

MENTAL ILLNESS STIGMA AND MENTAL ILLNESS SYMPTOMS: A TEST OF  
BIDIRECTIONAL INFLUENCES

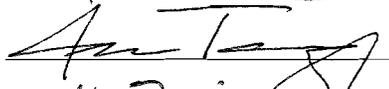
by

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A Dissertation  
Submitted to the  
Graduate Faculty  
of  
George Mason University  
in Partial Fulfillment of  
The Requirements for the Degree  
of  
Doctor of Philosophy  
Psychology

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Spring Semester 2013  
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Mental Illness Symptoms and Mental Illness Stigma: A Test of Bidirectional Influences

A dissertation submitted in partial fulfillment of the requirements for the degree of  
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## Dedication

I dedicate this dissertation to my parents, Stephen and Donna, and my brothers, Marc and Sean. I also dedicate this work to all those living with mental illness in hopes that it adds to your efforts to understand, cope with, and ultimately reduce stigmatization.

## Acknowledgments

Thank you, Dr. Jonathan Mohr: you have been my advisor, dissertation chair, teacher, mentor, and quite possibly one of the best people in the world. In fact, if there was a “Greatest Person In The World” competition, I would be the first to write your recommendation letter. You have supported me not only with this dissertation but throughout my graduate career. You took me on as your advisee and helped me navigate many personal and professional obstacles. I can only hope to be as good of a mentor and advisor to my future students and supervisees. And to my other committee members, Dr. Karen Rosenblum and Dr. Eden King, thank you for your comments and support. And thanks to my wonderful army of award-winning dissertation data coders: Alex Berman, Alex Nackley, Stephanie Powlen, Julie Montgomery, Allison Bowman, David Hanna, Caitlin Stauffer, and Georgia Korologos. You were recruited from the best students in one of the best Abnormal Psychology classes I have ever taught.

I also want to acknowledge other mentors that have helped shaped my career path. Dr. Patrick McKnight, I could always count on you to offer the best and most candid advice. I appreciate not only the career mentoring, but also the intellectual opportunities you afforded to me. Dr. Alan Bellack, Dr. Lisa Dixon, Dr. Melanie Bennett, and Dr. Amy Drapalski: the privileged opportunity to work in your labs at the Veterans Affairs Maryland Healthcare System has furthered my interest in applied clinical research with veterans. I appreciate your mentoring and supervision, and for creating an intellectually stimulating place for me to work where it never really felt like work.

Thanks to my friends and to my Clinical and Human Factors graduate psychology classmates for their constant support. I am forever grateful for my ice hockey teams, the Bulldogs (Fairfax) and Maple Leafs (Fairfax, Ballston, Reston), for their “assist” in helping me maintain sanity throughout graduate school at the expense of the occasional trip to the emergency room. There were a few fellow graduate students that became nerdy ice hockey players with me: David Cades, David Kidd, and Don Horvath. As we move our separate directions in life, I hope we all find friends who continue to push us both intellectually and physically.

And, my family. Marc and Sean, my brothers: I am glad after being mortal enemies as children that we have become best friends. Mom and Dad, thank you for all the years of love and encouragement. I assure you that someday I will have a “real job”...someday.

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## Abstract

### MENTAL ILLNESS SYMPTOMS AND MENTAL ILLNESS STIGMA: A TEST OF BIDIRECTIONAL INFLUENCES

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George Mason University, 2013

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People with mental illness cope not only with symptoms but also with stigmatization. Prior between-subjects, cross-sectional research has shown that perceived stigmatization is correlated with poor psychosocial functioning. However, little is known about the direction of causality between these variables or the extent to which their association reflects effects at the within-person level, between-person level, or both levels. The literature has also overlooked stigmatization in disorders other than schizophrenia, as well as the day-to-day experience of stigma. The purpose of the study was to examine bidirectional relationships between aspects of stigma (self-stigma, perceived public stigma, and severity of stigma experiences) and psychosocial functioning (anxiety and depression symptoms, impairment due to mental illness, interpersonal self-esteem), separate these relations into within- and between-persons components, and examine day-to-day and lifetime stigmatization experiences in a sample with more varied disorders. Participants were 112 community members with mental illness recruited nationwide from mental health advocacy organizations to complete daily diary surveys for a week. Of these adults, 96 provided sufficient amounts of data for inclusion in the main analyses. The within-person relationship between daily stigmatization and psychosocial functioning appears to be mostly unidirectional: self-stigma and

perceived public stigma predicted next day psychosocial functioning variables, except depression symptoms; the only psychosocial functioning variable to predict a next day stigma variable was anxiety symptoms, which predicted next day perceived public stigma. Most of the relationship between stigma and psychosocial functioning was explained by within-person processes. For example, when an individual was experiencing high levels of perceived public stigma and self-stigma relative to his or her own typical levels, the individual also tended to report more severe depression and anxiety symptoms, more impairment, and worse self-esteem. At the between-person level, such relations were only found with self-stigma. Because most participants were Caucasian, highly educated females with mood disorders, the results may not be generalizable to the overall population of people with mental illness. Nonetheless, this study is among the first to investigate day-to-day stigmatization experiences and bidirectional relationships between stigmatization and psychosocial functioning.

## Chapter 1: Introduction

Stigma encompasses the prejudice and discrimination endorsed by society towards an individual with a “spoiled” identity such as mental illness (Goffman, 1963). Individuals with mental illness suffer, then, not only from the effects of the disorder but also from the social ostracism they experience. Having a mental illness results in managing both one’s illness and how one interacts with a society that stigmatizes and discredits the individual for having mental illness.

Public opinion surveys, experimental research, and sociological research have provided ample evidence that mental illness is stigmatized in our culture (for a review, see Angermeyer, 2003). In particular, the public has long believed that individuals with mental illness are unpredictable, dangerous, irresponsible, need to be cared for like children, and need to be isolated from the community (Pescosolido, Monahan, Link, Stueve, & Kikuzawa, 1999; Stuart & Arboleda-Florez, 2001; S. M. Taylor & Dear, 1981). In addition, employers are often less willing to hire individuals with mental illness and landlords less willing to rent them apartments (Bordieri & Drehmer, 1986; Wahl, 1999; Webber & Orcutt, 1984). Furthermore, people are often less likely to pity, less likely to help and support, and more likely to become angry at persons with a mental illness as compared to individuals with a physical illness (Socall & Holtgraves, 1992; Weiner, Perry, & Magnusson, 1988). The public also tends to believe that individuals with mental illness have poor interpersonal skills (Segal, Coolidge, Mincic, & O’Riley, 2005) and generally prefers to maintain social distance from persons with mental illness (Lauber, Nordt, Falcato, & Rössler, 2004). People with less severe mental illness such as depression appear to be stigmatized in similar ways but perhaps to a lesser degree of severity than people with schizophrenia (Angermeyer & Dietrich, 2006). For example, about one-third to half of the public believes that people with

depression are “unpredictable” and violent. Nearly 40% of survey respondents attributed the cause of depression to the individual’s “own bad character”; one-third believed that people with depression are very or somewhat likely to be violent, and almost half preferred to maintain their social distance from a person with depression (Link, Phelan, Bresnahan, Stueve, & Pescosolido, 1999).

The pervasive discrimination and prejudice toward people with mental illness raise questions about ways in which stigmatization may negatively impact such people. Experiences with stigmatization may exacerbate or even create psychiatric symptoms and deteriorate psychosocial functioning. Research has begun to explore the ways that stigma can negatively impact the psychosocial functioning of people with mental illness, and—as described below—existing findings have mostly supported the hypothesis that stigma can impact symptoms and functioning. However, the limitations in the existing literature raise some questions that the current study seeks to address.

First and foremost among these limitations is that most studies have used a cross-sectional methodology to study the impact of mental illness stigmatization on psychiatric symptoms and psychosocial functioning. The focus on cross-sectional research has (a) limited understanding of the causal direction of the relationship between stigma-related variables and psychosocial functioning, (b) often required recall of events that have occurred over one’s lifetime, raising concerns about retrospective memory bias, (c) typically provided little information about the degree to which stigma manifests in everyday life, and (d) limited knowledge about the degree to which the association between stigma-related variables and psychosocial functioning is a within- vs. between-person phenomenon. In addition, most mental illness stigma research has focused on stigmatization among people with severe mental illness such as schizophrenia, generally neglecting the experiences of stigmatization among people with other forms of mental illness.

This study addresses many of these limitations by examining the within and between-person bidirectional relationships between mental illness stigma variables (i.e., self-stigma,

perceived public stigma, frequency and severity of stigmatization experiences) and psychosocial functioning (i.e., anxiety and depression symptoms, impairment, self-esteem). Data will be gathered on a daily basis for one week to examine within-person processes in individuals with a variety of mental illnesses. Studying stigma and its effects over multiple timepoints at the within-persons level can clarify the nature of the relationship between stigma variables and psychosocial functioning, and provide much-needed data on the manifestations of stigma in the everyday lives of people with mental illness.

## 1.1 Defining and Conceptualizing Stigma

Defining stigma has been a burdensome task for many researchers; the conceptual confusion can even cause some researchers to study one domain of stigma when they really intend to study another. A frequent conceptualization error is studying perceived public stigma when actually intending to study self-stigma. I have attempted to clarify the distinctions among the different manifestations of stigma throughout this study. The discussion below combines previous definitions and conceptualizations from literature reviews, theory, and research (Brakel, 2006; Brohan, Slade, Clement, & Thornicroft, 2010; Corrigan & Watson, 2002; Corrigan, Larson, & Kuwabara, 2010; Crocker, Major, & Steele, 1998; Goffman, 1963; Link & Phelan, 2001; Major & O'Brien, 2005).

A “stigma” is an attribute or mark that discredits and devalues an individual in a particular sociocultural context. Stigma cannot exist, or becomes less meaningful, without context and power differential. For example, society may stigmatize a person with depression less if the individual with depression is in a position of high social status or in a culture that is more accepting of mental illness. Stigma is thus not an attribute that resides within a person; rather, stigma encompasses processes of devaluation (e.g., discrimination, prejudice) in social relationships and contexts.

