic sheets, questionnaires, focus group interviews) allowed the investigator to collect a large amount of data points from which future considerations for research and action with this population can be explored.

Future Research and Action

This scope of this study was intended to shed light on possibilities for future research and action in order to benefit university students with mental illness. With regard to future research, it is recommended that researchers consider implementing qualitative research methods in an attempt to more clearly define the needs of this marginalized group. Additionally, a PAR approach may be particularly appropriate with regard to the collection and utilization of data by and for the subject population.

The rationale of this study was to develop the initial stage of a project that could later be expanded upon for future research purposes. As such, this particular study involved the questioning, information gathering phase of PAR. If the study were to be expanded upon, the next step would be for stakeholders to review the determined research questions and themes. For instance, a group of stakeholders might come together to reflect upon the data gathered from the present study, develop an action plan, and/or implement and refine said plan. In sum, the results of this study should be considered to be exploratory rather than terminal research.

It is recommended that any information generated and gathered by stakeholders and/or investigators be used to promote education among university administrators, faculty, staff, and students (both with and without mental illness) in order to make lasting change with regard to ways this population is viewed and interacted with. Education has been shown to reduce stigma and, thus, promote social acceptance and political inclusion (Corrigan, River, Lunden, et al., 2001). Also, education for individuals among the population with mental illness can promote success. Further, through education, policy-

makers may be better informed with regard to ways to integrate this population with the greater university culture. Finally, education and stigma reduction may allow for stakeholders to brainstorm ways to advocate for this frequently misunderstood group. Related to this, a campus department could take this project to the next stage in research and/or institute ongoing programmatic services (i.e., support groups, ongoing evaluation of services).

As previously mentioned, the number of participants who completed the present study was much smaller than the number of initial respondents to study advertisements. In the future, this should be examined further in order to determine methods to best include all interested individuals. Also, it might be possible to establish an initiative whereby those who do not complete the study itself participate in a brief online survey in an attempt to elucidate reasons for their lack of study completion. This may help researchers and activists to better understand how to include all interested members of this population in any future research or action.

It is recommended that helping professionals, particularly those in the realm of university counseling and student support services, use information derived from this study and other similar studies to consider ways in which to best work with this population. For instance, this information may be used to develop a handbook for best practices and clinical guidelines in work with university students with mental illness. Such an initiative may ensure that the broad array of concerns particular to this group is tended to in a sensitive and informed manner.

Finally, with regard to mental health research broadly, it is important to note that there is a continued need to clarify definitions of mental illness and psychiatric disability. Without proper classification, it is somewhat unclear as to who is, or should be, included in this particular social justice movement. With respect to the present study, inclusion and exclusion criteria were established based on preexisting literature. However, in excluding certain groups from the categorization of 'mental illness,' further stigma may be promoted and potential forces for action weakened within the community itself. Thus, it is vital for future researchers and activists to be very careful in interpreting and applying definitions of mental illness.

CHAPTER 6

Summary

The enrollment of students with mental illness in institutions of higher education is rising. The onset of mental disorders, ranging from mild to severe, often occurs between the ages of 18 and 25, a time when many young adults pursue postsecondary education and formulate career plans. Consequently, psychiatric symptoms can disrupt the completion of expected developmental and educational tasks and may have a negative impact on academic performance and retention rates. Termination rates have been linked to persisting psychiatric symptoms, systemic and social barriers, and ineffective support networks and services. However, when appropriate supports and treatments are in place, students with psychiatric diagnoses can and do succeed in college.

Mental health problems have a profound impact on all aspects of campus life at the individual, interpersonal, and even institutional levels. This issue represents both a growing concern and opportunity, because a large number of people could be reached during an important transitional phase of life. Universities provide a unique chance to identify, prevent, and/or treat mental disorders as campuses often encompass students' residences, social networks, and many services. Unfortunately, even when appropriate services do exist, stigma including inaccurate beliefs and harmful attitudes about mental illness may impede university students' use of available resources, thus limiting their capacity to be successful in their academic and personal pursuits.

The purpose of this study was to gain a more accurate perception of the experiences and needs of university students living with mental illness through the implementation of a participatory action research (PAR) approach. Since the vast majority of research conducted with this particular population has been obtained via quantitative means, the investigator sought to fill a gap in the literature by utilizing a qualitative methodology to yield information directly from the voices of members of the group being studied. The scope of this study involved open-ended questioning of participants in order to uncover themes that may be important in formulating future research and action with this specific population. This exploratory PAR initiative was conducted with eight university students enrolled at Wright State University in Dayton, Ohio. Each of the participants self-identified with mental illness. The study involved mixed methods including a demographics sheet, questionnaire, and focus group interviews.

Prompted by the open-ended research tools used in this study, participants disclosed various aspects of their experiences with mental illness and were given the opportunity to discuss such experiences among other individuals who identified in a similar way. Such discussions gave way to important information about the consistent yet unpredictable nature of mental illness symptoms as well as potential barriers to success for this population. Further, mental illness was discussed in relation to the construct of disability. It was noteworthy that most of the participants involved in this study acknowledged the impairing nature of their mental disorders yet were somewhat reluctant in identifying with a disability label.

The results from this study suggested that researchers, mental health professionals, and university administrators have much opportunity for growth in the analysis, development, and implementation of services and programs intended to serve students with mental illness. For instance, though mental health counseling and psychiatry services were available and utilized at the particular university involved in the study, participants disclosed problems with acquiring knowledge of and access to such services. Also, participants were largely unaware of the availability and benefits of disability services (i.e., academic accommodations) or other student support services on campus. This suggested a need for institutions to better advertise services available to this group. Also, institutions should improve the ways in they convey acceptance and inclusion of students with mental health problems and mental illness.

It was apparent, based on the findings of this study, that societal messages related to mental illness and disability perpetuated harmful stigma toward university students with mental illness. Participants confirmed that such stigma affected them in various areas of their daily lives. For example, participants not only reported the experience of negative or unwanted interpersonal interactions with others based on their mental health diagnoses, but also acknowledged societal messages that have influenced the ways in which they viewed themselves. Several participants in this study made references to the silence of mental illness based on stigma, suggesting that the topic is still taboo in most social circles. In addition, the fear of stigma or discrimination was shown to be a barrier to participants disclosing their mental illness to others. This was particularly concerning as some of the participants indicated that they would often choose to remain silent about their mental illness rather than pursuing services (i.e., disability services) or interpersonal

interactions (i.e., discussions with professors related to academic concerns) that would otherwise benefit them.

In order for lasting attitudinal change and institutional shifts to be promoted, it is crucial for research findings such as those derived from this study to be used for educational purposes as well as social justice initiatives. In relation to this, both members from the population with mental illness, as well as those in privileged positions based on membership in the majority culture, must come together to advocate for the needs of this often marginalized and oppressed group. Also, it is suggested that university administrators, organizations, and mental health providers implement services and programs aimed at awareness, acceptance, and integration with regard to students with mental illness. For instance, it may be beneficial to create and maintain identity affirming mental illness support groups on campuses. Also, educational programs for faculty, staff, and students may be designed to promote understanding of and attentiveness to mental health issues, thereby encouraging acceptance among the greater campus culture.

The results of the present study provided a foundation upon which future PAR projects can be built. If such a research study were to be expanded upon, the next step would be for interested stakeholders (i.e., university students with mental illness) to review the determined research questions and themes. For instance, a group of stakeholders might come together to reflect upon the data gathered from the present study, develop an action plan, and/or implement and refine said plan. In sum, the hope of the investigator is for the results of this study, which are exploratory rather than terminal, to be used for future research and action. The outcome of this study represents an important step in the development of appropriate university student support programs, the

acquirement of knowledge regarding the experiences and needs of individuals with mental illness, and the fight against mental health stigma broadly.

Appendix A

Advertisement Flyer

ATTENTION STUDENTS!

PARTICIPANTS NEEDED for a research study that aims to explore the experiences and needs of university students with mental illness!

- The purpose of this study is to gather information from current students that have been diagnosed with a mental illness (i.e., depression, anxiety, schizophrenia, personality disorder, etc.) in order to learn ways to better serve students with mental illness in institutions of higher education.
- All information gathered as a part of this study will be anonymous.
- The study will be held in a private location on campus.

We want to hear from you!



Please contact the primary investigator, Hannah Gammon, Psy.M., at (Email Address) for details about this study.

Appendix B

Internet Advertisement

PARTICIPANTS NEEDED for a research study that aims to explore the experiences and needs of university students with mental illness!

- The purpose of this study is to gather information from current students that have been diagnosed with a mental illness (i.e., depression, anxiety, schizophrenia, personality disorder, etc.) in order to learn ways to better serve these students in institutions of higher education.
- All information gathered as a part of this study will be anonymous.
- The study will be held in a private location on campus.
Please contact the primary investigator, Hannah Gammon, Psy.M., at (Email Address) for study details.

Appendix C

Consent Form

The Student Perspective:

An Exploration of the Experiences and Needs of University Students with Mental Illness

This signed consent form is to certify my willingness to participate in this investigational study.

Hannah Gammon, a doctoral student from the School of Professional Psychology at Wright State University in Dayton, Ohio, is conducting an investigational study to determine how university students with mental health diagnoses describe various aspects of their experiences of university life. I am being asked to participate in this study because I am a university student who has been diagnosed with a mental disorder.

My participation in this study will involve the completion of a demographics sheet, questionnaire, and group interview. The demographics sheet and questionnaire will take approximately one hour to complete. Immediately following this, I will engage in a one and one half hour, open-ended group interview with the principal investigator, Hannah Gammon, as well as a group of approximately 4-9 other participants from my university. This group interview will be audio taped. Following the interview, the tape will be transcribed such that all identifying information about me and the other group members will be removed, and the tape will be destroyed.

During the course of the study, I will be asked to answer questions about my experiences as a university student. I will also be asked some questions about my demographics, such as my age, student status, ethnicity, gender, and diagnosis. This information will not be used in any way to identify me. Information that I provide will be kept strictly confidential, and all responses I provide will not be associated with my identity in any way.

It is possible that my participation in this study may elicit mild psychological distress related to the disclosure of information of a personal and potentially difficult nature. If I experience psychological distress that is intolerable or beyond what I expect, I may choose to contact a mental health professional to address my concerns by asking my primary care physician for a referral.

There will be no direct benefit to me from participating in this study. However, the information that I provide may help health professionals to better understand the experiences of university students with mental illness and the effect of institutional and societal perceptions of mental illness. My participation or non-participation in this study will in no way impact my standing with Wright State University.

Any information about me obtained from this study will be kept strictly confidential, and I will not be identified in any report or publication. PARTICIPATION IN THIS

RESEARCH IS VOLUNTARY. I am free to decline to be in this study or to withdraw from it at any point. Further, I can choose not to answer any question during the course of the interview, for any reason, with no repercussions.

If I have questions about this research study, I can contact the principal investigator, Hannah Gammon, at (contact information), or Dr. Julie Williams, faculty advisor, at (contact information). If I have general questions about giving consent or about my rights as a research participant, I can call the Wright State University Institutional Review Board at (contact information). If I would like a copy of the group (not individual) results of this study, I can contact Hannah Gammon at the email address provided above. Estimated completion time of the study is July 2013 for those interested in obtaining a copy of the results.

I have read the above statements, and, by signing on the line below, I indicate my informed consent to participate in this study.

Signature

Date

Appendix D

Demographic Information Sheet

Thank you for your participation in this study. The purpose of this study is to examine the experiences and needs of university students with mental illness. The information collected in this study is strictly confidential and will not be used to identify you in any report or dissertation. Participation in this study is voluntary; therefore, you may withdraw from this study at any time.

1.) Gender (check one):

- a. Male: _____
- b. Female: _____
- c. Other: _____

2.) Ethnicity (provide in space below):

3.) Socioeconomic Status (SES) (check one):

- a. Lower SES _____
- b. Middle SES _____
- c. Upper SES _____

4.) Student Status (check one):

- a. Freshman: _____
- b. Sophomore: _____
- c. Junior: _____
- d. Senior: _____
- e. Graduate: _____
- f. Other: _____

5.) Number of years in college (provide in space below):

6.) Current age (provide in space below):

7a.) Current living arrangements (check one):

- a. On-campus housing (i.e., dorm room, campus apartment): _____
- b. Off-campus housing (i.e., apartment, house, etc.): _____

7b.) With whom do you live? (check all that apply):

- a. I live alone _____
- b. Roommate(s) _____
- c. Spouse/Partner _____
- d. Parent(s) _____
- e. Sibling(s) _____
- f. Other family member(s) _____
- g. Other _____

8.) What is your mental health diagnosis? (i.e., Major Depressive Disorder, Borderline Personality Disorder, etc):

9.) How old were you when you were given the mental health diagnosis described in question 8?

10.) Who gave you this mental health diagnosis? (check all that apply):

- a. Family Doctor/Physician _____
- b. Psychiatrist _____
- c. Psychologist/Mental Health Counselor _____
- d. Other _____

11a.) Do you currently receive mental health treatment? (check one):

- a. Yes: _____
- b. No: _____

11b.) If you answered yes to question 11a, please describe the mental health treatment you receive below:

11c.) If you answered no to question 11a, please explain why you do not currently receive mental health treatment below:

12a.) Do you currently receive academic accommodations from your university in regard to your mental health diagnosis? (check one):

a. Yes: _____

b. No: _____

12b.) If you answered yes question 12a, please describe the academic accommodations you receive below:

12c.) If you answered no to question 12a, please explain why you do not receive academic accommodations below:

Appendix E

Questionnaire

Thank you for your participation in this study. The purpose of this study is to examine the experiences and needs of university students with mental illness. The information collected in this study is strictly confidential and will not be used to identify you in any report or dissertation. Participation in this study is voluntary; therefore, you may withdraw from this study at any time.

Please answer the following questions. Consider the impact of your mental health diagnosis on your experiences in college when answering.

- 1.) What are the symptoms you experience as a part of your mental health diagnosis?

- 2.) In what ways does your mental health diagnosis impact your academic performance?

- 3.) In what ways does your mental health diagnosis impact your relationships with others?

- 4.) In what ways does your mental health diagnosis impact your ability to care for yourself?

- 5.) In what ways does your mental health diagnosis impact your physical health?

- 6.) In what ways does your mental health diagnosis impact your emotional health?

- 7.) Have you been discriminated against because of your mental health diagnosis?
If so, in what ways?
- 8.) Do you currently participate or have you participated in any university services, activities/programs, or treatment related to your mental health diagnosis? If so, please describe and indicate your overall level of satisfaction with these services below. If not, please describe why you are not involved in services.
- 9.) Do you have any suggestions for the development or improvement of services, activities, and/or programs to better serve the needs of university students with mental illness?
- 10.) Do you feel you have any unmet needs in relation to your mental health diagnosis? If so, please describe these below.

Appendix F

Interview Protocol

My name is Hannah, and I want to thank you for your participation in this study. The purpose of this study is to examine the experiences and needs of university students with mental illness. The information collected as a part of this study is strictly confidential and will not be used to identify you in any report or dissertation. Please be aware, however, that the participants in this group are not bound to maintain the anonymity or confidentiality of other participants; therefore, I would like to request that each you agree to keep all information shared as a part of this study confidential. Further, please note that participation in this study is voluntary; therefore, you are free to withdraw from this study at any time.

We will meet as a group for approximately one and one half hour. I am going to pose several questions to you in that time. The questions I ask will be somewhat structured, but please participate freely as you feel comfortable. Does anyone have any questions?

1.) Opening question: *Each of you is in this group because you have indicated that you have some type of mental health diagnosis. Please tell us your name, something unique or interesting about yourself, and how long you have identified as having a mental health diagnosis.*

2.) Introductory question: *Since beginning at Wright State University, have you been involved with any mental health or student support services or programs? If so, what services and programs have you been involved with?*

3.) Transition question: *Think back to when you first began as a student at Wright State University. What was the transition process like for you?*

4.) Key question: *What was particularly difficult about your transition to university life?*

5.) Key question: *What was particularly helpful to you in your transition to university life?*

6.) Key question: *In what ways do you feel your mental health diagnosis has impacted your experiences as a university student?*

7.) Key question: *Do you view your mental health diagnosis as a disability? Why or why not?*

8.) Key question: *Have you experienced negative reactions from others in regard to your mental health diagnosis? If so, in what ways?*

9.) Ending question: *If you had an opportunity to give advice to university administrators and mental health researchers regarding the experience of students with mental illness, what advice would you give?*

10.) Ending question: *I want to know how to improve the experiences of university students with mental illness. Is there anything that we missed? Is there anything that you came wanting to say that you didn't get a chance to say?*

Appendix G

Focus Group One – Transcript

Hannah Gammon (HG): My name is Hannah, and I want to thank you for your participation in this study. The purpose of this study is to examine the experiences and needs of university students with mental illness. The information collected as a part of this study is strictly confidential and will not be used to identify you in any report or dissertation. Please be aware, however, that the participants in this group are not bound to maintain the anonymity or confidentiality of other participants; therefore, I would like to request that each you agree to keep all information shared as a part of this study confidential. Further, please note that participation in this study is voluntary; therefore, you are free to withdraw from this study at any time. We will meet as a group for approximately one and one half hour. I am going to pose several questions to you in that time. The questions I ask will be somewhat structured, but please participate freely as you feel comfortable. Does anyone have any questions?

Participant One (P1): No.

Participant Two (P2): No.

Participant Three (P3): No.

HG: Each of you is in this group because you have indicated that you have some type of mental health diagnosis. Please tell us your first name, something unique or interesting about yourself, and how long you have identified as having a mental health diagnosis.

P1: My name is _____, and I have been depressive since eighth grade. I have been anxiety-prone since a freshman in college. I have been considered slightly bipolar since a

sophomore in college. This is my third year in college. Oh, and ADHD. I have been ADHD since sixth grade.

HG: You said sixth grade? Okay. Thank you!

P2: I'm _____, and I've been diagnosed with generalized anxiety and major depressive disorders. I got diagnosed when I was 23, so I've been living with it for almost two years. I am a psychology major.

HG: Great.

P1: Oh, I forgot to say something interesting about myself. I play drums.

HG: Yeah? Cool!

P3: My name's _____, and I've been diagnosed with panic disorder since I was 10, major depressive disorder since I was 16, um, ADHD since I was 21, and generalized anxiety since I was 17. And something cool about myself? I am a mother of two children.

HG: Oh, how old are they?

P3: My youngest son turned two at the end of September and then my oldest son is about to be three and a half. So they're exactly 15 months apart, so that's really crazy.

HG: Awesome. Thanks for sharing!

Anyone have anything they wanted to add to that? No? Then I'm going to move on.

Since beginning at Wright State University, have you been involved with any mental health or student support services or programs? If so, what services and programs have you been involved with?

P1: I've been at office of disabilities for my ADHD, and that's really about it.

HG: So nothing else? No other services on campus at all?

P1: Nope.

HG: Okay.

P2: I have been involved with the Office of Disability Services ever since I came here, because I have a physical disability as well. Counseling and psychiatry services, group therapy.

HG: Is that all on campus?

P2: Mmm hmm.

HG: Great.

P3: I didn't.. I know that there's like counseling services, but I just thought the disability services was more for like physical. I also have physical disabilities, but I never really checked into it.

HG: Okay. So you said you did know about the counseling services. Have you been involved?

P3: Well, I see a therapist outside of school so that's why I never really looked into it.

HG: Oh, okay. I see. So what you're saying is you have not been involved in any types of mental health or student support services on campus?

P3: Yep.

HG: Great. Thanks! Well, we're moving along quickly!

(Participant laughter.)

HG: Think back to when you first began as a student at Wright State University. What was the transition process like for you?

P1: I mean, for me it was very, I was pretty smooth but I was a music major so I had bad anxiety for performing. So even a lot of times I would get so shaky that I couldn't play right. So, I mean, that was a problem for me but then, after like the first three weeks, I went to see my psychologist. And he's helped me, he's.. Can I say names?

HG: If you want to. That's up to you.

P1: Okay, so I went to see Dr. ____ and then he went and sent me to go see Dr. ____, which he's a psychiatrist. So he helps me with prescribing different medicines for my anxiety problems and I haven't taken them since I've been a music major. No, I take that back. I took them a month before a party because there was like 50 people there and I couldn't handle it. But besides that I haven't taken them, I've been able to wean myself off of them, well not really wean; I wasn't addicted to them or anything, but I haven't had to take them. So that was pretty good.

HG: Okay.

P1: And, um, so I mean they've really helped me become more able to perform, but I still have anxiety about performing, I still, if I'm in front of a large group of people I talk really really fast, and I talk faster than I am talking now, I just keep talking and I'm going and going and going. But, I mean, I'm very, I get very nervous in front of other people and in a large crowd of people, like at King's Island I have to, like in the kids' section especially, I have to like hang on the outskirts to stay away from all the people. I just don't like huge groups of people.

HG: So then how was it for you, then, coming into the large groups on campus and things like that as you transitioned?

P1: Well, when I was a music major all my classes were really small, because I had music theory, and music education, and sight seeing, and all of that so classes at the most were about twenty-five students. So it was pretty small, and um, I'm really good at making friends and things. It's really easy for me to have a close knit group of people but people at like huge lecture halls or people I don't know, I always sit in the back. So that way I'm not in the middle of a group of people.

HG: Okay. How about for others? How was the transition to Wright State for you?

P2: I really didn't have a transition because I had just transferred from another school. So going to Wright State was just like oop okay. More classes, more work to do.

HG: What about the first time you transitioned to college?

P2: It was a lot different. I had gone to another school before I came to Wright State and the academics were a lot more difficult. Um, I felt really isolated because I was pretty much the only physically disabled student on campus. Um, so, yeah.

P1: That's one of the nice things about Wright State is that it's all very diverse, which I think is great. I want to be a childhood intervention specialist so I am going to work with handicapped people which I think is wonderful. I love handicapped people. They're so fun. They have such great personalities, so..

HG: (To P2) Was that your experience, too? That it was more welcoming?

P2: Um, it felt a little bit more familiar because there were people with disabilities around me everywhere and not as competitive as my last school was because my last school's diverse, too, but there are a lot more international students, and they were all on scholarships, and I was pretty much dependent on my parents to pay for it, and eventually they couldn't pay for it anymore, so I had to transfer here and my grades weren't that well to begin with. So when I came here everything just turned around for the better which is nice.

HG: Good!

P3: For me, it was, I was more excited than anything, because I, um, had my first son when I was not too young, I was out of high school, but I was like, um, 19 when I had him, so I didn't go right into college. So, it was a little bit difficult for me financially and trying to figure out all that. I was also pregnant with my second son when college started. It was really bad anxiety-wise because I had a lot of debt I had to pay off before I could even start here, so I had to use a lot of my school loans and stuff just to do that, so. And

then just really getting used to college. Like, I have a family who nobody really went to college, so nobody really taught me how to do anything. I just jumped in. And it was really hard to manage like time when I did my homework so I wasn't staying up too late. I was tired, I also worked and stuff so it was kind of difficult. Like I said, I was more excited than anything, so I was ready to do it, but it was really hard to stay on task.

HG: Definitely.

Okay, we're going to move on. The next two questions kind of link to the one that we just discussed. The first question is: What was particularly difficult about your transition to university life?

P1: For me it was very much I was brought up in a house that was very disciplinary; you couldn't go places you weren't allowed to be at after dark. And when I became a music major, they wanted you there six hours a day on top of your schoolwork to practice for each ensemble. So I was percussion, I had symphonic band, I had chamber orchestra my first quarter, I had a bunch of stuff. Plus I had like an hour of theory homework, an hour of musicianship homework which was just insane. So I was very behind, and my parents would want me home at dark, so I was home at dark. But I didn't have the practice that I needed and that was why I did so bad in my first year, because they'd be like "you need to be home now." "Okay, I'm coming." In the middle of practicing my stuff, so that would make me feel very.. My anxiety would just keep growing and growing and growing because they wanted me home so I would live by their rules, which I mean I could do, but it's easier now that I'm not a music major. And like there were concerts you had to go to, and they were after dark. And my mom would take me to the concerts, so I

mean it was so, I just live in a very strict household. So, um, I had a lot of problems, especially with my dad. So when I was a music major, I did very poorly because I couldn't practice six hours a day like they wanted me to. So it was very tough for me. That's when my anxiety problems really started to happen.

HG: So that's when you noticed it the most was around that time?

P1: Oh, yeah.

HG: It sounds like you were trying to balance a lot of different things.

P1: Oh, yeah.

HG: How about for others? What was particularly difficult about transitioning to college?

P2: How different it would be from high school, because people told me, "Oh, college is different. You're going to be putting in a lot more time." But I really didn't think it would be that different until I got to college and then I was struggling in school, which I had never done. And I was like, "What is going on here?" Then, um, my first semester, I got put on academic probation 'cause I had done so bad. And then second semester I got off. And, um, at my first school I never knew how I was doing because, like I said, the classes were so hard that every time I thought I did well, I'd end up doing bad. Then my anxiety would just keep going and going and going and it felt like I wasn't getting anywhere. I felt like I was chained to my desk all the time, because I never got out. I never talked to anybody. Um, I never had fun. I felt kind of stifled.

HG: Sounds like you felt a little isolated, too.

P2: Yeah. Big time.

HG: What about for you?

P3: I think for me it was also like a balancing act. Because like I said, I was already a mother and I was working. It was basically just trying to find a balance between everything and it was really difficult because like I didn't know any students at the time who were also parents. Now I know like a ton. But, I didn't know any at the time so I felt very also isolated and really weird. Now I see a ton of pregnant women on campus, but I felt like the only person, for whatever reason, when I started so I felt really weird. Really strange. I felt like an adult who was doing all these things that other people hadn't even done yet, so I felt really isolated. And, like I said, I was already a mother, and I wanted to put that first, and it was really hard to like be a good mother and really devote time to my son, and also my body because I was pregnant, and then also do my schoolwork and get really good grades. So really the balancing and I just felt really isolated because I didn't really know anybody with a similar situation at the time. And yeah.

HG: Okay. So it sounds like kind of feeling alone in some ways; just not knowing that there were other people that were going through something similar.

P3: Yeah.

HG: Anything else anyone wanted to add to that? No? Okay.

What was particularly helpful to you in your transition to university life?

P1: I mean, the friends I made in the music program they were very supportive. I would literally be like seriously like crying in the drum room because I was trying to practice and I knew I had thirty minutes and I had to be home but I had to get this done and they

would be like, “It’s okay, you’ll be fine,” but I wasn’t fine. It was very hard for me to be there and be at home living both lives. And my parents didn’t want me to live on campus so, you know, it was very hard for me to be able for me to do what the music program wanted me to do and be trapped at my parents house. Which I mean at the time was very hard for me to do everything plus, I mean, I didn’t have that many academics, but the music program, it was very tough. But my friends really helped me through it. I mean, they would take me out for ice cream and stuff and say “Don’t worry about it. You don’t need it. Come on, let’s go.” I mean, that really helped me and stuff.

HG: Sounds like they were very supportive and encouraging.

P1: We all do everything together in our program, especially the drum people. We all have our own drum studio and everything. It always helped to have everybody there.

HG: Great. Anything else?

P1: No.

HG: What about for others?

P2: Um, probably transferring here altogether helped, ‘cause at my other school I was having a really hard time with my academics and, um, my last semester there I started to experience times of depression and I always had extreme anxiety but I’d always thought it was just a part of me. And then once I came here, about around the quarter before I got diagnosed, I had a little episode and, finally, a university personnel was like, “Have you ever thought about going to see a psychiatrist?” And I was like, “No.”

HG: Who was it that referred you?

P2: Um, your supervisor.

HG: Oh, okay. On campus here. How did you know her?

P2: Um, I'm in the disability group.

HG: Oh, I see. Okay.

P2: And then, um, she said that, and I'm like, "No." And I felt my mom had already always had this predisposition about going to the psychiatrist, because she'd be like, "Oh, I don't think you need it," and I'd feel like she would get mad.

HG: Your mom would?

P2: Yeah, and I'd be like, "Okay, fine."

HG: Almost like agree with her?

P2: Yeah, and that time, the time I went, I didn't tell her until about seven months later. And then, um, I told her why, and I think she understands more now, because I think she's seen the positive changes that medication's had.

HG: Would you say that's something that's been helpful, too, is having support from family members?

P2: Yeah, most of my family members know. I would say just having support from the university who actually recognized that there's a problem.

HG: I'm glad that you had that positive experience. How about for you?

P3: Should I name something that is directly related to school that helped me? Like someone I met here? Or outside of school?

HG: It can really be whatever was helpful to you. So, I mean, it can be university related, or it can be just in general.

P3: When I very first came here?

HG: Yeah, during the transition period if you can back to that time; however you define that.

P3: When I first came here, and I took my first introductory psychology course, I actually think that professor helped me out a lot, because he was a psychologist, and I've always had mental illnesses, and I come from a family of mental illnesses also, so, I um, that's another way I felt really isolated because I knew I had a lot of problems coming in. But I remember the abnormal part of introductory psychology really made me feel like not so crazy I guess. I was like, "Okay, a lot of people have this." And like, I would talk to him afterwards and stuff. I didn't really realize how common a lot of it is. That actually helped me out.

HG: So almost like hearing that it was common and just getting knowledge about it and hearing those kinds of things made it seem more normal? Kind of like, well, this is something a lot of people deal with.

P3: Yeah, it did, because I have never really had friends who went to therapy or done a lot of the stuff. If I did, it was for like really major disorders and things, same with my family members, so it helped just to see that it's a pretty common thing for depression,

anxiety, panic, ADHD, everything. Which helps, I guess. And then just to be more informed about it from like a scholastic standpoint instead of just like hearsay and your own therapist and stuff.

HG: Good. Anything else you can think of? Or was that kind of the main thing that really helped?

P3: That was probably the main thing.

HG: Okay, good.

In what ways do you feel your mental health diagnosis has impacted your experiences as a university student?

P1: That's a good one. For me, it goes back to being a music major. It was very hard because I was balancing home life and school and not being able to perform because I was anxious about performing in front of groups of people. That really, really hurt my musical career. I pretty much said, "I can't do this anymore." So, I stopped. So that's one of the reasons why I'm not a music person anymore. But um, when I switched to others things it wasn't as bad. It wasn't nearly as hard for me to do stuff. It was just the music department. They put so much pressure on you and they want you to do all this stuff; 22 credit hours like above what you should be taking and they're like, "You need to practice for this and need to practice for this, and you need to do this and this."

HG: So it felt overwhelming? Like it was too much?

P1: Mmm hmm. And they want you to do it in a set way. Like there's a set of classes they want you to take at the same time. Like there's music theory and sight singing and music

education and private lessons and an ensemble and, then, they also want you to do like choir and an extra ensemble. Plus, you have to go to these concerts, 10 a quarter. So, I mean, that takes time.

HG: So almost like there were too many requirements?

P1: Right.

HG: And really high expectations.

P1: Oh, yeah. I mean, some people can do it, but I'm just not cut out for it. I couldn't.

HG: How did you feel your diagnosis played into that?

P1: I mean, I didn't really have an anxiety diagnosis until I started it. And that's when it really, I would just sit there and have panic attacks and pretty much collapse in front of the marimba. Yeah, I'd just freak out and that really hurt me a lot. Then I'd be depressive in certain things. I've been depressive since I was in eighth grade, so that continued on and got worse in the music department because I'd get so anxious then would get mad at myself for getting anxious and I felt like a failure and then it just went downhill from there. So I really had issues with that, and um, then the parents thing. I never had a good relationship with my dad.

HG: Almost like that played into it, too?

P1: Yeah. Yeah.

HG: Thank you for sharing. Is there anything else you wanted to say? Or is that pretty much it?

P1: That's basically it.