An individual with a social stigma may experience stigmatization in a number of ways. Public mental illness stigma is the degree to which most people, others, or society holds negative attitudes towards, negatively stereotypes, and discriminates against people with

mental illness. Despite the pervasive public mental illness stigma, individuals with mental illness may vary widely in the degree to which they perceive public stigma, agree with public stigma, and apply public stigma to oneself. For example, a person with schizophrenia might say, “Sure, the public believes that people with schizophrenia are dangerous and to be feared, but I disagree and I think people with mental illness, including myself, are no more violent or dangerous than anyone else.” This individual perceives the public stigma, but stops short of agreeing with and applying the stigma to himself. Self-stigma, on the other hand, is the product of internalizing perceived public stigma; the individual with mental illness believes that the public stigma applies to oneself. For example, an individual with depression might perceive public mental illness stigma (“I believe society thinks people with depression are depressed because they lack willpower”), agree with the public stigma about people with depression, in general (“I think people with depression lack willpower”), and take an extra step by self-stigmatizing (“I lack willpower because I have depression”).

Stigmatization experiences include witnessed or personal experiences of discrimination, prejudice, or negative stereotyping against people with mental illness. Stigmatization experiences are actually *perceived* stigmatization experiences because it is the individual’s subjective perception of whether or not a stigmatization experience has occurred. From a psychological standpoint, the experience will likely impact the individual if that individual perceives it as a stigmatization experience, regardless of the accuracy of the perception. Stigmatization experiences can be personal and directed toward the perceiver (e.g., a coworker tells the individual, “You didn’t take off work because you have a real illness, you’re just weak”) or vicarious and directed toward another person or the larger group of people with mental illness (e.g., the person with depression overhears a coworker commenting about throwing all the “crazies” in the “looney bin”). Research has identified myriad stigmatization experiences, many of which occur quite frequently throughout the lifetime of people with serious mental illness (e.g., Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009; Wahl, 1999). Stigmatization experiences can range, for example, from hearing an

inaccurate, stereotypical portrayal of mental illness in the media, to overhearing others discuss how they fear and prefer to keep their social distance from people with mental illness, to more extreme discrimination experiences such as being denied an apartment, job, or promotion (Brohan et al., 2010) or receiving substandard medical care (Druss, Bradford, Rosenheck, Radford, & Krumholz, 2000, 2001) because of an individual’s mental health status.

Research has shown that stigmatization experiences occurred “often” or “very often” in about one-third to half of mental health consumers surveyed, with specific personal discrimination experiences (e.g., being turned down for a job upon revealing their mental health status, difficulty renting an apartment) occurring much less frequently (Wahl, 1999). Another study found that about half of the psychiatric outpatients with severe mental illness reported that they were treated differently after being a patient in a mental hospital, and had been turned down for a job when the potential employer found out about their mental health status (Björkman, Svensson, & Lundberg, 2007). In a study of 732 participants with schizophrenia across 27 countries (Thorncroft et al., 2009), about half experienced negative discrimination from family members and in making or keeping friends during their lifetime, while nearly one-third experienced discrimination in finding or keeping a job. Stigmatization experiences differ not only in kind but also in severity; however, research has not yet quantified or analyzed the effects of stigma experience severity on psychosocial functioning.

## **1.2 Theoretical Considerations and Literature Review**

In this section, I review stigma theory that is most critical to understanding the experiences of the stigmatized and how they cope with mental illness stigma. First, I outline the theoretical mechanisms—notably, minority stress processes, concealability, and concealment coping—whereby stigmatization experiences, perceived public stigma, and self-stigma can adversely impact psychosocial functioning. I then provide an example illustrating the theoretical concepts. Following this theoretical discussion, I identify the existing empirical research for each of the three stigma variables in this study—stigmatization experiences,

perceived public stigma, and self-stigma—in relation to different psychosocial functioning outcomes. Next, I discuss why some stigma-related stressors might impact psychosocial functioning more than others. Finally, I provide a theory for possible bidirectional relationships between stigma variables and psychosocial functioning and a detailed description of longitudinal and bidirectional studies.

### **1.2.1 Stigmatization and Psychosocial Functioning**

#### **Stigma-related stress.**

Psychosocial impairment associated with mental illness can result from the actual illness (e.g., depression symptoms may make it difficult to work or develop satisfying relationships) or from stigma-related stress (e.g., employers discriminate against people with mental illness, the stigmatized individual perceives public stigma and thus avoids developing relationships with others). Minority stress theory postulates that stigma-related stress contributes to poorer psychosocial functioning within lesbian, gay, and bisexual (LGB) and among other stigmatized minority groups (Meyer, 2003) because they “are exposed to multiple forms of stressors, including discrimination, expectations of rejection, concealment/disclosure, and internalized homophobia” or self-stigma (Hatzenbuehler, 2009, p. 711). Some of these stressors are more distal (e.g., actual discrimination experiences, victimization, perceived discrimination), whereas some are more proximal to the individual’s self-concept and vary in the personal meanings attached (e.g., concealment, internalized homophobia or self-stigma, expectations of rejection). The current study examines proximal stigma variables of perceived stigmatization experiences, perceived public stigma, and self-stigma. Self-stigma is the most proximal to the individual because it depends least on external events: a person with mental illness can reject themselves absent any actual social rejection.

Theories of stigma-related stress implicate stress as a mediator in the relationship between a stigmatized social status, such as mental illness, and psychosocial functioning

(i.e., status → stress → psychosocial difficulties). The psychological mediation framework (Hatzenbuehler, 2009) notes that stress contributes to psychosocial difficulties but is first mediated by other psychological variables (i.e., stress → psychological mediators → psychosocial difficulties). Specifically, an increase in stigma-related stress can cause emotion dysregulation, social/interpersonal problems, and maladaptive cognitive processes which can then put the person with mental illness at greater risk for worsened psychosocial functioning. Taken together, having a stigmatized social status may lead an individual to experience negative stigma-related events in the form of minority stressors such as self-stigma, perceived public stigma and other stigmatization experiences, which then lead to psychological factors that mediate the resulting impaired psychosocial functioning.

Stigma-related stress is thought to impact general well-being and psychiatric symptoms among stigmatized populations with and without a mental illness. Specifically, stigma-related stress likely affects general well-being in people with mental illness in the same manner LGB-stigma would affect an LGB person's well-being, but stigma-related stress may also impact the clinical course of mental illness, itself (Link & Phelan, 2006). Stigmatization experiences, self-stigma, and perceived public stigma may all worsen depressive symptoms, placing that individual more at risk for future depressive episodes. Perceived public stigma can manifest itself the fear of being labeled as “depressed” or “schizophrenic” and seeking psychiatric help—which is also stigmatized. Such perceived public stigma and fear of direct stigmatization experiences may lead the individual to delay, avoid seeking, or be noncompliant with mental health treatment. Further, delaying, avoiding, or being noncompliant with mental health treatment may also protect the individual from self-stigma associated with help-seeking and admitting that one has a mental illness.

Another proximal stressor for stigmatized individuals is concealability, or the degree to which they can hide their illness and “pass” as a “normal” in society (Goffman, 1963; Jones et al., 1984). How easy is it to see or recognize the mark that sets one apart from another? For people with blindness, or facial deformities, their stigmatized identities are highly visible and thus cannot be concealed as easily. A person with mental illness, however,

often has a highly concealable stigma. Mental illness is not very easily seen or recognized by the general public: a person with mental illness can easily “pass” as they walk down a crowded street, unless they are actively psychotic, for example. The degree of mental illness concealability appears to depend upon an interaction between personality characteristics, current severity of symptoms, medication side effects that increase visibility of mental illness, and the social situation (e.g., Schulze & Angermeyer, 2003). Having a more visible stigma may increase the likelihood of experiencing certain types of stigmatization, such as personal discrimination (e.g., being shunned by others, being the direct target of prejudice). Having a less visible stigma may also make individuals more likely to experience certain types of stigmatization. An individual interacting with someone who has a visible stigma may choose his or her words carefully; however, if the individual is interacting with someone with a more concealable stigma then he may not use such discretion. He may be more likely to say something insensitive or degrading towards an individual with mental illness because he may be unaware of the individual’s stigmatized status.

The concealability of mental illness also affords the individual with mental illness to use concealment and secrecy to cope with stigmatization. Individuals with mental illness who are especially sensitive to perceived public stigma and who fear or experience stigmatization could be more likely than others to use concealment and secrecy to reduce the potential for stigmatization (Biernat & Dovidio, 2000; Corrigan & Matthews, 2003). People with mental illness have good reason to conceal: revealing one’s mental health status to others can result in rejection and discrimination (Corrigan & Kleinlein, 2005). Among participants who experienced stigmatization because of revealing their stigmatized mental health status, 95% “felt a lasting impact” from the stigmatization experiences, 57% “had lowered self-esteem or self-confidence” and 14% had “experienced an increase in problem emotions” (Wahl, 1999).

On the one hand, it may seem like concealment and secrecy coping strategies may help individuals effectively defend against experiencing direct stigmatization. By concealing one’s mental health status, the individual with mental illness can “pass” and protect

against direct stigmatization. On the other hand, some have theorized that concealing a stigmatized identity can worsen psychosocial functioning (e.g., self-esteem, self-efficacy, relationship functioning, social support) through cognitive (e.g., vigilance, suspiciousness) and affective (e.g., anxiety, depression, shame) mechanisms (Pachankis, 2007; Smart & Wegner, 2000). Concealing mental illness and using other secrecy coping strategies appear to increase social withdrawal (Link, Mirotznik, & Cullen, 1991), increase isolation, lower social support (Link, Struening, Dohrenwend, Cullen, & Shrout, 1989), and worsen psychosocial functioning (Luoma et al., 2007). Researchers also found that the lifetime frequency of stigmatization experiences was positively related to concealing one's mental health status (Bos, Kanner, Muris, Janssen, & Mayer, 2009). Such findings parallel literature in other stigmatized populations; for example, lesbians and gay men who conceal their stigmatized sexual orientation identity tended to have lower well-being compared to those who revealed their stigmatized identity (Beals, Peplau, & Gable, 2009). Some research suggests that people with mental illness may need to carefully disclose to others in order to benefit: careful and selective disclosure of one's mental health status can increase social support and self-esteem (Bos et al., 2009). Concealment appears to be a double-edged sword: it may help to protect against experiencing direct stigmatization, but may also cause a host of psychosocial problems.