HG: Okay. What about for others?

P2: Well, um, I kind of feel like my disability has made me have a harder time balancing school and social life, because I don't really have a social life I guess you could say.

Before I was on the medication, every time it was midterm time I would have like these little meltdowns where I would just lash out at people, cry, want to be alone, and, um, and then after a little while it'd be like, "Oh, I'm okay."

HG: And so it would kind of like cycle back.

P2: Yeah. And then, I'd be okay until another midterm point and then it would cycle back again.

HG: So you're saying the mental health diagnosis has made it really hard to balance school and social life, and when you have those "meltdowns" that would impact both of those areas, socially and academically?

P2: Academically, I guess, more. I couldn't deal with the pressure anymore.

HG: I see. Any other ways you felt like your mental health diagnosis impacted your experiences?

P2: I guess finding people that can understand what I go through, because even though I'm in a disability group, none of them have an anxiety disorder.

HG: So it's not more for psychiatric disabilities?

P2: Yeah. Yeah. I tried to tell one of my hallmates, a really good friend, about what actually happened which led up to me getting diagnosed. And then I feel like she doesn't understand only because she wasn't there at the time, so it's hard for me to explain to her why I feel like I still need the medication. 'Cause she'll be like, "Oh, why don't you just practice stress management or.."

(Inaudible reaction from other participants.)

P2: And that's one of the, I think, the harder things to try to get my mom to understand. "Oh, it's just temporary, you'll get over it."

HG: Snap out of it?

P2: Yeah. Now she doesn't really say that much to me about it anymore, because I think part of her sees what changes the medication's had.

HG: But still, it sounds like it has impacted your relationships, especially with people not being able to understand what things are like for you and how hard it is to manage these things and do all the things you're doing on top of it. Going to school and trying to have a social life.

P2: And trying to find a job.

HG: Yeah.

P1: That's one of the things disability services did, but they don't accept people with anxiety. Or depression. They don't. Which I think is just as bad as people with ADHD or anything like that. I think it's very almost prejudiced in a way. I don't want to say it like that, but it's kind of like they don't see it as that bad of a problem.

HG: Almost like it's not on the same level as other types of disabilities?

P1: Which it kind of is!

P3: I also want to add, too, that I think that's totally right and, like, I have seen multiple therapists and counselors and some of them think I have ADHD and others think that it's just caused by anxiety in itself, which can cause ADHD symptoms. So, like, if you're anxiety gets better, your ADHD gets better. They can be comorbid, so I think it's kind of stupid that somebody would not accept somebody with anxiety because anxiety brings along so many other disorders also and it also one of the biggest ones to affect you physically, too. So like I know I have heart problems and it affects my heart problems, too. So sometimes I have trouble with school because of that. And, like I said, I've been on medicine for ADHD and anxiety and I know that when my anxiety is better, my ADHD is better. So I always feel like, yeah, they don't really take it seriously. They call depression like the "common cold of disorders," but I think that they should take it a little bit more seriously.

P1: I agree.

HG: So it's almost like you have to have a certain diagnosis for it to count, and if you don't, somehow it's not as disabling or isn't impairing you in the ways that some other type of disability might. So it's almost like not seen as legitimate.

P1 and P3: Right.

P1: Which I think is really wrong, not recognizing it as a disability. So, I mean they've accepted me for ADHD, but they said, "We can't accept you for anxiety," but that's

what's really helped. That's more the reason I'm in there is for my anxiety, but they say "Well, because you have ADHD, we'll leave it this way." And I'm like, that's not right to go cheat the system in a way.

HG: It's almost like you feel you identify more with the anxiety as being the source of what's causing all these struggles, I guess you could say, in school?

P1: I've always had it. I almost failed out of school in fifth grade because I had straight Fs. I couldn't focus. I was so bad at that. What happened is, when I was little I was so smart that I didn't have to study or anything. Except spelling; I always sucked at spelling. But I could always just get things "like that," and when fifth grade came around and I had to study, I didn't know how. So that really put me back. And they were like, "Here, we'll give you something to help you concentrate." So that's when I started Adderall, and that was horrible. That was a horrible experience. I got addicted to it. I had shakes and withdrawal, and I wouldn't eat, and I was 90 pounds, and it was bad. It was a bad experience.

HG: So there were side effects to medications, too, that even played into..

P1: Well, that was in high school, though.

HG: But regardless, it was something that you noticed throughout your time that kind of impacted you.

P1: Yeah.

P3: I have the same thing, too. Adderall was really bad for me. I'm getting ready to get back on.. I decided like, I'm always trying to decide when to try a new medication,

because they don't work for me very well, and I always have such bad side effects. So the last thing I tried was Prozac to help with anxiety and depression, and like I said that makes ADHD a little better. So I've decided like, whenever we start our new semester, things will be a little bit calm enough to try a different ADHD medication, because I have to plan to miss school because I know I'm going to have side effects. So like she said, too, I was really bad with Adderall. It was horrible.

P1: I eventually went to Concerta, which is kind of like Adderall, but it's not rapid release. It's like long-term release. Which I think the rapid release, I wouldn't eat. I would go through a whole day at school, and I would just not eat. I would eat a cookie because it tasted good and I wouldn't eat anything else. Maybe a little candy bar for breakfast, hardly anything at lunch, and maybe a little bit of dinner, and I was losing weight rapidly. It was bad.

HG: (to P3) I heard you say you even had to plan to miss school, because you know there's going to be side effects to your medication, and it sounds like that might even be a barrier in some ways to your performance.

P3: It is. And even so, too, I've had kind of like a rough life, and if I'm in cognitive behavioral therapy every week, if I know we're going to be hitting something kind of heavy that I know I've been like avoiding for a while or something, I kind of like, I plan for that because I'm like I might be a little upset after talking about that, and I'll have to kind of like do my work ahead or put it off. Some teachers I can be really honest with and be like, "This is what's going on," and they'll be really nice. Some teachers just aren't as good. But yeah, it definitely affects it, too. Medicine, I kind of feel like it's a gamble

sometimes to take medicine. So I'm very skeptical of medicine. Like I want it to work for me, but it just hasn't yet as I would like it to or as I would need it to. I guess I can try again.

HG: These are all very good points, so thank you all for sharing.

And actually, in some ways, I think it kind of transitions well into the next question which is: Do you view your mental health diagnosis as a disability? Why or why not?

P1: I view it as a disability mostly because, I mean, I couldn't perform when I was a music major. I still have a hard time, and like the other day I was doing a presentation on the phases of the moon, and I was talking really fast, and I got through it, and I made the time, but I gave information so fast. Which around kids I'm not that way. It's more like my peers that I feel like are judging you. Kids, I feel like they look up to you, and they don't really judge you. I've always had a problem with people judging me in the past all the time. Throughout history, everybody got jealous of me, and I just didn't do well with that.

HG: So maybe it sounds like for you in some environments it might be more of an impairment than others?

P1: Right.

HG: How about for others? Do you view your mental health diagnosis as a disability?

P2: I do, because, um, my anxiety is really extreme without meds. I can't really, it's almost like I become paralyzed to do anything because I'm so busy thinking about pointless other things.

HG: It's almost like you're kind of frozen.

P2: Yeah, and I can't move.

HG: Then obviously that would cause an impairment for getting the things that you're expected to do done.

P2: Mmm hmm. And depression plays a role, too. You know, sometimes you're so tired and so moody you don't want to be around people. You don't want to do anything, even though you have to. And then, you know, you might get in trouble. And it's like, "How do I work around that?"

HG: So trying to balance that, then, too.

P2: Yeah.

HG: Big balancing act.

P2: Yeah, and I just don't like juggling a bunch of balls.

P1: Another problem for me is I'll start crying. Every time I hear Blue October's "Hate Me," I will bawl for hours, like one day it came on the radio and I was going to school and I cried for hours. I just sat there, and missed two classes, because I couldn't stop crying, because I've tied so much emotion to it. I'm a stuffer. I stuff emotions. I've been stuffing emotions since forever practically. I know it gets bad sometimes, and I can't do stuff.

HG: And, in that case, it sounds like it got in the way of even being able to attend class.

P1: Oh, yeah. And it's like uncontrollable crying. It's like you should stop crying, there's nothing to be sad about, and you're still crying. It's stupid.

HG: So it feels irrational, but at the same time you can't control it.

P1: I can't stop.

HG: I wonder if there's a fear that others will see it that way, too, as something you can control.

P1: Oh, yeah.

P2: Yeah.

P1: Like with my dad especially, he's like, "Stop crying. You're crying to get what you want." And that really hurts me. He also says you're using your looks to get what you want. I don't. No. I very much think beauty's a curse. I'm, it's, you know, very much.

HG: What about for you? Do you view your mental health diagnosis as a disability?

P3: Yeah. Majorly. Um, I guess I come from a family who I've been raised around mental illness, so I was like destined for psychology since I was a kid. But um, I grew up seeing what handicaps it did for their lives, like so much. And then, you know, when I started realizing that I had a lot of issues, too, with mental illness, um, it's a very big handicap, because I feel like it affects everything you do. Like not just everything you do, but it affects the way you think, the way you act, the friends you're around. And like she said, too, I had friends who just couldn't be my friend anymore, because I was just too sad to be around people who were happier. I've lost friends because people just don't get it who don't have disabilities, so they just don't understand. And I think that, I know as a

mother it's like so hard to have mental illness because like she said, too, you have to take care of kids. You have to. You're responsible for everything, for their lives. And it's really tough when you're always anxious because you're like always second-guessing yourself. At least I do as a mother, I'm always like "Am I doing this right? Am I doing this okay?" You're always like the helicopter effect. You're always hovering over your kids, and you get kind of depressed. Am I doing it right? Is this going to affect them? I'm sure I'm doing an okay job, but when you have a mental illness it affects everything; the way you think and behave. I so consider it to be a disability.

HG: So it's always there. It's not something you can turn on and off. It's always there with you. And, like you said, you can try to be responsible and do the things you need to do, but it's hard not to fall into that cycle.

P3: It is, and um, I think like there are better days than others and stuff. But in general, yeah, it's an ongoing thing. Some days I'm more depressed than anxious. Some days I'm more anxious and ADHD's worse, but in general I'd say that it's always there. Yeah.

HG: So not necessarily consistent, but..

P3: I'd say it's consistent, but I'd say I cycle back between depression and anxiety, and the different symptoms of my mental illness.

HG: Does anyone else have anything they want to add about this question about disability?

P1: I mean, I know that just from me having it for so long that I have become really good at putting a fake mask on. And I feel like I'm never myself because I always have a fake

mask on to be that happy-everybody-likes girl. And I'm really not. I'm the complete opposite actually. I'm very self.. hide in a hole type person. But I'm really good at putting off that really happy, you know, preppy nice person thing that I'm not really. I'm more of a like gothic emo person.

HG: It's almost like living two lives.

P1: Yeah! I think it's really interesting how people can put on these masks. I've done it all my life.

HG: And that sounds exhausting, too.

P1: Yeah, it is. But, I mean, it's one thing that I have learned to help cope so people don't think of me like I'm a weird person. So I very much put on a fake mask.

HG: Because you don't want to stand out?

P1: Right. I have a lot of fake friends who aren't really... I have one friend that I've had since forever. Her name's _____. She's the one I'm making the scarf for.

P2: Oh!

P1: We've been friends since fourth grade. And we've been best friends all the way through now. She's like one of the only people I can go to with anything. It's really cool.

HG: Good. I'm glad you have that.

Is it okay if I move on to the next question?

P1: Mmm hmm.

HG: Okay. Have you experienced negative reactions from others in regard to your mental health diagnosis? If so, in what ways?

P1: I mean, my dad. All the way. "You're crying to get what you want." Most people are very good about it. And I'm very good about hiding it out in public, but when I'm around my dad for some reason, it gets really bad. He'll push buttons, you know, saying things. And he holds grudges. And like this one time he didn't tell me to, you know, my grandma called. My mom's mom called and said, "We're gonna eat lunch when you guys are ready to come over." You know, my dad's out mowing the grass. He's like, "Oh, I'm going to finish mowing the grass." He got really angry at me for not telling him they're doing lunch, and he still brings it up to this day. He said that's when the problem started. I was like, I was trying to be considerate, you know? And for you to go and pretty much yell at me, you know, as a full-fledged yelling match, you know. But I don't yell back. I just sit there and take it.

HG: In terms of your mental health diagnosis, you said that you get a lot of support from people that you hide it from.

P1: Right.

HG: Are there people who know about it who you feel like react to you negatively because of it?

P1: No, not besides my dad. Well, nobody really sees it besides my family. So in social settings I'm the very happy, very nice girl everybody likes. I do kind things for everybody. But when I'm myself, when I'm at home, when I'm like being _____(name),

not the happy _____(name) – it's two personalities almost – that I'm very different. So people don't really see that.

HG: But your family does more so.

P1: Well, my dad brings it out in me. So, I mean, I even put on a happy face for my family mostly. So it's just my dad brings it out. He knows I'm doing (inaudible) or whatever, so he knows that I'm being fake, and he just wants me to be real. And when I'm real, he criticizes me for being me. So if I.. It's stupid.

HG: Yeah, that does sound hard. What about others? Have you experienced negative reactions from others related to your diagnosis?

P2: People that know about it are very few. Um, they've been supportive in trying to help me. Unfortunately, my disability led me to leave the social work program. But, um, everybody's trying to help me deal with it and, um, kind of, I guess prepare for future situations such as the work force and grad school.

HG: Do you feel like you've ever gotten any negative reactions related to any of the symptoms you experience or anything like that?

P2: Um, yeah, kind of. I was at an internship, I think it was last year, and I was at an agency that, um, helps people with disabilities. And I was working with MRDD clients. And, um, eventually when I would come to work I would seem miserable and moody and stressed out because I felt like I wasn't being a good enough intern or doing everything right that I was supposed to do. And I didn't have any direction from the staff, and I

didn't feel comfortable telling them because I would think they would be like "Oh, well you just need to find a way to.."

P1: Put on the face.

P2: Yeah, put on the face and be the employee and do what you're supposed to do. And there were so many times I wanted to leave and be like, "Screw this. I'm not coming back here." And, you know, then my experience with that just went downhill because my depression and anxiety increased big time and finally I had to leave.

HG: So it sounds like, in that case, you didn't necessarily get negative reactions from others but it was mostly because you didn't feel comfortable saying anything.

P2: Well, no, because one I was at work, because, well, that was my job and, you know, and I didn't feel comfortable talking to them and telling them these are the problems I have.

HG: So almost like the feeling that they wouldn't understand?

P2: Yeah. And they wouldn't do anything.

HG: And they would expect you to just, again, back to that theme of kind of "suck it up?"

P2: Yeah. Be like this is what you have to work with. We can't do anything about it.

HG: So almost like wouldn't accommodate you?

P2: Yeah. Which is really sad because it's one of the major disability agencies. A lot of it was the supervisor in the program, too, and like I said there were other issues.

HG: It sounds like for you, even though it was a disability-related agency, almost this feeling of it won't be recognized or taken seriously.

P2: Oh, yeah. Because it's not as obvious.

HG: Because it's a hidden disability.

P2: Yeah.

HG: How about for you? Have you had negative reactions from others related to your diagnosis?

P3: Yeah, I get like negative reactions almost daily. Especially from everybody in my own family, which is really frustrating because they have mental illnesses, too. Like my partner and doctors, because I have a lot of medical problems. And every time I go in and I'm like I'm having chest pains, they see that I have a psychiatric diagnosis and they'll be like, "Oh, are you under a lot of stress lately?" And I'll be like, "I'm a mom, I'm a student, I'm always under stress. Hello." And they just want to blame it on that. Or it's like, "Why don't you try some Prozac?" And it's like, well, I have chest pains. So it actually took a long time to get the tests I needed to have done, because everyone just kept saying it was anxiety. Even my therapist. I had to consider getting a new therapist and me and him had to have a really big talk, because I had to be honest with him because he was saying, "Well, these are all the symptoms of panic disorder; there's probably nothing wrong with your heart." And when I finally got to the doctor, there was something wrong with my heart and there really were things going on. So I had to have a lot of doctors apologize to me and stuff. And I went to apply for life insurance. And when I was pregnant with my first son, I was, I mean, I've always been very anxious and

emotional, and it makes it worse because your hormones are crazy when you're pregnant. So I was hospitalized for like a week. I wasn't suicidal or anything; I was just so depressed and anxious and everything. So when I went to apply for life insurance, they were like "Oh, you have a psychiatric background, so you can't get life insurance."