An example may best illustrate how theoretical aspects of coping with stigmatization applies to real world experiences. Stigmatized identities are often managed in the workplace. Consider the example of an employee with depression experiencing indirect stigmatization from her boss, who makes occasional references to "crazy people" and "nut jobs" in jokes and conversations. These stigmatization experiences convince her that her boss agrees with public mental illness stigma. She now perceives public stigma and believes that if her boss finds out about her depression she may be experience direct stigmatization. Further, if her coworkers discover she is taking antidepressants and her status is revealed, she may need to expend additional emotional energy to repair her self-presentation (Pachankis, 2007),

which may then tax the resources needed to regulate her emotions and cope with her depression. Her coworkers may also tell her boss and expose her to more direct stigmatization experiences such as not getting a well-deserved promotion, or being pitied and assigned less responsibility. Such experiences can cause stigma-related stress (Meyer, 2003) which may result in hopelessness, negative self-schemas (Hatzenbuehler, 2009) and pessimism (Hatzenbuehler, Hilt, & Nolen-Hoeksema, 2010), together worsening her already existing depression.

However, the stigma-related stress and concealment coping may worsen well-being and psychiatric symptoms absent any direct, personal stigmatization experience (Pachankis, 2007). Because disclosing her mental health status could expose her to direct stigmatization that could harm her self-esteem and career path, she decides to cope by keeping her mental health status a secret around the workplace. The concealability of depression affords her protection against direct stigmatization experiences but causes problems of its own. Now, she is worried and anxious about her mental health status getting leaked and must go to great efforts to keep her depression a secret. Keeping this degree of secrecy requires hypervigilance, or being “on-guard” to the potential threat of stigmatization, which can lead to fear, anxiety, rumination, social avoidance and isolation (Crocker et al., 1998; Hatzenbuehler, 2009; Link & Phelan, 2001; Major & O’Brien, 2005; Pachankis, 2007). The employee is afraid to get close to anyone in her workplace because they may discover her mental health status. The fear of stigmatization, real or perceived, causes her to struggle to develop positive work relationships which may buffer against depression symptoms and psychosocial impairment. Thus, direct and indirect stigmatization experiences, and lack of social support that eventually result from the psychological and behavioral responses (e.g., rumination, hypervigilance, social avoidance) to cope with stigmatization all combine to exacerbate depression symptoms and worsen psychosocial functioning.

### 1.2.2 Associated Empirical Findings

A recent meta-analysis provides compelling evidence for the harmful effects of mental illness stigma-related stress (Livingston & Boyd, 2010). The authors subsumed three distinct manifestations of stigmatization—stigmatization experiences, self-stigma, and perceived public stigma—under one category, “internalized stigma.” Internalized stigma was defined as “a subjective process, embedded within a socio-cultural context, which may be characterized by negative feelings (about self), maladaptive behaviour, identity transformation, or stereotype endorsement resulting from an individual’s experiences, perceptions, or anticipation of negative social reactions on the basis of their mental illness” (p. 2151).

In the 86 reviewed studies, internalized stigma was strongly and consistently significantly associated with psychosocial functioning variables of hopelessness ( $r = -.58$ , 5/5 studies), self-esteem ( $r = -.55$ , 30/34 studies), empowerment/mastery ( $r = -.52$ , 11/12 studies), self-efficacy ( $r = -.54$ , 8/8 studies), quality of life ( $r = -.47$ , 23/24 studies), but less so with social support/integration ( $r = -.28$ , 7/12 studies). In the 60 reviewed studies, internalized stigma was also highly and somewhat consistently significantly associated with symptom severity ( $r = .41$ , 50/60 studies). While the meta-analysis presents a helpful summary of the research, it is limited because it does not examine the distinct contribution of stigma-related variables to psychosocial functioning, nor does the analysis provide statistics calculated separately for specific symptoms (e.g., depressive, anxiety, psychotic). The following section reports findings separately for each stigma-related variable measured in the current study, and further divides the studies by psychosocial functioning variables and psychiatric symptoms.

#### **Self-stigma.**

Self-stigma has been consistently negatively related to quality of life (Luoma et al., 2007; Lysaker, Davis, Warman, Strasburger, & Beattie, 2007), as well as scores on measures of self-worth, including self-esteem and general self-efficacy (Corrigan, Watson, & Barr, 2006; Fung et al., 2007; Lysaker, Tsai, Yanos, & Roe, 2008; Rüschi, Hözer, et al., 2006;

A. C. Watson, Corrigan, Larson, & Sells, 2007; Werner, Stein-Shvachman, & Heinik, 2009; Werner, Aviv, & Barak, 2008; Yanos, Roe, Markus, & Lysaker, 2008). Self-stigma was also positively correlated with positive (but not negative) (Lysaker et al., 2007) and both positive and negative (Yanos et al., 2008) schizophrenia symptom severity. In one study, self-stigma was correlated positively with clinician-rated negative symptoms, but negatively with clinician-rated generalized schizophrenia symptoms (Werner et al., 2008). Self-stigma was significantly related to depressive symptom severity among samples with varying degrees of depression (Barney, Griffiths, Christensen, & Jorm, 2010), depressive disorders (Yen et al., 2005), social phobia and borderline personality disorder (Rüsch, Hözer, et al., 2006), psychotic disorders (Werner et al., 2009), as well as mixed disorder samples with severe mental illness (Ritsher & Phelan, 2004) and psychiatric disabilities (Corrigan et al., 2006). However, self-stigma did not significantly predict depressive symptoms in one study of patients on the schizophrenia spectrum (Yanos et al., 2008).

### **Perceived public stigma.**

Research supports the link between perceived public stigma and psychosocial functioning. For example, scores on measures of quality of life, life satisfaction, and overall well-being have been negatively related to perceived public mental illness stigma (Luoma et al., 2007; Markowitz, 1998; Mechanic, McAlpine, Rosenfield, & Davis, 1994; Rosenfield, 1997; Rüsch, Hözer, et al., 2006; Vauth, Kleim, Wirtz, & Corrigan, 2007). Scores on measures of self-worth, including self-esteem and general self-efficacy, were negatively related to perceived public mental illness stigma (Corrigan et al., 2006; Fung et al., 2007; Kahng & Mowbray, 2005; Lai, Hong, & Chee, 2001; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2002; Rüsch, Hözer, et al., 2006; Rüsch, Lieb, Bohus, & Corrigan, 2006; Vauth et al., 2007). Participants in the above studies mostly had psychotic disorders or the study did not specify the diagnosis (e.g., people with “psychiatric disabilities” or “severe/chronic mental illness”).

The research appears mixed as to whether perceived public stigma is related to psychiatric symptom severity. Schizophrenia symptom severity was related to perceived public

mental illness stigma in one study (Ertugrul & Ulug, 2004) but not others (Markowitz, 1998; Vauth et al., 2007). Perceived public stigma was also positively associated with depression symptom severity in some studies (Link et al., 2002; Markowitz, 1998; Vauth et al., 2007) but not in others (Corrigan et al., 2006; Kendra & Mohr, under review; Rüscher, Hözer, et al., 2006). Although stigma theory postulates that perceived public stigma would be among the stigma variables most closely linked to anxiety symptom severity (e.g. hypervigilance, preoccupation, suspiciousness), only one study has examined this relationship, finding significant associations between the two variables (Markowitz, 1998).

### **Stigmatization experiences.**

Most studies have linked the lifetime frequency stigmatization experiences to quality of life, empowerment, sense of coherence, disability, perceived social support, and self-esteem (Bos et al., 2009; Ertugrul & Ulug, 2004; Lundberg, Hansson, Wentz, & Björkman, 2009, 2008; Markowitz, 2001; Rüscher, Hözer, et al., 2006; Switaj, Weirka, Smolarska-Switaj, & Grygiel, 2009); however, others did not find the lifetime frequency of stigmatization experiences to be significantly related to a variety of psychosocial functioning variables, including quality of life and empowerment (Björkman et al., 2007; Dickerson, Sommerville, Origoni, Ringel, & Parente, 2002). People with schizophrenia who experienced stigmatization more frequently had more severe self-reported psychiatric symptoms (Charles, Manoranjitham, & Jacob, 2007; Ertugrul & Ulug, 2004; Switaj et al., 2009). No studies have examined the effects of mental illness stigmatization experience severity on psychosocial functioning.

### **Differential prediction of psychosocial functioning.**

Self-stigma is a more proximal stressor compared to stigmatization experiences or perceived public stigma (Hatzenbuehler, 2009). Because self-stigma is more closely linked to the individual's self-concept and it does not require one to perceive any external, distal events, self-stigma is "a form of stress that is internal and insidious" (Meyer, 2003, p. 682). Consequently, self-stigma lies in the own individual's response to stigmatization and is thought to

be more closely linked to one's self-concept compared to other manifestations of stigmatization which are more distal and primarily reside within the environment. Individuals who self-stigmatize likely suffer from all the difficulties that individuals preoccupied with perceived public stigma face, but also take the extra step of applying the negative beliefs about their social group to themselves. For example, the stigmatized may perceive the societal belief that "people with depression are lazy, weak-willed, and need to pull themselves up by their bootstraps" and internalize it as, "I am lazy and weak-willed." This internalization of public stigma is thought to produce shame, lowered self-esteem, and depression.

Rarely have the effects self-stigma, perceived public stigma, and stigmatization experiences been simultaneously examined in quantitative research or directly compared in reviews. Previous findings give reason to suspect self-stigma to be more closely linked to symptoms and psychosocial functioning than perceived public stigma (Corrigan et al., 2006; Kendra & Mohr, under review; Luoma et al., 2007; Ritsher & Phelan, 2004; Rüscher, Hözer, et al., 2006). Although self-stigma, perceived public stigma, and the frequency of stigmatization experiences appear related to similar psychosocial outcomes (e.g., self-esteem, depressive symptoms), theory and some research suggests self-stigma is more closely linked to psychosocial problems than other stigma-related stressors.

### **1.2.3 Bidirectional Relationships**

Much of the stigma and psychosocial functioning research has been cross-sectional, raising questions about direction of influence. Does stigmatization cause psychosocial impairment, or can psychosocial impairment predispose people with mental illness to perceive more stigmatization than may be warranted? Hatzenbuehler (2009) indicated that the relationship between stigma-related stress (self-stigma, perceived public stigma, and stigmatization experiences) and psychopathology is likely reciprocal, dynamic, and bidirectional (i.e., stigma-related stress  $\leftrightarrow$  psychosocial functioning). Some mental illness stigma researchers have suggested that not only might it be possible for stigmatization to exacerbate psychopathology symptoms, but that an individual's mental health problems may also cause

that individual to exaggerate or “over-perceive” stigmatization (Ertugrul & Ulug, 2004; Lyons, Hopley, & Horrocks, 2009).

Attribution theory provides a framework for understanding why people with more severe mental illness symptoms and psychosocial impairment may exaggerate or be more likely to report higher levels of stigmatization. Research on attributions suggests that people, in general, are more motivated to attribute their negative events and life circumstances to external sources in an effort to enhance and protect self-esteem (Abramson, Seligman, & Teasdale, 1978; S. E. Taylor & Brown, 1988). When individuals with stigmatized identities experience a negative event or receive negative feedback, it is often difficult to discern whether something external such as discrimination or more internal such as the person’s own limitations or impairment is the cause of the negative experience. This “attributional ambiguity” exists for many negative events in the lives of the stigmatized (Crocker & Major, 1989). Like attribution theory, attributing psychosocial difficulties to discrimination or stigmatization may shift causal explanations from internal to external, thereby protecting or enhancing self-esteem (Major, Quinton, & Schmader, 2003). People with mental illness might then attribute their psychosocial difficulties to external factors such as social stigmatization in order to protect self-esteem. The more severe the negative event or psychosocial impairment, the greater the threat to self-esteem, and thus the greater the motivation to protect self-esteem by attributing problems to external factors. Thus, people with more severe symptoms and psychosocial difficulties may be more prone to perceive public stigmatization and perceive stigma experiences in order to protect self-esteem.

Some have suggested that psychosocial impairment, alone, may predispose an individual to experience stigmatization, perceive public stigma, and self-stigmatize (Gaebel, Zäske, & Baumann, 2006) and to generally perceive more stigmatization than is warranted (Switaj et al., 2009). For example, schizophrenia symptoms such as paranoia may result in delusional perceptions of stigmatization; the worse the symptoms, the worse the perceived stigmatization. Similarly, a person with depression may over-perceive stigmatization due to their depressive symptoms (e.g., punishment beliefs, cognitive distortions). Further, people with

any kind of mental illness may be more depressed and anxious than others who do not have mental illness for reasons completely unrelated to stigmatization. The predisposing psychiatric symptoms may then increase sensitivity to social rejection and lead the individual to perceive more stigmatization, resulting in further symptom exacerbation. In a similar example, people with social anxiety symptoms may expect rejection and stigmatization more than others; these expectations may actually cause stigmatization experiences through self-fulfilling prophecies. Perceiving public stigma may then put an individual with mental illness at-risk for self-stigmatization. Others have also noted the difficulty of determining if the mental illness itself or stigmatization accounts for the decreased psychosocial functioning (Mueller et al., 2006; Wahl, 1999). Such causality questions have also been noted as potential areas for future research in the broad stigmatization and stress literature (Hatzenbuehler, 2009; Meyer, 2003).

Some longitudinal studies have attempted to investigate causality questions by examining the long-term effects of stigmatization on psychosocial functioning, and vice versa. Most longitudinal studies have demonstrated that perceived public stigma has long-lasting effects on psychosocial functioning. One study (baseline, six month follow up) found that baseline perceived public stigma predicted self-esteem at follow up (Blankertz, 2001). Another longitudinal study (baseline, seven month follow up) found that patients with higher levels of perceived public stigma reported more difficulty in social functioning at follow up, even after controlling for baseline social functioning and symptom severity (Perlick et al., 2001). Link, Struening, Rahav, and Phelan (1997) studied individuals in a mental health treatment program and found the negative effects of perceived public stigma on self-esteem often persisted despite successful mental health treatment. Perceived public stigma also appears to have a distinct and long-term impact on self-esteem above and beyond the effects of mental illness (i.e., after controlling for psychiatric diagnosis and depressive symptoms) (Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001). These studies suggest that stigma-related stress can be conceptualized as an added burden on psychosocial functioning, above and beyond the effects of psychiatric symptoms on functioning.

However, not all longitudinal research has shown perceived public stigma to predict psychosocial functioning. One study (baseline, six month follow up) found that depressed patients' agreement with perceived public stigma (e.g., participants who rated statements higher, such as, "If you were applying for a job, how much difficulty do you think you would have getting the job if the employer thought you had a recent history of depression?"), was unrelated to depression severity and indicators of psychosocial functioning (Roeloffs et al., 2003). A study of people in self-help groups and outpatient treatment (baseline, 18 month follow up) did not find a significant relationship between baseline perceived public stigma and changes over time in psychiatric symptoms or self-esteem; however, baseline perceived public stigma did negatively predict future decreases in life satisfaction (Markowitz, 2001). One forthcoming study (Kendra & Mohr, under review) found that during the initial phase of psychotherapy, baseline perceived public stigma was unrelated to changes over time in depression over the initial phase of psychotherapy. Thus, the findings regarding the impact of perceived public stigma on psychosocial functioning have been mixed, with no studies showing perceived public stigma to significantly predict future symptom severity.

Stigmatization experiences have been studied longitudinally much less frequently than perceived public stigma. One longitudinal study (baseline, 18-month follow up) of mental illness stigmatization experiences studied people in self-help groups and outpatient psychiatric treatment (Markowitz, 2001). Retrospectively reported baseline stigmatization experiences were positively related to future increases in psychiatric symptom severity and negatively related to future decreases in life satisfaction, but unrelated to future self-esteem. Another longitudinal study (baseline, 1 year follow up) did not find stigmatization experiences to significantly predict future perceived social support (Mueller et al., 2006). A multiple follow up study (baseline, 1 year, 2 years) examined recently deinstitutionalized psychiatric inpatients' experiences with rejection and stigma (Wright, Gronfein, & Owens, 2000). Most patients had schizophrenia, and all were former hospitalized inpatients. Participants experienced stigma consistently throughout the years. The frequency of rejection experiences did not have a direct effect on self-worth; however, rejection experiences positively predicted

future self depreciation and negatively predicted future sense of mastery.

Only one published longitudinal study and one under review examining mental illness self-stigma could be found. First, psychiatric outpatients with high levels of self-stigma experienced more depressive symptoms and lower self-esteem when assessed four months after discharge than those who did not internalize stigma to such an extent (Ritsher & Phelan, 2004). Second, a forthcoming study (Kendra & Mohr, under review) found during the initial phase of outpatient psychotherapy that self-stigma was negatively associated with growth over time in depression level. The latter finding was counter to prediction because it implied that clients entering therapy with the highest levels of self-stigma experienced the most rapid reductions in depressive symptoms.

The previously reviewed longitudinal studies in this area have examined how stigma-related variables predict future psychosocial functioning. Research on bidirectional relationships between stigma and psychosocial functioning consists of two studies examining perceived public stigma, one on self-stigma, and no studies of stigmatization experiences. One longitudinal study (baseline, one year follow up) found that perceived public stigma did not predict future perceived social support (Mueller et al., 2006). However, baseline levels of perceived social support were negatively related to perceived public stigma one year later, but only for people who have been in psychiatric treatment for less than 6 years. A year-long, five wave (baseline, three, six, nine, and 12 month) longitudinal study of psychiatric outpatients found that perceived public stigma at baseline predicted decreased self-esteem at 12-month follow-up after controlling for baseline self-esteem; however, baseline self-esteem and psychotic symptoms were unrelated to future perceived public stigma (Link, Castille, & Stuber, 2008). In the single study examining bidirectional relationships with psychosocial functioning and self-stigma, bidirectionality was partially supported: high levels of positive psychotic symptoms predicted self-stigma six months later, and the reverse relationship was marginally significant (Lysaker et al., 2007). Taken as a whole, there are very few studies examining bidirectionality, and the results are unclear or may differ depending on the specific variables examined.

### **1.2.4 Summary**

Mental illness stigmatization has been studied among the general public while neglecting the first-hand experiences of people with mental illness. This trend may have changed within the last decade, with a wealth of cross-sectional research correlating mental illness stigma-related stress with psychosocial functioning. Meta-analytic findings suggest that mental illness stigma variables are often related to psychosocial functioning and psychiatric symptom severity.

Some longitudinal studies found associations between perceived public stigma and future self-esteem, life satisfaction, and social functioning; others did not find perceived public stigma to predict future social support, other psychosocial functioning variables, or psychiatric symptom severity. Stigmatization experiences predicted future increases in psychiatric symptoms, decreases in life satisfaction, sense of mastery, and social support, but did not predict future self-esteem or self-worth. Self-stigma marginally significantly predicted future positive schizophrenia symptoms, significantly negatively predicted future self-esteem, and significantly predicted depressive symptoms in the expected direction in one study but in the opposite direction in another. Although some longitudinal work has investigated whether stigma variables predict future psychosocial outcomes, rarely has research investigated whether and which psychosocial outcomes predict different stigma variables.

## **1.3 Statement of Study Goals**

### **1.3.1 Test Bidirectionality**

The most important contribution of the current study will be to investigate the direction of the relationship between mental illness stigma-related stress and psychosocial functioning. Authors have consistently identified the cross-sectional nature of the current research as a significant limitation in the mental illness stigma literature. The existing, predominately

cross-sectional literature also does not adequately investigate the direction of causality between stigma-related stress and psychosocial functioning. It is widely assumed that stigmatization causes psychosocial difficulties (i.e., stigma  $\rightarrow$  psychosocial functioning), including lowered self-esteem, quality of life, and psychiatric symptomatology, but this finding is based on research at the between-subjects level which many have noted has significant limitations especially when examining causality (Bos et al., 2009; Charles et al., 2007; Janda, Markowski, Derlega, Nezlek, & McCain, 2006; Loganathan & Murthy, 2008; Lundberg et al., 2008; Lysaker et al., 2008; Swim, Hyers, Cohen, & Ferguson, 2001; Switaj et al., 2009; Thornicroft et al., 2009; Wright et al., 2000). The relationship may also be in the reverse (i.e., psychosocial functioning  $\rightarrow$  stigma) or bidirectional (i.e., stigma  $\leftrightarrow$  psychosocial functioning).