HG: So you were denied..?

P3: Yeah, and that really, really made me mad because I was like oh, this is great. You know? Now I've got all these diseases, I'm feeling like maybe I'll die soon. It felt like a lot of discrimination there because you could have certain other diseases but you couldn't have psychiatric diseases and history and hospitalizations to get life insurance. That really upset me, because then I thought this really hurts my future plans, you know?

HG: It almost felt like you were being denied rights in some way that maybe someone else would have based on this label?

P3: Yeah, and really hate it, too, because people are like "Oh, you were hospitalized," and it's not like I was suicidal; I was just really depressed. And I went into the hospital with a panic attack, and they were like "Do you want to come in here?" I didn't realize it was going to have all of these effects that like people think I'm just this crazy person and stuff.

HG: So even a stigma of getting help.

P3: Yeah, there is a stigma to that. And even with my partner. Like, he doesn't understand. It's more of the ADHD thing to him that I have problems with with him, because we have a busy life anyways so it's really important for me to be organized. But

I have the hardest time getting organized. It's like impossible. And I'm like, okay. I try to do all the cognitive behavioral stuff like make lists and things but even when I do that I'll lose my list; I won't look at the list. It doesn't matter. I'll have a structure like I'll do this, I need to organize this but then I'll like question the way I'm organizing things and bottom line is it's just impossible to get organized. So we have a lot of fights because he's [partner] like, "You forgot to do this again" or I left my wallet at the store or this or this or this. I'm always forgetful. And then he just doesn't understand. He's just like, "Why can't you just leave the keys in the same place? I don't understand why it's so hard for you to just remember things." If you don't have it, you don't understand. And I get a lot of "It's not my fault you forgot to do this. It's not my fault this or that." And I feel really alone in it, and people just give a lot of negative reactions. Like she said, it's part of the disorder; you can't just yell at me because I forgot to do this or this. Like, I really don't remember. Like I really forget this stuff. Like it's really a legitimate thing; you can't remember! People just don't get it, you know?

P1: My parents are always like, "You're gonna grow out of it. You're gonna grow out of it." I've had it since I was little.

P3: Right.

P1: I mean doctors said that I probably had it since I was born. Because when I was little, I mean, we have a really cool basement; there's a swing down there, there's a pinball machine down there; it's just cool. That was like my sanctuary. And then it's like, when I hit puberty and I like got emotional, that's when my dad was like hands off. And that's when everything fell apart. And that's just common from everything my doctor and my

psychologist says. It's very interesting how when that happened I was just hands off. They just didn't care. One time I was swinging in the basement; I would just swing for hours. That's how, like, that's just what I did. And I was crying, and he just ignored me. He just walked by.

HG: So almost like when you started to really recognize that these were issues you were dealing with you felt you started to be ignored.

P1: Right.

HG: Others weren't going to acknowledge this, "You're going to grow out of it." We're going to pretend that doesn't exist.

P1: Right.

P3: That's true. I've had that happen, too, and like I said, my family all have mental illnesses, too, so it was really like mind-boggling to me that they're able to be like "Yours doesn't exist but mine does" or I also have a lot of family who are like in denial about their mental problems; that might be it. But like she said, too, my mom would be like "Oh, you're just doing this to get attention" or like, "Oh, you're just a teenager." I hear that a lot. "You're a 17-year-old teenager; you're supposed to be emotional." And it's like, well, I'm not supposed to have these thoughts or it's not supposed to cause this much trouble with schoolwork and stuff. So it was a lot of not being taken seriously. And I would have gotten diagnosed with my illnesses a lot sooner if my mom would have taken me to get help, but she never, well a lot of other things, too. She'd be like "Well, if I take you to get help they're going to think I'm a bad mother" and she has a lot of issues, too. I just had a lot of that, too, from my family not really taking it seriously and just not

understanding or just refusing to understand or just, yeah, hands off like “It’s too much for me, and I’m just not gonna do it.” I still experience that today. I have like one or two family members who I really love and trust and who I really feel like understand me and everything and that’s about it. It is really difficult.

HG: That is definitely a lot to manage and it sounds like, you know, the three of you have a lot of things in common. Even though your experiences are very different, they’re similar, too.

If you had an opportunity to give advice to university administrators and mental health researchers regarding the experience of students with mental illness, what advice would you give?

P1: I would say that, you know, for the office of disabilities, anxiety is a mental disorder. That’s one diagnosis that I think they should very much recognize, but they don’t. I think for the teachers, they should recognize that in this day and age a lot of kids have these issues but are afraid of the social stigma. My dad had a friend whose daughter, his friend’s daughter, I mean they were really close, the daughter and my dad’s friend. And they put her in an institution, and she signed a hospital thing, and she can’t get certain things now. And she lost her honors scholarship for it. I think she’s at _____(name of university). She had a lot of things taken away. And then my cousin, she was anorexic or is still anorexic. My dad’s cousin sent her to _____ (city) and just did the hands off approach and that really messed her up. And she’s having a lot more problems than I am. She went to college for a while and dropped out and became pregnant and then she had a

miscarriage and then that's where she's at now. She's having a lot of problems and nobody understands her.

HG: So how do you think mental health researchers and administrators could help with a lot of the things that you just described? Do you have any advice to give us?

P1: I mean, I think people should just understand that people do have these problems and they shouldn't just put a blind sight to it. Oh, this person's just not coming to class today because they're lazy. I mean, I understand, I know a lot of my teachers do that. I wasn't in class the other day just because I wasn't. I don't dare tell them I was crying in my car for hours because there was a song on the radio. They'd be like, "Oh, you're crazy." So you know, I don't say anything to them aside from I wasn't feeling well.

HG: So almost like recognizing and accepting that mental illness is legitimate and in some cases it can even be disabling.

P1: Right. Right.

HG: And to just be open to it.

P1: Right. Like people who can't walk. I mean, people understand that, you know? They understand that you have issues walking.

P2: Mmm hmm.

P1: And some people are like, "Oh, you have a mental illness. You're fine. It doesn't matter." So it's like, you know, I find that discouraging that people will accept some disabilities but not others. We all have disabilities. It all affects us in certain ways. I think the administrators are just very cut and dry because these are the rules and this is how it's

always been. And “Oh, we’ve got ADHD because so many kids have it, and we’ll add that to the list. But not kids who have anxiety. That’s something they can figure out on their own.” It doesn’t work that way. I know there’s a lot of my friends, well, not my friends personally, but people who have parents who just ignore it. So they don’t send their children to counseling. I mean, when they sent me to counseling in the eighth grade, it was because I was like erasing myself. I mean, I did an infinity sign on my thigh, because I saw an infinity of pain because I got a C in gym class, and they really, really hurt me, because they said you shouldn’t get a C in gym class. And I’m like, I was grading myself. I gave myself a C. Why are you gonna punish me? Because I couldn’t hit the wiffle ball? I’m just like, I’m not gonna play wiffle ball because I don’t like it. I’m not going to do it today. So I would give myself an F for the day because I didn’t play. And, you know, I ended up with a C in the class because, you know, it’s gym. It’s not a necessary course, so.. I mean, that’s when everything went downhill for me.

HG: So even just, maybe, for us to recognize that, you know, everybody the way they experience it is different, but, for some people, it’s just even hard to maintain any kind of self-confidence in order to do the things you’re supposed to do and it’s hard to just muster that up. It’s not like you can just conjure that out of nothing; so recognizing that even that is a legitimate symptom in itself.

P1: Right.

HG: What about for others? Is there any piece of advice that you would want to give to researchers like myself or university administrators about these issues?

P2: I guess from a school standpoint I think there should be more support groups for students who have a mental illness because a lot of people are hiding their diagnoses from other people, and I think that if they had that in place they'd be more comfortable in coming out.

HG: It is like coming out in a lot of ways.

P2: And, um, I think from a workforce standpoint, I think they should have, I don't know how they would do this, but like educate agencies employees on mental illnesses, because I think they would have a better idea of how to handle certain employees that may be having a quote unquote bad day because when I was at my agency I would be really tired, sometimes really moody and anxious. And I would get complaints from my supervisor saying that "They're saying to me that they feel like you just don't care and that you don't want to be there," and that made me really angry and upset because I felt like I'm acting this way because I'm anxious about the job because you want me to do, because I'm not sure what you want me to do and under stress because I feel like I can't and I'm moody because I don't have any supervision.

HG: It sounds like you feel misunderstood.

P2: Uh, yeah! And I would try to, you know, obviously improve and it would be like a huge cycle. Like getting nowhere.

HG: So maybe educating others about that cycle would be helpful.

P2: Mmm hmm.

HG: Any other things that you think would be good pieces of advice for me and for others who are working to serve students like you?

P2: Maybe like have, because one thing I really like about Wright State is that they have a psychiatrist on campus and some other universities don't. So I feel like due to lack of transportation or resources, some people may just forgo seeing a psychiatrist.

HG: Right. That's true in many universities.

P2: I know, obviously, funding is tight, but people with mental illnesses are increasing.

HG: So maybe administrators and researchers like myself really advocating for that and advocating for that as a need for students to have that. So then making proposals for funding those kinds of services?

P2: Yeah.

HG: Okay. What about you? Any advice that you would want to give to researchers or administrators?

P3: Well, I really agree with her, too, but I kind of want to take it in another direction. Like how she said you should be educating the employees who work in an agency? I really feel like my experience with a lot of mental health agencies is a lot of those people aren't informed. Because, like, even the receptionist at the desk; I've gotten some weird looks before when I'm like, "I really need to get therapy on Tuesday instead of Thursday. I just can't do it this week." And she's like, "Well, uh, we're real tight this week and stuff." I feel like if you're gonna work at a mental health agency, you should probably know about mental health, and a lot of the people just get in there because they're like,

“Oh, I want to help,” but they’ve never really experienced it with family members or with themselves especially. And it’s like really frustrating for me because I’ve lived it my whole life. I’ve known people with every mental illness, so I know it going into the game, and I know a lot of people in psychology who are like, “Oh, you have anxiety?” And I’m like, how can you look at me like that if you’re in psychology?

HG: So almost like a stigma even within the mental health profession.

P3: I definitely think there is. One of the things, too, when I was in the hospital for mental illness, they came in. I was depressed. That’s what I was hospitalized for. They came in and told me that my insurance company wasn’t going to cover for me to be there anymore because I was too depressed. Because I wouldn’t get out of bed, I wouldn’t go to group. And I’m sitting here like (laughing) “Okay.” So I mean like people just aren’t educated enough even within the field of mental health. And I really feel like maybe they should have to go to therapy sessions, not like personal, but maybe they should have to sit on group therapy for people with severe mental illness. People who have kids with severe mental illness. I mean like, the mother who I have now adopted me. And her son has autism which is a form of mental illness, too. And her life has just been so hard dealing with him. So I really think that it would help mental health professionals to be around people who may not even have it themselves, too, but who have struggled with it within their family, because you’re gonna get an array of stories and things, and I don’t think you’re gonna know how to deal with it unless you’ve really seen people suffer, and I don’t feel like a lot of people have.

HG: And maybe almost exposure to it, because that's what I'm hearing. I'm hearing that exposing yourself to those kinds of issues or people who are dealing with those kinds of problems. But I get the sense from what you're saying, that the exposure would not be in a voyeuristic way but in a very positive way. Like trying to really experience and understand it from a human perspective. Is that kind of what you mean?

P3: Yeah, it's true. Yeah, and also I kind of feel because it's their field they should be educated in it. If you're going into clinical psychology or social work or any of those helping fields I kind of feel like you are in it, you should be in it, from a humanistic standpoint because you have an urge and a need to help people. I don't really get that feeling with a lot of people and I've been through a lot of agencies in my life from social work to counseling to psychiatry to just about everything and there have been maybe like a few good people from each agency that really I could tell cared about my situation and stuff. I don't get that sense often enough, I guess, from people.

HG: So I hear you almost say for mental health professionals to be a part of the community; I mean, as much as it can be. For each person it's different. But joining in the community as an advocate and, really I hear as an ally.

P3: Yeah. I know that part of the job to be a good counselor or therapist is that you have to be able to distance yourself, and I realize that. But I'm just saying that I feel that there's within the mental health agency, I don't know, there's just not enough empathy I guess and there's just not enough awareness. And if there is awareness, I feel like people get it from an educational point. I know that there's a lot of jobs that you can do with a four-year degree in psychology, I mean not a ton, but there are some jobs that you can do.

But I still think that doesn't really matter because in four years of psychology we don't really even go into clinical psychology and do much or abnormal and stuff. So people really aren't ready for those jobs. I know that one of the professors here who does psychology of personality, he did a psychology club and said that when he was in graduate school it was required that everybody there had to go to therapy for two years for themselves and they had to go to group therapy. And I think that's awesome. I wish that they would still do that in psychology programs because it's like how are you going to be a therapist if you've never been to therapy yourself? You know? You really learn a lot about yourself when you're in therapy. I don't think you have to be crazy to go to therapy, you know? And a lot of people feel like, "Oh, I don't need therapy. I'm fine." But I'm like maybe just talk to somebody. So I would love for that to still be a part of programs. You have to go to therapy. You have to see what people with mental illness see, because I feel like it's a job where you've really got to know it to be able to do it well.

HG: And almost like you could empathize better if you've been in the seat of the client.

P3: Exactly.

HG: Experienced what that role is like. I definitely hear you. And, in some ways, if you're saying, "No, I don't want to do that," it's as if you're perpetuating the stigma. If you believe in therapy, why wouldn't you, then, feel okay to experience it yourself?

P3: (Laughter.) Uh huh!

P1: I know at Wright State, at one point, my psychologist came here for his Ph.D., and they were actually accepting people who had been to therapy before him. A long time ago

they would accept people who had had therapy before people who didn't. He had therapy, and he got accepted in. It's interesting that they would put someone who had therapy first before they would accept somebody who had straight As. I thought that was really cool back then. I don't know if you guys still do that or not.

HG: I think, you know, we're seeing less and less of that and kind of moving toward it not being a requirement whereas in the past maybe it was.

P1: It was back then. Because he didn't have straight As, but he was up there. But there was someone who had straight As, but they didn't have any therapy. They never went to therapy and he did. So they took him before the guy with straight As.

HG: So it's almost like the personal experience would be a qualification. Like a job qualification.

P1: That's how I see it.

P3: Me too. That's how it should be.

HG: What did you say?

P2: A benefit and a (inaudible).

P3: I think nowadays it's looked at as more of a negative thing, if you've been in therapy, if you've been hospitalized, if you've been on medicine. Like "Oh, can they handle the work? We really want people who can keep straight academics and stuff." And I guess that's one thing, too, that I would kind of add for mental health professionals is, like, whenever you do go to get in graduate school. Like I have a lot of anxiety about applying for grad school and stuff because of my mental health history, and because I'm afraid that

they're gonna look at me and be like, "Well, you had a really bad.." Because, you know, they go over your whole record. When they look and see that I had a bad, had a hard time in school because I was having a lot of mental stuff, I feel like they're going to be like, "Well, she can't handle it" or "She can't really be consistent, and we need somebody who's gonna be consistent." I think that they should be a little bit more understanding and I feel like it's life experience, like it's already job experience if you've been through therapy and you've been into a hospital for a mental illness and stuff. That's the environment you're going to be working in.

HG: Definitely. Okay, well, I'm actually going to move on to our last question just for the sake of time. The last question's just kind of open ended. I want to know how to improve the experiences of university students with mental illness. Is there anything that we missed? Is there anything that you came wanting to say that you didn't get a chance to say?