A major conclusion from a recent meta-analysis by Livingston and Boyd (2010) was that the lack of longitudinal research has severely hampered the clinical relevance of stigma research. For example, if the relationship is bidirectional, reducing symptoms or improving self-esteem among the stigmatized may also eliminate the threat posed by stigma or at least help individuals cope better with stigma-related stress. If effective treatment that reduces symptoms and improves functioning also improves stigma, there may be less need for stigma-focused groups or for treatment providers to specifically address stigma in addition to treatment as usual. However, if the relationship is not bidirectional, improving symptoms and functioning may not necessarily lead to less stigmatization. Consequently, mental health treatment that only focuses on symptom reduction may not address or protect against stigmatization, and thus future instances of stigma-related stress can become a risk factor for relapse. In such cases, it may be helpful for patients struggling with stigmatization to enroll in support or therapy groups that specifically target stigmatization in addition to treatment as usual.

Questions still remain as to the causal relationship between stigma and psychosocial functioning. Such questions may be answered with longitudinal studies carried out over the course of months or years, but may also be studied using a within-persons approach, in a

shorter timeframe, and with more frequent measurement occasions.

### **1.3.2 Examine Stigmatization in the Context of Everyday Life**

Most of the research in this area is cross-sectional and does not allow for the examination of change over time in the context of daily life. Among the existing longitudinal research, most studies have been baseline and long term follow up; none examined the daily, weekly, or even monthly effects of mental illness stigma. The lengthy time to follow up (i.e., six month to two year) and low frequency of measurement (e.g., two to four measurement occasions) in existing longitudinal work does not provide a nuanced picture of how stigma affects individuals during their daily lives. Further, no study has provided information regarding the frequency or variability of stigmatization experiences using prospective data collection. How often is “very often” or “sometimes” throughout the lifetime: Daily, weekly, monthly? A more nuanced understanding of stigmatization experiences and psychosocial functioning may be better addressed with a daily diary methodology. Research among other stigmatized populations has recently begun to investigate how within-person variability in psychological processes are associated with changes over time in stigma-related stress. For example, within-person depression and anxiety symptoms increased over time for LGB individuals reporting experiencing a stigma-related stressor (Hatzenbuehler et al., 2010). The current research seeks to extend this trend toward studying minority group stigmatization from a within-persons approach.

Examining daily stigmatization may also be a useful way to address problems with retrospective report. Studies examining stigmatization experiences have typically asked participants to respond how often they experience stigmatization over the course of a long time period, often their lifetime. Some stigmatization experiences may be improperly encoded in memory and thus be susceptible to memory bias including primacy and recency effects. Retrospective report may also obscure the frequency and severity of stigmatization experiences. Participants may be more prone to focus on one major stigmatizing event while overlooking other, more minor but more frequent events that may cumulatively be

detrimental. Retrospective, cross-sectional designs may not provide an adequate within-persons understanding of how the same individuals react to stigmatizing experiences given changes in mood and context.

### **1.3.3 Studying Individuals With a Variety of Mental Illnesses**

The literature does not provide an understanding of how separate manifestations of stigmatization vary between different disorders or degrees of illness severity. Generally, mental illness stigma research has been reserved for those with severe mental illness such as schizophrenia, neglecting the experiences of those with less severe mental health problems. Authors noted that studying stigma among less severe mental illness is worthwhile because it is unclear if patients with less severe mental illness are equally affected by stigmatization (Wright et al., 2000).

Some suggest people with schizophrenia may be more stigmatized more severely and be more strongly impacted by such experiences than those with other disorders (Angermeyer & Dietrich, 2006). Supporting this theory, quality of life was more strongly negatively related to actual rejection experiences in people with psychotic but not affective disorders (Lundberg et al., 2008). Qualitative studies indicate that individuals with less severe mental illness tend to have similar stigmatization experiences to those with more severe mental illness (Dinos, Stevens, Serfaty, Weich, & King, 2004; Kranke, Floersch, Townsend, & Munson, 2010; Moses, 2010). For example, one third to half of participants noted they experienced stigmatization in peer relationships that often led to losing friends, and many were stigmatized by their parents and school staff. Parents prohibited their children from dating or being friends with some of the adolescents with mental illness. Further, people with depression noted that others kept their social distance, blamed them for their mental illness, excessively pitied them, or told them they would never recover. Others were teased, ridiculed, ignored, or victims of violence because they had mental illness. These experiences appear similar in kind to stigmatization experiences in people with schizophrenia; however, may yet differ in severity or degree of impact.

In turn, I examined a wider spectrum of illness severity among individuals with mental illness. Although there are some researchers that studied stigmatization in people with a wide range of mental illness, most studies have examined a single illness, usually psychotic disorders. Studying the population of people with mental illness, broadly, represents an effort to examine how stigmatization affects individuals in the social group of mental illness with varying illnesses and varying degrees of illness severity. It is certainly possible that different stigma-related variables may better predict specific psychosocial functioning variables (and vice versa), and the strength of the relationship may depend on the specific disorder under investigation.

#### **1.3.4 Simultaneously Studying Multiple Manifestations of Stigmatization**

Rarely have different stigma variables been examined in the same study, even in literature reviews and meta-analyses. The majority of research on stigmatized individuals with mental illness has focused on perceived public stigma as opposed to other areas of stigma-related stress, despite theoretical and some research evidence to suspect other stigma variables to be more closely linked to symptoms and psychosocial functioning than perceived public stigma. A review found that perceived public stigma was assessed in 79% of mental illness stigma studies, followed by stigmatization experiences in 46%, and self-stigma in 33% (Brohan et al., 2010). Self-stigma and stigmatization experiences have also been the subject of significantly less longitudinal research than perceived public stigma. Although mental illness self-stigma has historically received less attention in the literature, many newer studies are focusing on self-stigma because mounting evidence suggests it may have more detrimental effects on well-being than perceived public stigma.

Never has a single study examined mental illness self-stigma, perceived public stigma, and stigmatization experiences simultaneously, though such research may be useful in clarifying the causal link between stigma and psychosocial functioning (Wright et al., 2000). Among LGB populations, researchers found that different manifestations of stigma were associated with distinct psychosocial outcomes (Hatzenbuehler, Nolen-Hoeksema, & Erickson,

2008), providing support for simultaneously studying multiple manifestations of stigmatization to identify which aspects of stigmatization best predict symptoms and dysfunction. The mental illness stigma literature has not been developed enough to adequately determine which stigma-related stressors are better predictors of psychosocial outcomes. This study provides an important investigation of these relationships by studying many aspects of stigmatization in the same study. Some examples of hypotheses articulated above but yet to be adequately tested include (a) self-stigma may impact most psychosocial functioning variables to a greater degree than perceived public stigma, (b) perceived public stigma may be more closely linked to anxiety than self-stigma, and (c) the more proximal stressor of self-stigma would be better related to psychosocial variables that are more closely linked to the self-concept (e.g., self-esteem) compared to perceived public stigma.

## **1.4 Psychosocial Functioning Variables Most Closely Linked To Stigmatization**

What aspects of psychosocial functioning are most influenced by mental illness stigmatization? It is possible that stigmatization worsens certain types of psychiatric symptoms in people with any type of mental illness (general effects) and can affect symptoms specific to the individual's mental illness (specific effects). The same stigma-related stressors (e.g., self-stigma, perceived public stigma, stigmatization experiences) have been linked to increased psychiatric symptoms among individuals with different mental disorders (e.g., depression, psychotic disorders) and in various stigmatized groups (e.g., LGB, HIV/AIDS populations). Some evidence suggests that the effects of stigmatization may also be specific to one's illness, depending on the specific symptom investigated. For example, while stigmatization may increase psychotic symptom severity in people with psychosis, we would not expect stigmatization to increase psychotic symptoms in individuals with non-psychotic disorders. Stigmatization thus appears to have both general and specific effects, affecting general symptoms (e.g., depression) across different mental illnesses and stigmatized groups, but

also affecting symptoms that may be specific to a single disorder (e.g., psychotic symptoms).

Because I am studying stigma associated with a broad range of mental disorders, I chose anxiety and depression symptoms as indicators of psychosocial functioning because they have general effects. Symptoms like anxiety and depression can appear in many different disorders (e.g., major depressive disorder, bipolar disorder, schizophrenia, post-traumatic stress disorder), making them good variables to measure in a sample of a broad range of mental disorders. Previous research has shown depression symptoms to be among the psychiatric symptoms most consistently linked to manifestations of stigma in individuals belonging to a variety of stigmatized groups. While there is ample theory to suggest anxiety symptoms may be an outcome or predictor of stigma-related stress (especially perceived public stigma), there is little empirical evidence linking stigma variables to anxiety symptoms (or vice versa) in mental illness. The current study thus facilitates comparison with previous work by examining depression symptoms, and extends previous work into a new variable of anxiety symptoms that has been understudied despite its theoretical relevance to stigmatization.

I chose interpersonal self-esteem and psychosocial impairment due to mental illness as other indicators of psychosocial functioning. Self-esteem is an important factor in the development and maintenance of different mental illnesses (Mann, Hosman, Schaalma, & De Vries, 2004), in recovery models of mental illness (Bellack, 2006), and is also linked empirically to self-stigma and perceived public stigma (Corrigan et al., 2006; Livingston & Boyd, 2010) and theoretically to all three stigma-related stressors examined in this study. Besides symptoms, self-esteem appears to be the most frequently studied psychosocial functioning variable in relation to dimensions of mental illness stigma (Livingston & Boyd, 2010). Stigmatization is a social process and does not simply exist within an individual, making it important to understand the stigmatized individual's self-evaluations in interpersonal and social contexts. Examining such social aspects of self-esteem in the current study would both facilitate comparison with prior work on global self-esteem and acknowledge the social and interpersonal ramifications of stigmatization. Despite ample theory connecting

stigmatization to psychosocial impairment, impairment due to mental illness is less frequently examined in the mental illness stigmatization research. Similar to the rationale for operationalizing psychosocial functioning as depression and anxiety symptoms, selecting self-esteem facilitates comparison with previous work while selecting impairment due to mental illness extends can provide new insights into an understudied domain theoretically relevant to stigmatization.

## 1.5 Statement of Hypotheses and Research Questions

The main hypotheses in this study pertain to the bidirectional relationship between mental illness stigma (self-stigma, perceived public stigma, and frequency and severity of stigmatization experiences) and psychosocial functioning (anxiety and depression symptoms, psychosocial impairment, self-esteem). The above review provides some basis for making specific predictions, below, and displayed in Figure 1.1.

1. Higher current levels of stigma will predict poorer next day psychosocial functioning (higher anxiety and depression symptom severity, psychosocial impairment, and lower self-esteem), controlling for current psychosocial functioning.
2. Poorer current psychosocial functioning (higher anxiety and depression symptom severity, psychosocial impairment, and lower self-esteem) will predict higher next day levels of stigma, controlling for current stigma levels.

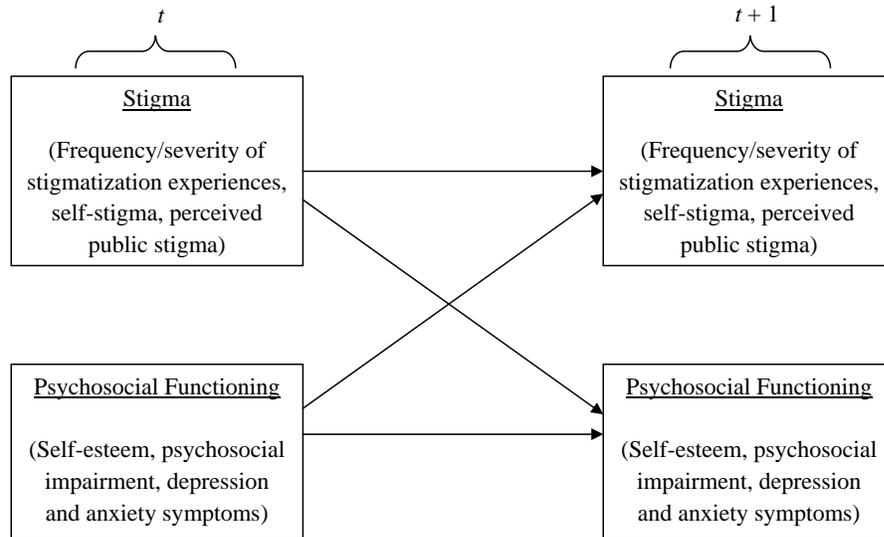


Figure 1.1: Conceptual model of hypothesized bidirectional relationships between stigma and psychosocial functioning variables.

Secondary goals of the study include examining descriptive statistics to learn more about the role of stigma-related variables in the lives of people with mental illness, including the frequency of stigmatization experiences in everyday life and the degree to which the relation between stigmatization and psychosocial functioning is due to differences between people versus differences within people over time. Specifically, some individuals have higher levels of self-stigma and because of this, generally have high levels of depression (between-person variability). Alternatively, perhaps when a specific individual has days of higher than usual levels of self-stigma they also tend to report more depression (within-person variability). Other goals include examining which stigma variables best predict future psychosocial functioning variables. I hypothesize self-stigma will better predict self-esteem and depression symptoms than perceived public stigma, and perceived public stigma will better predict anxiety symptoms than self-stigma.

## Chapter 2: Method and Results

### 2.1 Method

#### 2.1.1 Participants

I recruited participants from state chapters of the National Alliance on Mental Illness (NAMI), predominately drawing from Washington, D.C., Virginia, and Maryland chapters. I also recruited from Families for Depression Awareness (FDA). NAMI and FDA distributed flyers at meetings, over their email listservs, and posted to their organization social media pages. I also encouraged a snowball method where participants shared the research announcement with other potential participants.

#### **Inclusion criteria.**

Participants were at least 18 years of age, self-reported to be currently diagnosed with an *DSM-IV-TR* Axis I mental illness other than substance use disorders (individuals with substance use disorders were not excluded if they reported another Axis I disorder), had nightly Internet access, consented to share their email address, consented to be emailed on a daily basis to complete the surveys, were not currently hospitalized, and were currently receiving outpatient mental health treatment. A total of 112 participants passed four screening items that reflected the inclusion criteria (see Appendix C), gave electronic informed consent D, and enrolled in the study.

#### 2.1.2 Procedure

I chose a daily diary sampling methodology to collect daily observations for one week. The use of regular measurements enabled the use of time lagged analyses, which can be useful

for testing the direction of influence over time among variables.

The lack of within-person research on mental illness stigma made it difficult to decide how frequently to assess variables. Cohen, Kessler, and Gordon (1997) suggest that daily recordings for three to four weeks should produce enough variability in mood scores to test temporal relations between daily stressors and mood, but also noted this time frame could burden the participants. Having a smaller sampling time frame such as one week could reduce burden, but more participants will be needed to compensate for loss of statistical power. To illustrate these points, researchers initially planned once daily sampling with medically ill patients for four weeks, but found this burdened participants and switched to a two week time frame which was still sufficient to find day-to-day relations with negative mood predicting next day physical symptoms (Carels et al., 2004). Previous work has captured within-person variance (46%) in negative affect over the course of just eight days (Mroczek, Spiro, & Almeida, 2003), and significant within-person effects were found in a study of HIV stigmatization experiences with once daily sampling for 3 weeks on only 7 participants (147 observations) (Janda et al., 2006).

Given the uncertainty in the time frame needed to capture within-person variability mood and stigmatization scores, and the high potential for participants feeling overburdened, I aimed for more participants within a smaller time frame. For example, recruiting nearly 100 participants to complete daily surveys for a week would produce 700 observations given full completion, but probably about 500–600 with missing data. This number of observations should be enough to test both within- and between-person relations. Once daily sampling for a week should capture this within-subjects variability in psychosocial functioning variables while not burdening participants. Hopefully the within-person variance in stigma variables will also be captured, but this is difficult to predict given the lack of research on mental illness stigmatization within-persons.

Previous procedures for daily diary studies (Baker, 2003; Beals et al., 2009; Janda et al., 2006; Swim et al., 2001), as well as best practices for conducting daily diary research (Bolger, Davis, & Rafaeli, 2003; Cohen et al., 1997; Green, Rafaeli, Bolger, Shrout, & Reis,

2006; Tennen, Affleck, Coyne, Larsen, & DeLongis, 2006) guided the current study design and procedures described in the next two paragraphs.

The success of daily diary studies (and longitudinal studies, generally) depend on a “collaborative engagement” between researcher and participant. To encourage this collaboration, participants were given non-monetary reasons to participate in the study (e.g., learn more about mental illness stigmatization experiences, raise awareness about stigma and mental illness, combat stigma, etc.). I warned potential participants that the task may be burdensome. I kept daily surveys to less than 10 minutes to optimize participation. Relatively rare events – which mental illness stigmatization experiences may be – may best be captured reliably at the end of the day as opposed to random sampling throughout the day. Participants were invited to email me if they were unsure about any of the items or the procedures.

Further, there was no universal agreement on whether electronic or paper diaries are better, and the effectiveness of each likely depends on the frequency of measurement, the population, and other methodological and practical considerations. For the current study, electronic daily diaries appeared most effective, especially for recruiting and maintaining participation with ease. Electronic daily diaries enabled me to collect daily data without meeting in-person or mailing diaries and forms, expanding the sample nationwide and easing the cost and burden of data collection on both myself and participants.

I created a recruitment flyer (Appendix A) for organizations to post to email listservs, social media websites, and newsletters. Participants responded to flyers by following a weblink to the study website (<https://sites.google.com/site/mentalillnessstigma/>). Participants then read more detailed information about the study (Appendix B) and were instructed to click an Internet link directing them to the screening items (Appendix C) and informed consent form (Appendix D). If participants consented, they immediately completed the demographics and baseline items (Appendix E).

At the end of the baseline survey, participants were instructed to complete the daily survey every evening for the next seven days after all expected social interactions had

occurred (e.g., right before going to bed). Participants were encouraged to carry a notepad so they could note stigmatization experiences that occurred throughout the day to facilitate recall later that day.

If the participant forgot to complete the survey the night before, but remembered first thing in the morning, they could complete the survey then and reflect upon their experiences yesterday. If it was more than 24 hours late, participants were instructed to leave the survey blank, the survey would be missing data, and they would complete the next survey reflecting on today only.

Participants were paid \$5 for completing the baseline survey and at least one daily survey, and an additional \$10 for completing the baseline and at least 6 daily surveys. Some participants elected to donate their payment directly to the NAMI (\$270 was donated), or FDA (\$185 was donated).

### **Security questions.**

All surveys included a question (see Appendix F) that instructed participants not to respond, with the goal of detecting inattentive or disengaged participants. Two participants responded to the survey security question. I inspected the data for both cases and did not detect any evidence of inattention, incomplete, grossly inconsistent, or repetitious answers, and thus opted to retain these cases in the final dataset.

### **2.1.3 Final Sample Size**

Table 2.1 displays the distribution of surveys completed. Best practices recommend three time points for modeling longitudinal growth curves and changes over time (Singer & Willett, 2003); this recommendation may or may not apply to daily diary data over a much more restricted time frame. Because the main analyses are within-person questions, requiring at least three time points would perhaps provide a better estimate of within-person variability rather than estimating from only 1 or 2 time points. Only participants who completed at least three daily surveys were included in the day-to-day analyses and analyses

separating within- and between-person components. This decision only excluded 5 additional participants (7 measurement occasions) from these analyses because 11 would have been excluded for not completing any daily surveys. The final sample size was  $n = 96$  for the dataset examining day-to-day relations and analyses separating within- and between-person components; descriptive statistics and frequencies were calculated using these data. All results use the  $n = 96$  dataset, except the complete,  $N = 112$  dataset was used for exploratory analyses describing stigmatization experience frequency, severity, targets, and sources.