P1: Mmm, not really. I mean, the only thing I wish Wright State would do is they accept people with all disabilities except anxiety. I don't think they should do that. I also think that people shouldn't discriminate people with anxiety and stuff just because they have it. I mean, just like your experience with health insurance, I think that's terribly unfair. I know that they're private-owned and that they can choose, but I still think that's, you know, they're taking some of our rights in a way. I think that's very much wrong.

HG: How about for either of you? Is there anything you had wanted to say or feel like we missed?

P2: Um, I feel like counseling services should be free to everybody. Because I know here that people who have the university insurance it's free, but people who don't it's not after you go over 12 sessions. And I kind of don't think that's fair.

HG: What don't you think is fair about it?

P2: Um, I know some people need counseling for longer than 12 sessions and once you get billed \$10 a session, it's like "I need counseling, but can I afford it?" And I don't think that's really something that university students should have to worry about until they get out of school.

HG: Anything else you feel you want to add?

P2: No, I think that's it.

HG: Okay, thank you. How about for you? Is there anything that you would like to add?

P3: I was just gonna say that, going back to the thing about considering it a disability, you know like I said, the woman who adopted me, her son had autism. I, you know, I guess it's just kind of hard to word.

HG: That's okay.

P3: Okay. I'm frustrated with, you know, the mental health agency because I feel like they let everybody down. Um, like, her son, you know, has autism but it took him years to get diagnosed with autism. And I realize there's all these tests you have to do and everything, but he ended up in teenage years going to jail because of the fact that his autism prevented him from being able to understand certain rules in society that you should understand if you don't have autism. And when he was in court and stuff they

basically said, “Well, we don’t recognize autism as an illness that would prevent you from following the law” and, like, she had to run out of the room crying because she was like, “Are you kidding me? I’ve been dealing with this my whole life. You haven’t.” I really feel like in the mental health agency there should be more communication between the mental health agency, the law system, and between educational systems. I feel like it’s more isolated. Like if you go to school and you have a mental health history it’s like, I don’t know how to explain it. I just feel like it really lets people down, because the pain and the struggle that you have to go through in order to even get diagnosed with something, and places don’t even take it seriously until you’ve been officially diagnosed with something. I really just feel like there should be more empathy, I guess. I don’t even know how I’m trying to word this.

HG: You’re doing a good job.

P3: My whole life I’ve struggled with it. I’ve seen everybody I know struggle with it; just to get people diagnosed.

HG: So even that process in itself can take a really long time, and then it’s almost like not getting the help that you need in that meantime.

P3: Yeah. Yeah, I guess that’s one thing I would add, too, is that the diagnostics as far as getting diagnosed and stuff I don’t feel like are the best. And I have it on a larger scale. But, like I said, I’ve had someone tell me I have ADHD; they came and they did a test and then said, “No, you don’t have it.” Okay, well, I don’t feel like if I performed like okay or up to par for an hour on this test just totally doesn’t mean I have ADHD. Don’t

put me on medicine for it. I think that there should be more like, not surveillance but more monitoring of it.

HG: Almost like more follow up? So if you say, “No, it’s not that,” well, then let’s figure out what is going on.

P3: Exactly. Instead of just, “Oh, you don’t have it. Let’s take you off this medicine right away,” even though you’re already addicted to it.

HG: Right. I heard you say, too, more communication between different systems, right? Like different institutions, different systems. I guess what I was hearing is so people don’t get lost between the cracks.

P3: Yeah.

HG: Is that kind of what you mean?

P3: It is. I know that I received assistance through the government because I’m a very poor person; I come from a very poor background, and I know that my therapist has had to write letters before just to get me approved for certain assistance programs and things because I do have legitimate disabilities. I think there needs to be more of a constant communication. I don’t think it should have to get to the point that somebody’s writing letters, begging you to please take them for this assistance or for this. I feel like there just be an overall like people know you have this coming into a job or coming into school or going to apply for assistance.

HG: It’s almost like you could be more open about it.

P3: Yeah.

P1: Another thing I wanted to add is that people have a certain stigma. So if you go to a psychologist, you're crazy. I think that's so wrong. I know certain people who are like "Oh, you're bipolar. You're gonna get all angry and smack a kid in the face." That's something in the education department that they're scared of is people with bipolar. But I mean, the only reason they consider me bipolar is because I have running thoughts. That's the only reason. I don't really have that big of mood swings, but because when I get into a place my thoughts run and that's when they said it's like bipolar. But I'm so scared that they might tell me I have bipolar because then they won't let me be a teacher. That's where I'm kind of like it's not really bipolar, it's just running thoughts. That's where I'm like psychologists and psychiatrists have to be more precise with their diagnosis, because they might diagnose you "Oh, you have bipolar," but they don't realize that yeah, you have bipolar, but they're not going to give you a job in an education department if you're considered bipolar even if it's not technically bipolar. But the minute that they're giving you bipolar it's considered bipolar that's why they say you're bipolar.

HG: And I also hear you saying that certain labels have a stigma attached to them maybe more so than others.

P1: Oh, yeah. Right. I think that's wrong, too. I mean, every person's different, so why put everybody in one big pot and say, "Hey, you're all depressive so you're all going to be suicidal." No, you're not. Not everybody's suicidal that's depressive. Some are. I was but not everybody is. I don't think it's fair for people to be like, "Oh, you're depressive, so you're going to commit suicide at some point so you should go into the pot. And

you're bipolar, so that means you're going to be angry and sad so you're going to go in this pot."

HG: A lot of labeling and assumptions.

P1: And I think that's very wrong because everybody has different, I mean, there's depression but there's different levels of depression. There's some people that can't get out of bed in the morning, which I mean, that's a type of depression. There's some people that, like me, who just can't control their emotions, and they consider it depression. And suicidal thoughts, they consider that to be depression. I mean, there's so many different things.

HG: It's almost not considering the spectrum of where someone might be.

P1: Right. It's like, oh, depression – this is your pot. When in that pot there's like seven or eight different groups. So I don't think it's very fair for them to do that.

HG: Not a clean cut system yet people are put in boxes.

P1: Right. And that's what I think I've noticed.

P3: There needs to be a lot of filling in of the mental health system, too. And like, once you have a diagnosis, it's there. They can't just take it off your chart. So I've been hospitalized, but am I going to kill myself? No. Was I going to kill myself then? No. But whoa, we can't give her life insurance because she might kill herself. Or she's depressed so she might die earlier because she's putting stress on her body. I just think that's really sad.

HG: It is a harmful assumption, to assume that someone with a mental health diagnosis is any more likely to do those things. And maybe the stats show that, but to make that assumption across the board..

P3: I know that I had one psychiatrist who, oh man, when I was diagnosed with ADHD, they gave me Adderall. So I went to him because I had a question about how I was behaving on the Adderall, so I wanted the dose changed. He accused me of trying to get drugs and trying to abuse Adderall because people abuse Adderall a lot. So he took me off of it immediately, cold turkey, which is so bad for you anyway. Then he broke privacy, like he got in a lot of trouble for it. He walked me out to the front desk and told the receptionist that he had reason to believe that I was abusing drugs.

P2: Oh my god.

P3: I know. So then I couldn't get any prescriptions for anything for like months. They had to do this big meeting and all this stuff, and I just had a question about it because, like she said, they put me on rapid release, and I knew that the extended worked better for me. So I asked if I could get an extended so my whole day is like that, so I don't have any downs like falling asleep when I was driving. And then, yeah, he said I was abusing drugs. And I was like, "Oh my God. Are you kidding me?" I had to call my counselor, and they had to have a big meeting before I could do any medicine again.

HG: So almost like assuming that someone is trying to work the system or taking advantage of the system.

P1: Now, there are some people that do. I know some people that do, but to think that everybody does that? I think that's wrong.

P2: Yeah, that's unfair.

HG: I agree. Well, thank you so much for all of your responses. Did anybody have anything else that they wanted to say? Feel pretty good about where we're at?

P1: Yeah.

P2: Yeah.

P3: Yeah.

HG: I do just want to personally acknowledge all of the things that you shared. I know it can be hard, especially in a room of people you don't know, to share some of these things, so I commend you for doing that, and I genuinely thank you, too, because like you, I share in a lot of these feelings. So hopefully, by people like us continuing to come together, we can work so that our voices are heard in these institutions, so mental illness is considered to be a little bit more legitimate than maybe you all have felt like it has been. I think the more that we get this background information from people, I think we have more power in that, and we can use that information to get some of the things that we're needing, that we don't have. So again, I thank you. Anything else that you would like to say to me? Or anything about the process? No? Well, thanks so much and I guess, then, you're free to go. Like I said, I will keep all of your materials confidential. If you have any questions or if anything comes up, please feel free to use the email address that I have given all of you to contact me, and you can contact my faculty advisor as well. Alright. Thank you so much!

P1, P2, P3: Thank you.

Appendix H

Focus Group Two – Transcript

Hannah Gammon (HG): My name is Hannah, and I want to thank you for your participation in this study. The purpose of this study is to examine the experiences and needs of university students with mental illness. The information collected as a part of this study is strictly confidential and will not be used to identify you in any report or dissertation. Please be aware, however, that the participants in this group are not bound to maintain the anonymity or confidentiality of other participants; therefore, I would like to request that each you agree to keep all information shared as a part of this study confidential. Further, please note that participation in this study is voluntary; therefore, you are free to withdraw from this study at any time. We will meet as a group for approximately one and one half hour. I am going to pose several questions to you in that time. The questions I ask will be somewhat structured, but please participate freely as you feel comfortable. Does anyone have any questions? No? Okay.

Each of you is in this group because you have indicated that you have some type of mental health diagnosis. Please tell us your first name, something unique or interesting about yourself, and how long you have identified as having a mental health diagnosis.

Participant Eight (P8): Okay, I'll start. I'm _____, I was born in _____(country). I lived there until I was about five or six. Am I supposed to say what I have?

HG: If you want to.

P8: I'm bipolar and I have posttraumatic stress symptoms for about two years now.

HG: So you've been diagnosed for two years?

P8: Yeah.

HG: Someone else?

Participant Six (P6): I'm _____. Something interesting about me? I'm from _____(state). I've been diagnosed with psychosis NOS. I've had six episodes, and they don't really know why, since I've been 14.

HG: Okay, great. Thank you.

Participant Four (P4): I'll go. My name's _____. I really like rocketry. And, um, I think it's four months now that I've been diagnosed with early stage schizophrenia. They can't call it schizophrenia, because I haven't had the symptoms for more than six months.

HG: So you don't meet the criteria right now because of the time period?

P4: Yeah.

HG: Thank you, _____. Anyone else?

Participant Five (P5): I'm _____. I'm studying Chinese. And, uh, I've been diagnosed with bipolar and posttraumatic stress disorder since I was 23. I'm 31.

Participants: You don't look like you're 31.

P5: (Laughter.) Thank you.

Participant Seven (P7): My name's _____. I'm trying to think of something unique. I'm a graduate student in the social work program right now. I've had depression since I was 19 or 20, and I'm 27 now.

HG: Okay, great. Thank you all.

Okay. Since beginning at Wright State University, have you been involved with any mental health or student support services or programs? If so, what services and programs have you been involved with?

P8: I haven't been involved with anything other than.. Oh, I have narcolepsy. So I have to use their, um, student health. Um, I forget what it's called. I wasn't there since the first two months of school. Um, oh, the disability services. They help me with like my classes and everything. Like they get me note takers if I fall asleep in class. Anything really with my mental health I don't use.

HG: So nothing related to your other diagnoses?

P8: No.

HG: Okay. Thank you. Um, anyone else want to share?

P5: None.

HG: None? Okay.

P7: I don't have any either. Well, not here.

HG: Okay.

P6: Um, I do see somebody at CWS which is the Counseling and Wellness here.

HG: Is that, um, like a therapist? Or is it a..

P6: Yeah. It's like, I don't know what you call it. A counselor or therapist. Yeah.

HG: Okay.

P6: I think she's an intern.

HG: So you're seeing someone for therapy. Are there any other mental health or student support services that you've used?

P6: I do use a lot of um, they call it ODS, the Office of Disability Services, because I have CP, too. So I have stuff with that.

HG: Oh, okay. But nothing related to your mental health diagnosis?

P6: Other than the counseling, no.

HG: Okay. Thanks. Did you want to share on that question?

P4: Um, yeah, I went to the counseling and wellness place and after a half an hour meeting they sent me to _____(local agency) to go to a doctor there, and I'm seeing a doctor there.

HG: You said at _____(local agency)?

P4: Yeah. I'm a military child.

HG: Oh, okay. So then you're continuing to see the person at _____(local agency) rather than at CWS?

P4: Mmm hmm.

HG: Okay. Great, thank you.

Okay. Think back to when you first began as a student at Wright State University. What was the transition process like for you?

P7: Um, I'm pretty much a brand new student at Wright State University. I'm getting my masters, and I'm new this semester. I don't know where half the places are even though on the phone list they give us there's always that bottom portion of services and things like that. But I haven't had anyone come to the classroom to talk about it. I only know where to find it if I access it, and I don't feel like I have access to anything.

HG: So almost as though no one has explained the services to you.

P7: No.

HG: So you're not aware what's on campus?

P7: Right. I could look it up, I guess.

HG: What about for others? What was the transition to Wright State University like for you?

P8: For me, it was a lot easier. Because of my narcolepsy I get to schedule my classes and work around everything. Um, it was just kind of overwhelming because there's just so much more work than I'm used to. (Inaudible)

HG: So when you say overwhelming, what specifically are you referring to?

P8: I get overwhelmed easily. I don't like stress. I don't like new environments. I don't like, you know, large crowds. My anxiety gets too high. So I just like freak out all the time.

P6: As far as me, it was like really exciting because I got to be on my own for the first time and stuff, but at the same time I was really nervous that I would like, you know, somehow wind up into a psychotic state someday. I'm still nervous about that, because I don't what they're gonna do. It's very nerve-wracking.

HG: So it sounds like on one hand you were really excited to be here on your own, and you said it was something you've never experienced before. But at the same time, with that, came that fear that something might happen.

P6: Yeah.

HG: Was it a fear that there wouldn't be support for you?

P6: No, it was a fear that I'd wake up one morning and not be able to function and start hallucinating and not know what to do, because I have no warning of it.

HG: Right, definitely. That's a big concern. What about for others? What was the transition to Wright State like?

P4: The first two weeks was fine for me. Went to a friend's house, no drugs of course. Um, something would twinge in my brain and I suddenly had schizophrenia. I heard full blown voices, thoughts that weren't mine. Before that, classes were fine, everything was fine. Then something went wrong, and I have trouble going to classes, because I have anxiety around large crowds now. I, uh, I get worn out easily for some reason, which is in part probably because of medication. I have voices in my head, and, uh, they were not the best.

HG: I can imagine.

P4: Suicidal, like, suggestions from the voices but never even thought of doing what they say. Hurt myself, hurt others, and I would get at random times muscle soreness all over my body. My muscles would lock up. And, uh, I get confused easily now. And, it's just, it's hard to go to class when you have all of that going on and, at times, regular room lights will be too bright. Like I would have to wear sunglasses everywhere I went, and then..

P8: I do that all the time. My narcolepsy makes me have migraines so if I'm at work or something where I'm not just laying in my bed I turn off all the lights or put on sunglasses or something.

P4: I wear sunglasses at night. It helps me relax.

P5: I do that when I have a migraine, too, wear sunglasses at night. Other people just think I'm weird.

P7: (Inaudible)

P6: Yeah, like, I know what you mean by the voices. Like, you don't want to do what they say but it's really hard. When a voice says something, like mine have never said mean to me or bad, but they're like, "Do this first or do this first," and you can't not do what it says.

HG: Number four, I want to go back to what you had said when you said that this started two weeks into when you first transition to Wright State, is that right?

P4: Mmm hmm.

HG: Are you a freshman this year?

P4: Yeah.

HG: So this was pretty soon into your transition, then. That happened pretty early for you.