Table 2.1: Subsample Size By Number of Daily Surveys Completed

Survey completed	$n$	Cumulative $n$
Included in day-to-day analyses and analyses separating within- and between-person components		
Baseline + 7 daily	58	58
Baseline + 6 daily	25	83
Baseline + 5 daily	6	89
Baseline + 4 daily	2	91
Baseline + 3 daily	5	96
Additional cases included in all other analyses		
Baseline + 2 daily	2	98
Baseline + 1 daily	3	101
Baseline only	11	112

Did the participants excluded from the main analyses ( $n = 16$ ) differ from participants included in the main analyses ( $n = 96$ )? All statistical tests used using  $p < .10$  for statistical significance, given the small sample size for the excluded participants. Crosstab

analyses with Pearson chi-square tests compared participants included in the main analyses to participants excluded from the main analyses. Participants did not differ on education level, sex/gender identity (except the excluded sample had one female to male transgender participant, and the included sample had none), marital status, employment status, number of lifetime psychiatric inpatient admissions, frequency of seeing mental health providers, frequency of mental health service utilization (e.g., individual psychotherapy, medication), or whether or not they had a mental illness stigmatization experience in their lifetime. A one-way ANOVA indicated the excluded sample was younger (Main Analyses $\bar{x}$  = 38.08, Excluded $\bar{x}$  = 28.53,  $p < .01$ ), and diagnosed with mental illness at an earlier age (Main Analyses $\bar{x}$  = 24.78, Excluded $\bar{x}$  = 19.29,  $p < .05$ ), but did not find statistically significant difference between the two samples in amount of time passed since first diagnosed, age of mental illness onset, duration of mental illness, number of years in mental health treatment, number of years on medication, medication side effect severity, or impairment due to mental illness. Thus, the excluded participants were demographically similar to included participants except that excluded participants were younger and were diagnosed with mental illness at an earlier age.

#### **2.1.4 Measures**

The baseline survey (Appendix E) included basic demographic items (e.g., age, sex/gender identity, employment status), demographic items relevant to mental illness (e.g., self-reported current diagnoses, age first diagnosed with mental illness, involvement in mental health treatment), a measure asking participants to describe and rate three of their most severe lifetime stigmatization experiences, and a baseline measure of psychosocial impairment due to mental illness (the Work and Social Adjustment Scale; see below).

Existing measures of self-stigma, perceived public stigma, and stigmatization experiences were not used in this study because they were not suitable for daily report or were created for hospitalized populations with more severe mental illness. Before completing the stigma measures, participants were instructed “The following questionnaire uses the term,

‘mental illness’ to describe what others have called many different terms (for example, ‘psychological problems,’ ‘psychiatric illness,’ or ‘a mental health condition’) but please think of it as whatever you feel is the best term for it”; similar to instructions for the Internalized Stigma of Mental Illness scale (Ritsher, Otilingam, & Grajales, 2003).

### **Stigmatization experiences.**

A review of stigmatization experiences measures provided some guidelines for instrument selection (Brohan et al., 2010). I reviewed 10 published measures of stigmatization experiences; however, such measures are all designed for retrospective and not prospective report with more frequent measurement occasions. Measures also did not assess the severity of stigmatization experiences (i.e., the degree of perceived stigmatization involved in each experience).

I created a measure of stigmatization experiences suitable for daily report (Appendix G). The measure asked participants, “Did you have a mental illness stigma experience *today?*” A daily stigma experience was defined as anything that “happened today to make you aware of others’ negative attitudes or stereotypes about people with mental illness. This could involve prejudice, negative stereotyping, or discrimination directed (a) toward you, (b) toward someone else, or (c) toward all people with mental illness.” The measure instructs participants to describe and rate stigmatization experiences for people with “mental illness”, broadly, instead of just toward people with their specific illness. There is good reason to believe that people with many different mental illnesses perceive stigmatization toward their social group of “people with mental illness” as a whole and not just toward their specific illness. For example, people with depression may witness stigmatization experiences directed toward a person with schizophrenia (or vice versa) and this experience may still represent vicarious stigmatization even though the target has a different mental illness. Evidence for the broad, stigmatized social group of people with mental illness stems from organizations representing the broad stigmatized community of people with mental illness as opposed to single mental illnesses (e.g., NAMI and Mental Health America).

Participants were given examples of possible events, including:

- Witnessing hurtful or offensive things about people with mental illness in the media (e.g., television, movies, books);
- Being rejected, insulted, or ignored because of having a mental illness;
- Noticing others feeling uncomfortable around you because you have a mental illness;
- Experiencing unjust discrimination and being excluded from opportunities (e.g., in housing, employment, education, medical care) because of having a mental illness;
- Hearing about another person being treated poorly because she or he has a mental illness.

Participants also indicated the target of stigmatization, that is, whether they (a) experienced stigmatization directed toward themselves, personally (direct stigmatization experience), (b) witnessed stigmatization directed toward another individual, or (c) overheard or witnessed stigmatization that was directed toward people with mental illness, generally. Participants described each stigmatization experience that occurred during the day and rated each experience according to the degree of stigmatization severity present ( $1 = \textit{almost none}$ ,  $3 = \textit{some}$ ,  $5 = \textit{extreme}$ ). The measure provided two continuous variables, the first of which was the “severity of stigmatization experiences”, and the second was a count of how many stigmatization experiences participants had during the week, “frequency of stigmatization experiences.” Because I coded people who did not rate stigmatization experience severity for that day as a “0”, the severity variable partly reflects whether or not people even had experiences. Thus, this variable reflects the degree of severity of stigmatization experiences, but also includes an element of whether or not someone had such an experience.

### **Coding stigmatization experiences.**

Upon inspecting the qualitative data on stigmatization experiences, some responses did not meet the above conceptualization of stigmatization experiences (i.e., an actual event involving prejudice, negative stereotyping, or discrimination directed toward the participant, toward someone else, or toward all people with mental illness). For example, some participants reported difficulty managing their symptoms of mental illness (e.g., accruing major debt due to excessive spending in manic episodes), and difficulties with their providers and family unrelated to stigmatization. Thus, it was necessary to code the qualitative data to ensure that the stigmatization experiences variable was consistent with my conceptualization.

I recruited 8 undergraduate research assistants who had recently completed an abnormal psychology course to assist in data coding. Data coders were asked to determine if each response met the working definition of a stigmatization experience: Yes, No, or Maybe (see Appendix L). Coders were given specific instructions on what responses to code as “Yes”, “No”, or “Maybe”. Coders were instructed that the main task was to identify the responses that were clear “No’s” and eliminate them from the dataset. Coders were also given examples from the dataset to illustrate each of the three categories, and each example explained why it was rated in the specific category. To ensure coders were qualified and adequately trained, coders practiced coding on 17 previously coded, “gold-standard” responses (Part 1). After the 17 responses, coders received detailed feedback on all responses and were able to ask further questions. When approved, coders completed another iteration of 25 more responses (Part 2) and then I decided whether or not they were ready to begin the actual coding. Coders who diverged from most other coders and the gold standard rating (e.g., rated a “No” when everyone else rated “Yes” or “Maybe”) were given individualized feedback after both Part 1 and Part 2.

Coders were also trained on how to code for the source of stigmatization. A list of all possible sources was constructed with input from previous research on sources of mental illness stigmatization (Loganathan & Murthy, 2008; Thornicroft et al., 2009; Wahl, 1999)

and the research team of my advisor and 8 coders (see Appendix M). Codes could specify other sources during the actual coding.

Research assistants coded each of the responses for whether or not they were stigmatization experiences. A response was retained in the dataset if at least 6/8 coders (75%) rated the response “Yes” or “Maybe.” After the first round of coding, 17 responses were eliminated from the dataset because at least 75% of the coders agreed that the responses were a “No”. There were 16 responses with high disagreement (i.e., between 3 and 5 coders indicated “No”). I met with coders to discuss such responses and come to at least a 75% consensus on whether or not each response should be included in the dataset: 5 of these responses were eliminated from the dataset. In total, 22 (7.5%) stigmatization responses, including their respective frequency and severity ratings and identified targets of stigmatization, were eliminated from the dataset.

Research assistants then coded the source of mental illness stigmatization. Some stigmatization responses described multiple sources, and the answer choices were nonmutually exclusive. If at least 4/8 (50%) of coders indicated a stigma source for a response, the source was coded for that response. I lowered the threshold for coding sources (50% of coders) than coding for excluding “NO” responses (75% of coders) to prevent errors of omission because coders were heavily taxed with rating 37 sources for each stigmatization experience. I also preferred to give participants the benefit of the doubt if a source was sometimes difficult for many coders to discern. After the first round of coding, 19 responses were reviewed as a group to agree upon the source(s) because less than 4 coders agreed upon a source for the response. The coders and I further divided sources into higher order source groupings (see Appendix M, Figure M.1).

### **Daily self-stigma and perceived public stigma.**

I used a 14-item measure of self-stigma and perceived public stigma developed by Kendra and Mohr (under review) for use with outpatient psychotherapy clients with less severe mental health problems (Appendix H). Participants rated 7 self-stigma items (e.g., “I feel

ashamed of myself for having a mental illness”) and 7 perceived public stigma items (e.g., “In general, others believe that having a mental illness is a sign of personal weakness or inadequacy”) on how much they agreed with each item today on a scale from 1 (*strongly disagree*) to 4 (*strongly agree*). In the original study, Cronbach’s  $\alpha$  was .91 for self-stigma and .84 for perceived public stigma. Self-stigma and perceived public stigma scores were positively correlated with the degree to which a person with mental illness keeps their problems a secret, and degree of difficulty with stigmatization experiences. Self-stigma but not perceived public stigma scores were found to be positively correlated with depression symptoms. Cronbach’s alpha calculated at the aggregated, person-level was .96 for self-stigma and .84 for perceived public stigma in the current study.

#### **Impairment due to mental illness.**

The 5-item Work and Social Adjustment Scale (WSAS) is a commonly used measure of functional impairment due to mental illness (Mundt, Marks, Shear, & Greist, 2002). The WSAS asks participants the degree to which mental illness has impacted their functioning ( $0 = \textit{not at all}$ ;  $8 = \textit{very severely}$ ). A sample item is “Because of my mental illness, my ability to work is impaired. 0 means not at all impaired and 8 means very severely impaired to the point I can’t work.” A total mean score  $> 4$  indicates moderately severe psychopathology, between 2 and 4 is associated with significant functional impairment but less severe psychopathology, and  $< 2$  appears to be subclinical. Validity and reliability evidence for depression and obsessive-compulsive disorder samples was provided in the original study, with other studies providing validity and reliability evidence in people with phobias (Mataix-Cols et al., 2005). In the current study, Cronbach’s alpha was .97 for psychosocial impairment calculated at the aggregated, person-level, and .88 at baseline.

#### **Daily self-esteem.**

The State Self-esteem Scale (SSES), Social subscale (Heatherton & Polivy, 1991) was used to measure interpersonal self-esteem/social insecurity, feelings of self-worth, and well-being

(see Appendix I). Participants rated items (e.g., “I have been worried about what other people think of me”) on a scale of 1 (*not at all*) to 5 (*extremely*). The scale was reworded to refer to how participants felt about themselves “today” as opposed to “at this moment.” Cronbach’s alpha was .97 for interpersonal self-esteem in the current study, calculated at the aggregated, person-level.