P4: Yeah. I looked back into everything and there was no trigger whatsoever. And that's kind of, that's kind of, uh, I take meds to get rid of voices. But it's still a little stressful when you can't focus and you have work to do. And even if you have a completely dark room, and the computer's off, everything, and you're just sitting there with a piece of paper in front of you; it was basically having something constantly yelling at me in my head. Which, it's kind of hard to focus with.

HG: Oh, absolutely.

P8: Does the medication, like, help with the voices?

P4: Uh, it shuts them off now. But now I'm dealing with the side effects of that: extra muscle soreness, weight gain; I gained twenty pounds in the past two weeks.

P7: Yeah, the side effects of medications are absolutely the worst. And then when that one doesn't work, you have to switch to something different. I think the scary part about medication's that in the first few weeks, months, whatever, you don't even know what you're going to do. You can't really, it's like you can't trust yourself.

P8: My meds, my meds, uh, when I first got on, uh, for bipolar I didn't have the right combination. You just have to have the right combination for it, but we went through all these meds, and I dropped down to 98 pounds, and because of that I barely gain weight.

I'm up to 105 now, but I eat like I'm like 400 pounds. So it's not like I'm not eating, it's just messed up my body, and I can't gain weight.

HG: Okay. Well, for the sake of the interview I'm going to move on because I think some of the things we're talking about will lead into some of the future questions. You're doing a really good job at participating freely, so thank you.

Oh, I'm sorry, did you get a chance to answer that last question? I just realized maybe you didn't.

P5: No.

HG: I'm sorry. Can you tell me more about what your transition was like?

P5: Well, I first came here like 11 years ago, and I was not medicated or diagnosed. And I was doing really badly. Like, uh, I failed. I did so badly. And so I dropped out. And I came back a year ago after I had been treated in therapy and medication. And, I thought, I'll try. So I just took like two courses. And the thing that helped me transition was the fresh start. They erased my grades from when I failed. So now I have a 4.0.

HG: Wow.

P5: I was like that's amazing. That's one thing that Wright State did for me.

P7: They have a program that does that?

HG: The program's called "Fresh Start," you said?

P5: Yeah. If there's been, I think, like two years between when you left and you came back, it was more than that for me, then they'll erase your grades and give you a fresh start.

HG: Wow. That's great. Thank you for sharing. Was there anyone else I skipped on that question? I apologize.

P7: No, I do have a question, though. When you talk about university life, the transition to university life, can I share even if I've had the experience but not at this school?

HG: Yeah, you can share something if you'd like. I'm asking specifically about Wright State, but you can feel free if there's something you'd like to add.

P7: Okay.

HG: What was particularly difficult about your transition to university life? And I think this is a little more general than Wright State.

P4: Money.

HG: Money? Okay, sure. Can you say more about that?

P4: Um, my first job was over the summer, so I didn't have much monetary value saved up for college. Thankfully, my parents gave me the GI bill which is going to get cut off and I'm going to have to pay back. So it was just, uh, getting the money and getting all the stuff that you need for your room rather than getting what you want. Trying to find the right balance of what you need and what you want.

HG: Thank you. What about for others? What was particularly difficult?

P7: I'd say I left Dayton and I moved to _____(another university), and I moved there by myself. I knew one other person. I think that's typical of a lot of students that they live here and they're in an apartment by themselves. And, uh, not knowing many people, not being able to connect fast enough with other people, you crave being with other people. And I never really felt safe. And then, not knowing where things are at. And the maps do nothing for me.

Participants: (Laughter.)

HG: What about for others? What was particularly difficult?

P6: I think for me it was mainly, along with the worrying about the future and stuff, I think it was mainly that I had never really been away from my parents. So it was finding and doing everything by myself, because I'm from _____(state) so my parents are like ten hours away and they can't come help me with anything. So it was more like finding things, because I get lost too still. Just doing everything new and starting over pretty much is the hardest thing.

HG: For sure.

P8: I think mine was just the workload, you know with school, and then I work like 30 to 40 hours a week, and I still had soccer. Like, I kind of rushed into things. I mean, I've always worked 30 to 40 hours a week every year, but now I don't work anymore. To me, that's a huge thing for me. I don't know how to do it. I don't know how not to work. That, and, because I work so much, you know, I don't really talk to my friends anymore. I have, you know, like a handful of friends, but only one of them, two of them, goes here.

P5: Being, uh, you know, uh, when you have mental illnesses you're afraid of falling back into how it was before. When you start something new, uh, am I going to be able to handle it?

P6: Yeah.

P5: Am I going to be able to handle.. especially since where I'd been to Wright State before. I didn't want to fail. I wanted to do even better than I had before. Every time I take on more responsibilities, I have a terrible fear. And even like meeting new people; I'm very nervous. (Inaudible)

HG: What was particularly difficult for you in coming the first time?

P5: Uh, off medication it was, uh, showing up to class. My sleep schedule was terrible. Remembering to turn in things, because I just couldn't focus for any length of time. That was the main thing, my sleep schedule. I was so off. I wouldn't know what day of the week it was. "I have class today? Really?"

HG: And you said it was really hard to focus as well.

P5: Oh, yeah. Especially if you're manic.

HG: Sure.

P8: Freshman and sophomore year of high school. Completely – I'm just surprised I even graduated high school because I was so manic.

P5: When you're manic, it's hard to pay attention. When you're depressed, it's hard to get out of bed.

HG: What was particularly helpful to you in your transition to university life?

P4: Friends.

HG: Friends?

P6: Friends.

P7: Yeah, friends.

P4: Just coming in, and I had connected with my roommate and a bunch of people on my floor, so that helped. Even though my family was 15 minute away, it helped to have friends here.

HG: So you're in a dorm, then? So it helped to be in a dorm with other people on your floor?

P4: Yeah.

HG: Good. What about for others? What was particularly helpful in transitioning to university life?

P8: I don't know, to be honest. I think I just kind of got used to it.

HG: Maybe time? (Laughter.)

P7: Yeah, time was definitely a big factor.

P5: I made an effort to go to the UCIE parties and made a lot of international friends who had similar studies and are more my age. I made a lot of friends.

HG: Good, good. So it sounds like for you, you kind of reached out to a campus organization or a campus group and that helped you.

P5: Yeah.

HG: Good.

P7: I think my job helped me to make good friends. We had to park all the way on what they call west campus, and you park in one huge lot and take a bus all the way in. And every day you'd be on the bus next to someone, and weirdly enough, I rarely made a connection with anyone on the bus. Instead of looking at each other, we would just look down and never even talk to each other. It was very rare. But, you know, people you had classes with, eventually you would talk to each other. And you were able to make some good connections there.

HG: Good. So that seemed to help you?

P7: Yeah.

HG: Good. Anyone else want to share things you found to be particularly helpful? Or anything we haven't mentioned?

P6: Just friends.

HG: Yeah. Okay. Well, it sounds like social supports is the main thing that got you through that really tough period of transitioning for anyone. I think it's hard for any college student, let alone having some type of mental health diagnosis. Which I think can really impact that and make it harder in some ways.

In what ways do you feel your mental health diagnosis has impacted your experiences as a university student?

P8: I'm just not so social. Like, you know, when there's those big parties? I just can't do it.

HG: Can you say more about why you can't go?

P8: Um, like I said, I can't be around like a bunch of noise and everything. I just can't be around large groups of people. My anxiety goes up too much, and I just don't have fun.

P7: I'm an introvert. I remember at one point I just used to be so fun-loving. (Inaudible.) I remember a stage when you just experience nothing and then there's this naiveness that just kind of went away and you're just guarded all the time. And, I don't know, the experience was you'd just rather go home alone and (inaudible) and have a beer. Rather than go out on campus. Especially with all this rape on our campus, I'd never wanna.. I'm terrified whenever I leave at all.

P8: And that's why I don't schedule any classes at night. I'm not going out.

HG: Sure, yeah, that makes sense. Um, what about for others? How do you think your diagnosis has impacted your experiences as a university student?

P6: Um, I don't get enough sleep, and I think that it's just that I need a lot more sleep than most people. I'm always tired and I just always want to go take a nap, and they're like "No, hang out with me, do this," so I always have to, I feel like. And then on top of the worry that if I don't get enough sleep one day I'm gonna end up not sleeping for like three days and being in another psychosis, you know? That's always in the back of my

mind. Like, people tell me you can't worry about it, but it's always in the back of my mind.

HG: Sure. It's hard not to worry about it.

P6: Yeah.

HG: Any other ways you feel your mental health diagnosis has impacted your experiences as a university student? Maybe in ways that others wouldn't have experienced?

P5: I'm very cautious and I have a lot of trouble trusting people. Like I find a lot of my friendships are superficial. And when I enter a room, I'm always checking the exit. I keep something close to me that I can use as a weapon. Part of the PTSD, I guess. Things like that. I guess you could say I'm a little paranoid. It's a little silly, I admit. If I have a class at night, which I try not to, but if I do, I do the keys in the hand.

Participants: Oh, yeah.

P5: Little things like that, all the time. I get really paranoid if I'm walking down the stairway and somebody's also walking.

HG: It sounds like a feeling of where you're almost always on edge, and it's hard to relax.

P8: I always sit at the back of the class, because I don't like people behind me. Or I like to be near the door.

P6: I'm the opposite. I don't like sitting in the back of the lecture hall, because I look down and start panicking because there are so many people.

HG: So you try to sit in the front?

P6: Yeah, I sit in the front.

P5: I always think of like, I feel old sometimes because I see the girls in the sororities and I'm like, "you silly girls." I don't know. I feel like I've gotten too old for these kinds of things. That's why, you know, I can't participate in those big social parties. You know, because it always looks silly to me. And, like you, I'm kind of more of the beer and the movie at home. That always sounds good to me. I try to do a few outgoing things like the parties with the international students. I'll go to that, an hour or two of that and I'm done. That's a lot for me, and I'm tired afterwards.

P7: I usually go for like a half hour. (Laughter). And it's like, okay I've seen all I can see. (Laughter.)

P5: It's a lot.

HG: Sure, sure. It's exhausting.

P5: I'm really, really tired afterward.

P8: With my narcolepsy, if I have too much emotion, like if I'm laughing really hard I get this feeling in my muscles. Like I just can't move them. But it just makes me extremely tired. I have so much anxiety that I'm just going to go home and go to bed.

HG: Sure. Something you were saying, number five, reminded me almost like a feeling of alienation from others, or feeling disconnected from other people. Would you say that that's true?

P5: To some degree.

HG: What about for others? Are there other ways that your mental health diagnosis has impacted your life as a university student? Academic life? Anything like that?

P7: Academically, the staying focused thing. And when I get home I'm like "Oh, I'll take a nap" and next thing I know I'm like sleeping for hours and sleep through class. And then I went through periods when I was not on medication where I would just lie to everybody, because I was just so ashamed that I couldn't keep up with things. I couldn't keep up with my school, I couldn't make it to my job. It would get so close to where I was failing. And I was in a relationship for years, and the guy broke up with me, and I went into a complete depression and I was failing. (Inaudible). I'd say that depression without medication, without any kind of therapy, any kind of treatment – you just don't really care enough about yourself. You don't even care to talk to other people. Your family (inaudible).

HG: Were you going to say something?

P4: Um, basically after my brain went twang, I met my girlfriend the day afterwards. Everything was fine and I was going pretty well. Four days later in a single text she dumped me, saying that she didn't understand. So with that and the aversion to crowds, I just can't be in crowds anymore. It's just, I don't talk much anymore, because I always, there are bouts where I'll get angry and get upset for no reason. And that I can't control,

which makes me feel much worse not being in control. Um, and it's just that am I going to say something wrong? I mean, I already came out of that shell once when I joined tech crew at my school and I became outgoing more than I usually was. Now it's just back down.

HG: And it sounds like you feel that wouldn't have been the case had you not had this, um, for you it's this pretty recent and new mental health problem. And you think otherwise things would have been..

P4: I've never taken that many.. (phone rings) Sorry.

HG: You're fine.

P4: Um, with me it is. What was I going to say? It's staying focused.

HG: Well, you did have a distraction there. (Laughter.)

P4: I forgot what I was going to say. I never took that many medications before. I took two for allergies. Now I'm on five different things and it's also now having to take medication to function is really not good.

HG: That's hard, for sure.

P8: I think it's worse when you're in college remembering, oh, I need to take my medicine at like this time and everything. I'm horrible at taking medicine.

P6: I'm terrible, too. There are some days that I'm like, oh, I forgot. Just like one pill for me I know that if I skip it once or twice I'm sunk, (phone ringing). So then I start worrying.

P7: Some are long-acting, some are short-acting, yeah.

P4: I'd just like to apologize for the phone.

HG: No, you're fine. You're fine.

P7: Then it's just like, oh, it's just a day. Sometimes it's two or three. When you get off schedule, one day throws you off.

HG: I'm going to move on to the next question if that's okay with everyone. Do you view your mental health diagnosis as a disability? Why or why not?

P7: I think I'm at odds with that one.

HG: Tell me more about that.

P7: I don't want to view it as a disability. I've learned how to deal with it for as long as I know, but I have never really dealt with it. I've gotten through it, I think. It is a mental, I'd say it's a mental disability. You can't control it. You don't know what days you're going to be fine and what days you're not. Some days everything is just heightened. And you just don't want to even do anything or leave the house or whatever, and force yourself just to (inaudible) things. Yeah, I guess it's a disability, but I've never tried to get any services for it because of I would say stigma, of course. You know? People say, "Oh, you can deal with it. You're fine. It's just a little depression." Almost like it doesn't warrant services. But I would consider it a disability.

HG: What about for others? Do you consider it to be a disability?

P8: Kind of. You know, I've dealt with it for, you know, two years with my bipolar, but I've always had it. Ever since I can remember. So I've always dealt with it, so I know to, I know if something's happening, like, I know how to deal with it in the situation and everything. But you know, people who say things like "Well, I can't do this and I can't do that," you know, they don't work, you know. Like I said, I work over 30 hours a week, and I still deal with it. You know? I guess that's just how I was raised and everything. And you know it always helps just because, you know, your mind's not (inaudible) and everything. Sometimes it is a disability, and then it's not. It's not something that, you know..

HG: It doesn't mean you can't live your life.

P8: Right.

HG: But it sounds like what your saying is that it impairs things for you. It makes things maybe harder in some ways, but what I'm hearing is that it does not make it so you can't live a life just like anyone else would. Is that what I'm hearing?

P8: Yeah. Right, basically.

P6: Um, I think it is a disability, like, I wouldn't want to think of it as a disability, because, like, "disability" is just such a negative word. Because I've heard it used my whole life not just because of my mental health but because of my physical challenges and stuff. So I don't really like to attach the word disability to it, but that's what the rest of the world considers it, so I guess it is. I like to consider it more of a characteristic, kind of.

HG: So almost like a part of your identity more so than something that is wrong or..

P6: Yeah! Just kind of like the same kind of thing as I have brown hair.

HG: Right, right. What about for others?

P5: I'd say it can be. There was a time, let's see, shortly after I was diagnosed with posttraumatic stress disorder and it was really really bad and, uh, I was in the hospital. I could not function at all. I was suicidal, I mean there was nothing much at all left in my being. And that went on maybe two or three years before I had successful therapy for that. And during that time, I would consider myself disabled, because there was just no functioning. But I think that's more of a combination of (inaudible).

HG: So almost like it could, it depends. Depending on the diagnosis, depending on how severe it is at the time. Is that kind of what you mean?

P5: Yeah. Whether it gets treated, how it's treated, maybe in certain situations. And I think you can come out of it.

HG: What about for others? Does anyone else want to share whether they view their mental health diagnosis as a disability?

P4: I, mine is more of a quality because when I am able to focus, I have better ideas for some reason. But it's a disability in the fact that it keeps me from doing normal day to day things. Like, I couldn't focus enough last week to get my laundry done. It was always something else on the mind, something else on the mind, and in that case, it is a disability.

P8: I guess it's like how severe it is to me. Now, if it's just, well, I'm just in such a bad mood, you know, to me a bad mood is a bad mood. Like, you know, my uncle, he has schizophrenia. What happened you know, when we found out he lit himself on fire. That night is when it all started happening. Well, you know, he's on disability. Can't work and he can barely take care of himself. That to me, yeah, that's an extreme disability. But, you know there are people who when I hear disability really aren't, shouldn't be on disability or anything. Could just like, you know, put, you know, a bad reputation for people who actually have it. I know a girl in high school who's depressed, you know, and she really wasn't but she wasn't but she was getting, you know, checks for being disabled. For depression, you know? That's crap. Because, you know, I don't have to work. I don't have to do anything because of my narcolepsy, but I still do.

HG: Sounds like it isn't a perfect system.

P8: Right.

HG: It isn't, maybe, easily defined to the point where we can have a clear picture so we can make those kinds of determinations and decisions so that it seems, I don't know, black or white. Either you have a disability or you don't. It sounds like there's a lot of gray area.

P8: Yeah.

P7: Everyone functions at different levels. I kind of view the situation where based on people's environments and how they grew up and how they learned to cope with things. I hear someone with a lot of work ethic in their family, like, "I have to work," you know. You don't have a right not to. You should work. That's how it was in our family. That's

why I didn't want to view it as a disability, because it's an excuse from working. It does affect the functionality of my work, um, you zone out and you just can't talk to anybody. But, um, I may have seen my parents cope well with something, but someone else's depression or with another mental illness might have had parents or guardians who they watched not cope with things as well, and that rubs off on you.

HG: And they might not know how or..

P7: Yeah.

HG: There's a lot of factors that go into it. I think you're absolutely right.

P7: There are just so many factors and so many things to think about. You don't even know when it's going to happen, how it's going to happen, what it's going to affect, what's not. And the world's always trying to attach a label or a stigma or a name to something like "disability." And no matter how many times you change that word, they're still going to put their own label to it no matter what. (Inaudible)

HG: Thank you. Any others want to share on the topic of disability and your mental health diagnosis? No? Okay, well, then we can go ahead and move on to the next question.

Have you experienced negative reactions from others in regard to your mental health diagnosis? If so, in what ways?

P8: Just by my parents. They're, you know, they're so cautious. My, you know, when I wasn't getting treated for being bipolar I had periods where, you know, I don't remember anything. I just became really depressed, and I overdosed. Don't remember doing it, but I

woke up in the hospital and was like, “Why am I here?” So even now I have everything under control, you know, they lock up all the medications which makes me so mad because I use so much medication and I can never get to it. And that was four or five years ago.

HG: So it feels like they’re overly cautious and almost don’t trust you?

P8: Yeah.

P6: My parents are the same way, especially like my mom. Because I don’t have the voices in my head all the time but occasionally I’ll have the voice in my head. I named her, and so I’ll have her in my head and she’ll be telling me to do things and I tell my psychologist back home and mom overhears. She’s like, “WHAT?! You’re hearing voices?! We have to get you to a hospital immediately!” I’m like, no, no, it’s not like that. And, it’s like the overreaction, it’s kind of stressful to deal with it. Like I know she cares and stuff and I know they care, but it’s just hard.

HG: So even though your mom has good intentions and she really wants to do the right thing, it really sounds like it feels like it almost has a negative effect unintentionally.

P6: Yeah.

HG: Though she doesn’t mean it that way?

P6: Yeah.

HG: What about for others? Any negative reactions in relation to your mental health diagnosis?

P7: I'd say sometimes family or friends tiptoe if they know that you have a mental illness. They tiptoe around things that could upset you or use different wording to make it sound sugarcoated. Or they won't tell you things just to forego you feeling anxious about something. They leave you out of family situations or situations, because I've had friends not invite me out places when I was having like a mental breakdown or something a long time ago, because they just didn't know how to deal with me.

P5: Sometimes they don't tell me when people die.

HG: Really? Wow.

P5: That just makes it worse.

HG: Sure.

P5: They think it makes it easier, but it makes it worse.

HG: So again, it's that idea of having good intentions but it actually backfires.

P7: "Oh, we're trying to protect you." But that's not true.

P5: I find it's very difficult to date.

HG: What do you mean when you say difficult to date? Is there anything in particular that makes it hard?

P5: Well, if you enter into any sort of relationship, you need to have that on the table. And putting that on the table almost immediately loses that other person.

P8: Trust issues.

P5: Trust issues.

P8: You know, I have nightmares due to my PTSD.

P5: I do, too.

P8: You know, I have, well, I don't know what we are, it's been off and on for two years, but he understands everything. That was like the first person that was okay with it. You know? Like didn't freak out if I had a nightmare, just wakes me up. Say, you know, "You're sleeping, you're fine." Other than that, you know, no one really knows how to deal with it. So you know, I don't want to go out to find a different person, because I don't want to sit there and explain everything. And him like think, "Oh my God, she's crazy. She's gonna kill me one day." (Laughter.)

HG: Right, yeah, for sure.

P5: And I also have to deal with the night terrors, too.

P7: Nightmares are the worst, because all of your insecurities and all the fears that you just don't talk about on a daily basis. Like, I hit my boyfriend the other night. I had a horrible dream that he cheated on me, and he's just not the type. He's a sweetheart. But the dream was just so awful based on an experience I had when I moved away to college for the first time. So I woke up and I was like batting at him and telling him to move away or whatever, I don't know what it was. And he was like, "What's going on?" He didn't know what was going on. And he just had to sit there with me on numerous times when I was on different medications and people who have been on Prozac, they can see how bad it really is. No one else.. My sister, she experienced the same things that I do,

but he would sit there and if I would start crying. I would walk, he would come over, and I'd be cooking dinner one minute and I'm waiting for him to get back and, um, I'd walk out of the kitchen, and he'd go sit on the couch with a beer or something, and I'd just start crying out of nowhere. It's ridiculous! I'd be like, "I don't know why I'm crying." And it's just, it's embarrassing. You don't know how to deal with that. And you feel lonely, even though the other person's in the room. And how do you explain that to someone? It's like in your head.

P8: I just feel like there's times where I'll be laughing and then I'll just sit there and start bawling my eyes out. No one, my mom just sat there, and she always tries to make me laugh when I was in that stage, when I would start crying. She goes, "I don't understand this." Well, I don't either. But I'll make jokes out of it. But, yeah, I've woken up screaming at other people because if you're in my dream, I would just wake up with that emotion like, "Don't do that!" And they're like, "What did I do?"

P7: For the whole entire day, you carry that for some reason. Poor guy. Poor girl.

HG: What about others? Has anyone else gotten any negative reactions from others related to their mental health diagnosis?

P4: Um, my mom, she's an Air Force captain. Did college with being, did college, Air Force, and was a mother to both my brother and I when we were very young.

HG: And you said a single mother? Single mom?

P4: Yeah, my parents divorced when I was five. Um, I'm okay with that. Um, but she is very much a doer. And I was perfectly up with that, and um, she's going off what I was

able to do before this popped up. And she pushes me which most of the time it just makes me feel like I can't be right. I can't do things correctly. But she does know a little bit about mental illness, my grandfather had bipolar and narcolepsy, too. They go hand in hand for some reason.

P8: Yeah. That, and depression. It's hard. Especially when you're tired, you're like, "Really? I don't want to do this right now."

P4: And, uh, my dad has, uh, PTSD from Air Force special operations, flying several years in that. And I can really talk to him. He pushes me, too, but it's in a more understanding way. But it's kind of hard not being able to do things when, uh, you were able to do things the rest of your life and before and you're an Eagle Scout and you have to be able to do things because you're an Eagle Scout, and it's just a lot of extra things just being pushed on you. Just because of what you could do and not, my mom just doesn't take into effect the severity of what's going on.

P8: I think they just don't want, they just don't want to think it's real.

P4: Yeah.

P8: And it's just like, you know, I'm not lying, you know. You need to understand, okay, they don't have to because they don't have that problem. So it just makes everything ten times worse. They're like, "No, it's not that bad." No, it really is.

HG: Did you have something you wanted to add that?

P5: I just wanted to add that my dad is obviously mentally ill, but he's never been treated. But he's just, he's very much an achiever. All of his life. In the military and high up in

rank (inaudible) a winner and all these things. But at the same time, his brother killed himself. It runs in his family so badly. It's really bad. And his other sister was depressed, and they were all treated. But he doesn't want to admit that has a mental illness, even though he very obviously does. But he, and he also doesn't, he never wanted to admit that I did until I was well and getting treated. I think he just can't, even when it's very, very obvious.

HG: Others? Anything that we haven't said that people have noticed in terms of negative reactions from others?

P6: I don't tell a lot of people about my illness, this, the worst parts of my illness because it scares a lot of people, but the people that I do decide to let in have honestly been more positive than negative so that's been a good thing.

HG: Good, good.

P6: Um, because I find that if I tell people they start freaking out and wondering if I'm going to go like psychotic right that second. And so I don't tell, I often tell people who have told me that they have a mental illness, because then I feel like we have something common to keep together.

P8: I don't think it's as bad as it, you know, probably a couple years ago, because a more and more people have it. It's more, you know, accepted. That's really not the right word. Like it's understood more.

HG: Well, unless someone has something that they want to add, I'm going to go ahead and move on to the next question. Is that okay?

Participants: Yeah.

HG: If you had an opportunity to give advice to university administrators and mental health researchers regarding the experience of students with mental illness, what advice would you give?

P4: To make the teachers more lenient. Because instead of having three classes I could possibly pass this semester, I'm down to one because the other two won't yield just to let me pass with a C. All I want is the lowest grade to pass the class, and they just won't yield just a little bit so I can at least pass the class.

P7: I personally don't like the attendance thing. I mean, we're paying to go to school, but I know instructors don't want to come to class and no one be here, but if we want to pass the class, we go to class. I think it's up to us to decide how many classes we want to go to, and, um, sometimes really you just can't get enough motivation to get up and go to class, even if you'd really like to. And then you feel so, you beat yourself up more about not going than anybody else can. I just feel like there shouldn't be a set, you know, I agree with the lenience thing. Don't have a set limit on how many classes you can miss. Let us talk to you about it, based on our situations (inaudible).

HG: Contextual, kind of?

P7: Yeah. Don't just be like you don't get a chance now because you weren't here, so no exceptions. There are still some teachers who do that.

P6: Yeah, like I've had, because I also have epilepsy, um, and I've had seizures like right before tests and I'm like, I really don't want to take this test right now, but there's no

makeup, so I have no choice. You know, and I have to take the test and I didn't fail that test I don't think, but it just, there's sometimes you just don't.. I don't think it's really, I agree, professors don't really consider your situation. Every situation is different, so leniency is really important.

P7: I say we should have a choice to decide.

P6: Because, like she said, we're paying for it. It's not like elementary school or high school or middle school where we're not paying. We're paying for our education, so if we're willing to pay to miss a class..

HG: Right, sure.

P8: See what got me was I had a math class that's on the computer but you had to go to class, and it was Monday, Wednesday, Thursday. 8 o'clock in the morning. You know, our teacher didn't show, you know, we had proctors, just watching us and if we had a question, they would help us answer it. Well, then, why can I not come to class if they're at home? I literally had to say since I can take my test in a room, which is fine, no cheating (inaudible). And you know you had to be in at least six classes. Any less than six, and you completely failed no matter what your grade was. So what I had to do, I literally it took about a month (inaudible). But I was like really? That's just kind of stupid. I pay for this class.

HG: So having attendance records is kind of problematic for you, it sounds like for many of you that's kind of a struggle, having to be at a set number of classes and having that weigh into how you're evaluated at the end of the term.

P7: I can see how it's also a good thing to have that. I know that I mentioned it as a bad thing, but the good thing is that it forces us to go out there, but forcing you against your will sometimes, and then this sounds odd, but sometimes you really feel like you're forcing yourself to do something that you just could not do at that moment and it's just going to make it worse if you try and do it now. Like, for example, if you're around people and you don't feel like being around people, then you feel anxiety, stress, and you're like "Uh, I've got to get in my car, I've got to drive to class, I've got to sit around all these people.."

HG: Rather than taking care of yourself.

P7: And, and, and, and sometimes I cannot just sit there and take any more noise. I can't do it. You just, you get there and you walk out again. You just can't do it. I don't know.

P8: It's like embarrassing.

P7: It is embarrassing.

P8: Because, you know, there's been times that I've like walked out of class and bawled my eyes out in the bathroom. And it's like, you know, can I just go home? And I don't want to, you know, when I cry it's completely noticeable. My face is always bright red, and I'm blotchy all over. And it's like, you know, just let me leave. And if I have to leave class, and I wasn't here to get the information, then it's my fault and everything.

P7: They even say that it's up to us to get our information from other people, and if there was someone else we might trust in that classroom, I don't think we'd abuse it. I think

others might think we're abusing it or a teacher might think we're abusing that privilege, uh, to not come to class. You know?

P6: I agree. I guess I can see why they do it, but it doesn't like, the attitude is that everyone has perfect health and everyone can come to class, but there's always situations that..

P8: And if you notice, you know, people who have mental disorders, you know, we're so stressed and our immune systems are crap. I know I get sick at least once a month, you know, where I'm vomiting. And I'm not coming to class if I'm vomiting, because I'm going to vomit on somebody (Laughter.). You know, it's like what do you do? Do you go to class, you know, can't you, you have to sleep because you feel like crap? Or can you just stay in bed and sleep where that's easier on your body?

HG: Are there any other things that you all would say in terms of advice you would give to mental health researchers or university administrators?

P6: I think don't worry. I find that, it's weird, I find that with my (inaudible) there are people who are very nice, very kind or whatever. And then there's people who freak out. And then there's people who you're like, wait, I just passed out and you didn't come over and say hi. That's kind of messed up. So I think that people need to, not chill, but it seems like there needs to be a set protocol for things. Like, I don't know how that would apply to you but if someone was having an issue with their (inaudible) and then they thought of something that brought it back, then there would be like a protocol.

P7: Almost like debriefing. Right?

P6: Yeah, because I find that a lot of people who study mental illness don't have a mental illness. And that's not a problem, but it's hard for you to connect with somebody when you don't really know what they're going through.

HG: Sure, absolutely.

P8: That's why, you know, I want to become a psychologist, because a lot of the therapists and counselors that I've had were crap. You know? I didn't trust any of them. Even with tears running down my face, oh, I'm fine, don't worry about that. "Okay, well, then you don't need to come here anymore."

HG: Are you saying you almost got a sense whether someone could relate or could not just based on the way that they interacted with you?

P8: I felt like they were judging me.

HG: Oh, okay.

P8: That, and they told my parents everything. Everything I'm said. I'm like, can't you get in trouble for that? So I stopped talking to them. I didn't want them to know if I was having a bad day. They'd just freak out. The information I'm wanting to tell you, you're just going to go tell my parents. If I wanted to tell my parents something, I'm going to tell my parents something.

HG: Right, sure.

P8: But they don't know for a reason.

HG: Um, number six, you were saying something and then we kind of got off into this other topic about wanting researchers.. You said, you feel like many researchers don't understand mental illness because they themselves do not have a mental illness. Can you say more about what you meant about that or what would be helpful for us researchers in general, regardless if we have mental illness or not, to know?

P6: I think that it's not just for mental illness. Like, if you don't go through something and then you try to study it, you know, you might have an interest. But at least talk to somebody with a mental illness who's gone through it, because stuff you get off the internet is not really valid or helpful. You don't really know what that's gonna do. Like, even if it's like you're trying to learn Chinese and you've never been to China, you don't go on the internet and look up a bunch of stuff about China and then it's like you went to China.

Participants: (Laughter.)

P6: It's like, talk to a Chinese person!

HG: Well, I'm really glad you're bringing this up, because I think this is an important aspect of this particular study, and I think that's something that's different about this research. And I'm hoping this feels more along the lines of what you're speaking of.

P6: Yes.

HG: Actually hearing from those and involving those.. And I guess that's the point of this question, too, is what can I do as a mental health researcher to serve you all and to serve people that are in situations similar to yours?

P7: Well, the focus group, I think, is good.

HG: The focus group was helpful? Okay, good.

P6: Yeah.

P5: Yeah.

P7: I would say no one discloses to me on a day to day basis if they have a mental illness or anything. Um, but it's um, to be in a room of people that can kind of understand what it's like on some level, um, a lot of people I can't talk to. They just don't get it.

HG: Absolutely.

P5: My financial aid counselor mentioned once that counseling was available here if you needed it, and I was like, okay, I was like I'll look it up online. But they didn't say where it was, and I tried to look it up online with no, I was like, how do I look that up? And I entered in a bunch of different searches. Nothing. So I think maybe if y'all made that easier to find or more available. Like if somebody were in crisis or something here and the school accepts it as a problem and other schools and then they kill people or they have, you know..

HG: So almost as if it's some kind of universal thing that all students are given, so students know that there are resources available to them and know how to access those resources?

P7: I've heard about counseling and wellness, but that could be where I need to get my flu shot. I mean, I don't know. Is that for my physical, mental, emotional?

P5: Like with the financial aid counselor, they're like there's counseling at this school. And I was like, really, okay.

P7: (Inaudible.) It isn't a very easy find.

HG: Well, it sounds like we have a long way to go at least at this university, but my guess is at universities across the entire country in terms of communicating the resources that are out there and even having the resources in the first place.

P8: Right. I was like, you know, I think that's different, you know, where I'm friends with (inaudible). You know, just this year, at my school, they've already had nine suicides. And it hasn't even been a full year. So you know, it's like, I'm happy it's here if I need it and it's not like, you know, it's free for the first what? Up until the first fifteen, ten, twelve, twelve? I know that just having a university class, you know, they talk about it feels like a waste of your time, um, but where you know other schools and other colleges don't and everything, so..

P7: I wanted to mention a long time ago that it's the money. I know I've gone for treatment before and I've tried to go to places and people but it's like you only get a certain number of visits.

P8: Or did your insurance cover it?

P7: The first one's always the worst. You never get anywhere with the first initial assessment. You sit there and ask you all these questions and you feel like you, you almost don't even want to go back. There's got to be something in that initial meeting that makes you want to come back. But typically you go in there and they ask you all

these questions, and it makes you delve into it and then leave, and you're left with all these thoughts in your head and you don't know where to go with them, because you don't deal with it right then.

HG: Almost like I hear you saying you leave without hope that there's going to be something to even help in the future, because it's kind of just like we asked you all these questions and we'll contact you.

P8: Well, I've actually had the whole "How do you feel about this?" And it's like, I'm telling you how I feel about this, and I'm getting angry! Are you going to help me?!

Participants: (Laughter.)

P8: It's like, you know, I mean, yeah, I do vent. But okay, "How does this make you feel?" I know how it makes me feel. It just doesn't get me anywhere.

P7: They just want you to hear yourself think. And I understand that, I do.

P8: But it doesn't always work.

P7: It doesn't always work, no. I agree with that.

HG: Does it feel one-sided? Like almost..

P8: I can just sit here and talk to a wall.

HG: That's kind of what I got the sense of, that maybe you were saying that it felt very one-sided.

P8: Right.

P7: I like doing exercises. That helps me. Not like physical exercises, but, um, make you really think about a situation or helps them understand what it is. I don't know what kind of tool there is for that, but..

HG: Sure.

P7: Maybe starting with the little things. Maybe not start with a big thing right away. Start small. But sometimes they ask you a question right before you leave that is then lingering, thinking "I wish I hadn't said that. I wish I hadn't told them."

P8: I wish I hadn't told them, yeah.

HG: Any other advice for mental health researchers? Specifically in university settings? Or are those some of the main things?

P7: I think that's all.

HG: Okay, well, we just have one last question. We're actually doing really well on time, so it looks like y'all are probably going to get out of here a little bit early.

The last question is: I want to know how to improve the experiences of university students with mental illness. Is there anything that we missed? Is there anything that you came wanting to say that you didn't get a chance to say?

P6: I think for me, like, when my friends, when I tell my close friends about having a mental illness and I've been to, like, a psychiatric hospital, a lot of them say.. I want the negative stigma to be erased, because I'm sitting here with a bunch of intelligent, nice people who don't look like they're going to kill me. So it seems weird that people think that all these people, like, in these hospitals and in these places are like out to kill you and

they all hear voices and they're all.. It's just so negative, and I don't like it, because these people are real people. We all have, it's just a characteristic or a disability. And it's really, really, really, really frustrating.

HG: I share your sentiments exactly, and I'm really glad you say that, because I think that's a good thing to point out. We are sitting in a room of people who are having a very civil conversation about a very specific topic, and we're very much staying on that topic. And I haven't noticed any major red flags..

Participants: (Laughter.)

HG: And so, I think you're right. I think there is a really big stigma, and I really do thank you all for being here because it helps in the fight against the stigma of mental illness. Was there more you wanted to add to that?

P6: No, but that was one of the reasons that I decided to participate, because I wanted to be around people who share the same sentiments, because I don't have a lot of friends that have this, you know?

P5: Maybe there could be an awareness day, kind of like they do for all the other causes. The sororities could take it up and have bracelets.

Participants: (Laughter.)

P7: I thought they already had one. I know they have one for Alzheimer's.

P8: And then the other thing, you know, with people who actually have a mental disorder, you know, it's always like, "Oh, let's have a suicide awareness event. Because, you

know, it happened.” Okay, well, what about people, you know, who actually aren’t killing themselves?

HG: Right, and are living with it.

P5: Have an awareness day.

HG: Absolutely. I think that’s a great idea.

P7: Living with it, everyone lives with something on a daily basis. I would kind of compare it to having migraines or something like that. It’s constant, all day long, and even though it’s unseen, it’s still there and it impairs your functionality.

P8: Whoever said, you know, my life is perfect (Inaudible; Laughter.)

Participants: (Laughter.)

HG: (Laughter.) Sure. Anything else that anyone wanted to say today? Or maybe things that we touched on that you think, you know, you just want to reemphasize? Anything that you would like me to know or to take away from this experience?

P4: Um, joking about it sometimes helps quite a bit. My friends refer to me as a vampire, because of the aversion to bright light that I have. So they call me the schizophrenic Mexican vampire. (Laughter.)

Participants: (Laughter.)

HG: But it sounds like it’s in a very endearing way and that it’s something that..

P4: Yeah, like I had times when I was walking to the café with them or to Meijer, and coming back I would lose the ability to walk, and they would help me out.

P8: I had that..

P4: Yeah.

P8: You know, with my narcolepsy. You know, my friends, like lately, they try to make me fall asleep. You know, like being scared and I can't (inaudible). I say things, and I just lose control of my muscles and pass out. You know, I'm awake, and I understand what's going on, I just can't move and I just like fall. My friends like intentionally try to scare me, or you know, they would try to make me laugh too hard or something to see if it happens. But you know, if they're making me do it they're going to catch me. But you know, if I'm really tired, it could happen. There's only been a couple times when I'm really active that I will fall asleep. And there was a time, you know, when my friend just like caught me. You know, by my shirt, pulled me up and everything. And you know, they joke about it. And that really is a coping skill.

HG: So what I'm almost hearing based on the things that you both just said is that it actually is nice for people to talk about it, and even joking like "the schizophrenic vampire," that's so much better than avoiding talking about it.

P4: Yeah.

HG: And it's okay for it to be a part of your identity and a part of who you are just like, you know, being like you said, Mexican? Is that your heritage?

P4: Um, half Hispanic.

HG: Ah, you're half Hispanic. Anyway, that's just another variable about us just like having a mental health disorder or diagnosis. So what I'm hearing is that it's actually better to talk about it than, like you said earlier, to tiptoe around it..

P7: Yeah.

HG: And almost pretend..

P4: Mmm hmm.

P7: Yeah.

P8: I feel like we're so open, but you know, we're not going to go and start a conversation about it. If you have a question, I'll answer it openly. You know, like, if somebody says, you know, what's wrong with you? Or is this, you know, you're having a bad day. You're crying, you know, is this because of this? Because, you know. I'll completely answer you.

HG: Sure.

P6: I would rather, about any of my disabilities, I would rather you ask me a question, I'll answer any question you have, than either don't ask me and keep wondering or talk about it behind my back to somebody else. That drives me insane. You should have just come to me.

HG: For sure, definitely. I can definitely see that. Anything else on this topic or anything else at all that you feel like you would like to say before we conclude for today? We still have plenty of time, so we can continue to talk if you want. That's completely up to us.

P8: I think we could probably go on for like hours.

Participants: (Laughter.)

HG: I think you're right. I think we could go on for hours. I think this is a topic that, you know, is kept silent. So I think, you know, for any of us affected by issues related to mental illness, once that door is open, there's so much that can be said; especially in a safe environment where people really understand themselves.

P8: The thing that gets me is, you know, everyone's like, you know, people are like, you know, yeah, "Come to me for help," you know? But you're really not. You're judgmental. I can tell. Just like, you know, the way you talk to me or the look on your face. I can tell when you're judgmental. So, like, don't, I'm not going to go to you.

HG: Mmm hmm.

P8: But, you know, everyone comes to me and I'm completely okay with that. I love, you know..

P4: (Inaudible.)

P8: Yeah, like I'll get like calls in the middle of the night, and I don't know what to do. But if you ever need help, I'm here for you. They're really not. They just want to be that good friend, but they don't know how to actually be there.

HG: They don't know how to help.

P8: Yeah.

P7: I think just understanding it; having an idea of what it might be like. And it can be somebody that.. Like, if I wasn't diagnosed with a mental illness but I knew someone who I truly loved that did have a mental illness, I think I would understand more than someone who's never seen it in their life.

HG: For sure. And, you know, as a researcher I can say that there's literature out there that suggests that those with mental illness are maybe, in some ways, more compassionate and more empathic than the average person, because they're dealing with these things day in and day out, and they get it. They know what it's like to feel oppressed or to feel like they need to hide whatever it is that's going on with them. So I think, in some ways, that's a gift that comes along with mental illness, and it's something that I'm glad you all have shared with me today.

I guess, at this point, is there anything else that anyone wanted to say?

P6: The only thing is, I just sometimes, when I want to talk and I want to vent, I don't really want you to tell me a bunch of like, I have this friend, and she's a really good friend, but sometimes it's just like, I'll be like, "my guinea pig just died." She's like, "you can get another guinea pig." I'm like, I don't really want you to tell me all of the things I could do. Sometimes I just want you to listen to me.

HG: It's almost like advice giving isn't helpful.

P6: Yeah.

HG: I don't want advice, I want support.

P6: Yeah.

P7: I completely agree.

P8: It's not always the words that help us. It's the actions. When I get upset, I just want you to shut up. I want to watch TV. You know I'm upset. Let's not talk about it. And it makes me feel so much better.

P5: There are people who know and people who don't know. Maybe because I'm older, I've come across people in my life that know when to listen and when to talk.

P7: I just won't even go to people sometimes, because I know they're going to throw advice at me. And all I want to say is, I'm having a crappy day. I'm having one of my days. And I'll tell my boyfriend, and he's really good just sitting there with me. But if I start talking to mom, she'll start sitting there and she'll go, "Oh, I'm a bad mother. What did I? How did this?" It's almost too much for someone else to take on sometimes. And, uh, they just want to give you advice, because they just want to make it better for you, and they can't. You kind of have to ride it out. You've got to ride the wave out.

HG: Almost like they want to make it go away?

P7: Yeah, they just want it to be a quick fix. And, you know, it's not a quick fix. It's never a quick fix.

P4: Sometimes you just have to sit there and let it roll by, and there is no fix.

P7: Crawl in your bed. Lights out. Pass out. You know, I'll wake up in the morning and this will all be gone. I'll be fine.

P8: You know, I feel like this thing, you know, just talking about it in here. (Inaudible.)

Other people have to understand that you guys aren't, well, you know, "you should try

that, you should try this, you should try this” kind of thing. Just talking about it relieves it, so it’s not so bottled up and everything.

HG: I wonder what your thoughts are about like a mental illness support group.

P7: That’s the exact thought that was going through my head just now.

HG: Oh, was it? Then I was on the same wavelength.

P6: Yeah, I would totally join that.

P8: I would rather talk to a bunch of people who have mental disorders than a counselor.

P7: Yeah, I agree.

HG: Which is a little different than group therapy. It’s something where, kind of like this, we’re talking about the issues versus trying to work through individual problems. A support group can definitely be different and, I guess, maybe that’s what I’m kind of hearing.

P7: It’s good to have a mediator, you know? To kind of like bring up new topics, but I think it is really nice. And therapy can be in different forms and some just can be anybody to talk to. It’s not just a licensed therapist.

HG: Sure, yeah.

P7: Just talking makes me feel like I’m not hiding something. Like, I feel so much better, because you go day in and day out and you feel this way, but you don’t talk to anybody about it. You just kind of push it to the back of your head and think.. You deal with it. You don’t really get a chance to talk about it, which is like, what, once in a blue moon?

Participants: (Laughter.)

P7: You know, I didn't know what I was going to say when I first got here..

P6: Me either!

P7: But I feel better. Like a weight is lifted off of me in some ways.

HG: Good. Great. I'm really glad to hear that. That's a nice side-effect, I guess, to being a part of the group (Laughter.)

Participants: (Laughter.)

HG: That's good. I'm glad at least the two of you who had mentioned it, and I think maybe you chimed in as well, are having that experience. You know, it kind of normalizes your experience. It's kind of like, "I'm not alone."

Participants: I'm not alone.

HG: I'm not alone in this, and there's others out there, even within Wright State, who are dealing with things in a very similar way and can certainly relate to the experiences.

P8: I don't know if you guys have ever looked at, well, I like there's a show on MTV. It was like forever ago, you know, um, "If You Knew Who I Was" or whatever. And it was just like, you know, a bunch of teens out of high school. It doesn't matter who you were they gave you like numbers. And you'd have to say, well, you know, "If you knew me, you would know, well, you know, I would have bipolar. Or, you know, went through this. Anxiety." You know, that was a good thing that people experienced and that more people should experience this. You know, because, you know, everyone has their own problems

to all certain degrees, you know? You know, her problem might not, it's not going to be my problem, you know?

HG: So it sounds like connecting with one another without judgment is really helpful.

P8: Yeah.

HG: Good. I think that's helpful. And I think you have given me, at the very least, a lot of really good ideas. And, like I said, there's going to be a total of three focus groups that end up meeting. I already met with another group earlier this month. And there will be another one, it's looking like probably early next semester. So it will be interesting to see what all three groups' experiences were like in terms of being similar, being different. I think each discussion will have some similarities and some differences depending on who is in the room. So I would certainly encourage you all to look for the outcome of this study when it is all said and done. Like I said, hopefully that will be in July or sometime in the summer after then.

But does anyone have any questions for me before we go? Or anything else to add? No?

Well, you've been a great group to work with. I very much appreciate your participation in this study, and the things you have shared, I can tell you right now, have been really, really crucial, I think, for the fight for, really, equality with other people in terms of those with mental illness being seen in a way that isn't stigmatized, in a way that's just, you know, as a person. I guess also with it being okay to be a part of our identities. It is a part of our identity. You do identify with having PTSD or having schizophrenia or whatever it is. So that's part of my hope in this study, so I'm really thankful that you all shared in that with me today.

Anything else?

P7: Thank you for, you know, having us.

HG: Oh, you're welcome. Absolutely. My pleasure.

Participants: Thank you. (Inaudible.)

HG: It is a scary thing, I think, because it is such a silenced topic and there's a lot of stigma, and it's hard to know.. Well, first of all, it's hard to know what my motive was coming in here, so I can see how that would be kind of scary. I just really do appreciate you all taking the risk. I hope you all take care and have a good holiday season. Like I said, if you have any questions, feel free to contact me via email to follow up. Okay?

Participants: Thank you!

HG: Take care!

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