### **Daily psychiatric symptoms.**

Subscales of the Positive and Negative Affect Scale (PANAS-X, Appendix J) were used as a measure of psychiatric symptom severity (D. Watson & Clark, 1994). The PANAS-X consists of one-word items grouped into subscales assessing specific dimensions of affect and has substantial evidence for validity and reliability in daily report. I used the 5-item Sadness subscale of the PANAS-X to measure daily depression symptomatology. Participants rated the extent they have felt the emotions and feelings in each of the items (i.e., sad, blue, downhearted, alone, lonely) “today” on a scale of 1 (*very slightly or not at all*) to 5 (*extremely*). I used the 6-item “Fear” subscale of the PANAS-X to measure daily anxiety symptomatology (i.e., afraid, scared, frightened, nervous, jittery, shaky), rated on the same scale. Another study used the Sadness and Anxiety subscales of the PANAS-X as a measure of daily depression and anxiety symptoms in adult outpatients with depression and anxiety disorders (Gunthert, Cohen, Butler, & Beck, 2007). Cronbach’s alpha was .96 for the both subscales in the current study, calculated at the aggregated, person-level.

### **Debriefing Survey**

At the end of the final daily survey, participants were asked debriefing questions to understand what participants learned from doing the study (Appendix K). I asked participants:

- if being in the study increased, decreased, or did not affect their tendency to notice stigmatization experiences;
- whether participants felt mental illness stigmatization experiences were a major part

of their lives;

- what they learned from doing the study;
- to rate the degree to which they under-, over-, or correctly estimated the frequency of stigmatizing experiences and subsequent effects on their daily life, and
- if they would like to receive a summary of the research findings.

## 2.2 Results

### 2.2.1 Descriptive Statistics

Table 2.2 displays the participant demographic characteristics at baseline. Participants were mostly Caucasian, female, and had at least some degree of college or graduate school education, but varied widely in marital status, employment status, and living situation. Mean age was 38.08 ( $SD = 11.10$ , range 19–60). Of the 48 participants reporting residential data, participants resided in 29 U.S. states, Canadian provinces, and Washington, D.C.

Table 2.2: Descriptive Statistics At Baseline

	<i>n</i>	% of sample
Sex/gender identity		
Male	16	16.67%
Female	80	83.33%
*Race/ethnicity		
African American/Black	4	4.17%
Asian American/Pacific Islander	1	1.04%
Latina/Latino/Hispanic	4	4.17%
Native American/American Indian	2	2.08%

	<i>n</i>	% of sample
White/Caucasian/European American	88	91.67%
Middle Eastern	1	1.04%
“Human”	1	1.04%
“Multiracial”	1	1.04%
Marital status		
Married	28	29.17%
Separated	4	4.17%
Divorced	14	14.58%
Single (never married)	50	52.08%
Employment status		
Employed full-time	39	40.63%
Employed part-time	18	18.75%
Self-employed	1	1.04%
Unemployed	20	20.83%
Retired	2	2.08%
Student	10	10.42%
Homemaker	6	6.25%
*Living situation		
Alone	19	19.79%
With parents	17	17.71%
With children	20	20.83%
With partner/spouse	37	38.54%
Group home/residential living/shelter	0	0%
With others (friends/housemates)	12	12.50%
Other	10	10.42%

	<i>n</i>	% of sample
Education level		
High school degree	2	2.08%
Some college	44	45.83%
College degree (B.A. or B.S.)	20	20.83%
Some graduate school	4	4.17%
Post-graduate degree (M.A., Ph.D., etc.)	26	27.08%

\*Categories were nonmutually exclusive.

Table 2.3 displays demographic data for categorical variables related to mental illness. The most frequently reported diagnoses were bipolar disorder (over 1/2), depressive disorders (about 1/3), and generalized anxiety disorder (about 1/3). Four participants reported being diagnosed with schizoaffective disorder, and none reported a schizophrenia diagnosis. About 2/3 of the sample reported at least one prior psychiatric inpatient hospitalization. Most participants were seeing a psychiatrist, taking psychiatric medication, and in individual psychotherapy or counseling. Nearly all reported having at least one mental illness stigmatization experience in their lifetime, though there were 6 (6.25%) who did not.

Table 2.3: Mental Illness Demographic Frequencies At Baseline

	<i>n</i>	% of sample
*Current diagnosis		
Bipolar disorder/manic depression	55	57.29%
Depressive disorders	35	36.46%

	<i>n</i>	% of sample
Generalized anxiety disorder	29	30.21%
Attention disorder or learning disability	17	17.71%
Obsessive-compulsive disorder	16	16.67%
Post-traumatic stress disorder	15	15.63%
Personality disorder	11	11.46%
Eating disorder	7	7.29%
Other	7	7.29%
Social phobia	5	5.21%
Schizoaffective disorder	4	4.17%
Panic disorder	4	4.17%
Dissociative identity disorder	2	2.08%
Specific phobia	0	0%
Schizophrenia	0	0%
Number of lifetime psychiatric inpatient hospitalizations		
Never hospitalized	34	35.42%
1 time	24	25.00%
2-5 times	29	30.21%
6-10 times	6	6.25%
> 10 times	3	3.13%
*What providers are you currently seeing for mental illness?		
Psychiatrist	71	73.96%
Psychologist	28	29.17%
Licensed professional counselor	27	28.13%
General practitioner or other physician	23	23.96%
Social worker	15	15.63%

	<i>n</i>	% of sample
Psychiatric nurse	11	11.46%
Peer counselor	11	11.46%
*What types of mental health services do you currently use?		
Psychiatric medication	84	87.50%
Individual psychotherapy/counseling	67	69.79%
Consumer-led support groups	24	25.00%
Group psychotherapy/counseling	13	13.54%
Case management	9	9.38%
Have you ever had a mental illness stigmatization experience?		
Yes	90	93.75%
No	6	6.25%

\*Categories were nonmutually exclusive.

Table 2.4 displays demographic data for continuous variables related to mental illness. Though there was a fair amount of variability, most participants reported, on average, having a mental illness for over 20 years with the onset in the teenage years but not diagnosed until their mid-twenties. On average, participants have been taking psychiatric medication or receiving mental health treatment for a total of 10 years during their lives, and reported experiencing mild to moderate side effects from their psychiatric medications. Duration of mental illness and age mental illness was first diagnosed appeared normally distributed with a fair amount of variability. Medication side effect severity, the number of years on psychiatric medication, and the age of mental illness onset were all markedly positively skewed.

Overall baseline functional impairment due to mental illness was moderate to moderately severe and normally distributed. A Wilcoxon Signed Ranks Test was used to compare

the degree of impairment in the five separate impairment items, indicating participants were equally impaired in work, home management, and ability to form close relationships with others. Compared to these domains, participants were statistically significantly less impaired in private leisure activities but more impaired in social leisure activities. Social leisure activities with others was rated as the highest level of impairment, suggesting that participants' mental illness strongly impacted their social functioning and perhaps reflected particular difficulty in managing the social aspects of a stigmatized illness.

Table 2.4: Mental Illness Descriptives At Baseline

	<i>M</i>	<i>SD</i>	Actual range
Age of mental illness onset	16.04	9.17	0 <sub>a</sub> -51
Age first diagnosed with a mental illness	24.78	9.36	6-51
Duration of mental illness (years)	21.95	12.11	1-49
Number of years receiving psychiatric medication	10.84	8.15	0-40
Number of years receiving mental health treatment	11.61	9.37	0-44
Medication side effect severity	2.02	.99	1-5
Functional impairment due to mental illness	3.76	2.07	0-8

<sub>a</sub>One participant claimed to have developed mental illness before 1 year of age.

Table 2.5 displays the aggregated, participant-level means, standard deviations, and theoretical range for all variables assessed at the daily level, aggregated by participant. Histograms for each of the aggregated participant-level means for daily-level variables were inspected to test normality. Self-stigma, perceived public stigma, impairment, and interpersonal self-esteem levels appeared normally distributed. Anxiety symptoms were markedly positively skewed and depression symptoms were slightly positively skewed, suggesting I

should use a model robust to non-normality.

One main goal of this study was to determine the degree to which people vary in stigma and psychosocial variables over the course of the week, within- and between-persons. The intraclass correlation coefficient (ICC) represented the proportion of variance in stigma and psychosocial functioning levels attributable to stable between-person differences, whereas the remainder represented day-to-day variance within-persons and error. ICCs suggested that over 80% of the variance in self-stigma and impairment was due to stable differences between participants; perceived public stigma, depression, anxiety, and interpersonal self-esteem were also driven mostly by between-person processes but to a lesser degree. In contrast, less than 10% of the variance in stigma experience severity was due to between-person processes, with most of the variance explained by differences within an individual over time and error.

Table 2.5: Aggregated, Participant-level Descriptive Statistics for Daily Variables

	<i>ICC</i>	<i>M</i>	<i>SD</i>	Possible range
Self-stigma	.84	2.44	0.70	1–4
Perceived public stigma	.71	3.08	0.37	1–4
Stigma experience severity	.08	0.47	0.64	0–5
Anxiety symptoms	.59	1.81	0.80	1–5
Depression symptoms	.58	2.34	0.92	1–5
Impairment	.83	3.52	2.09	0–8
Interpersonal self-esteem	.66	2.72	1.01	1–5

*Note.* *ICC* = intraclass correlation coefficient.

## 2.2.2 Main Analyses

### Day-to-day, bidirectional analyses.

I hypothesized bidirectional, within-person relationships between stigmatization experiences and psychosocial functioning from day-to-day. Analyses were conducted using Mplus Version 6.1 (Múthen & Múthen, 2010). I centered continuous variables at the person's own mean to remove all variance due to differences between persons. A model developed by Asparouhov (2005, 2006) was used to adjust standard errors for nonindependence of observations due to repeated measurements within-persons. Robust maximum likelihood methods were used to produce parameter estimates and standard errors robust to non-normality.

To test one direction of the bidirectional hypothesis, that is, that stigma variables will predict next day decreases in psychosocial functioning, I used a 1-day lagged procedure. Here, stigma variable levels on a given day are hypothesized to affect changes in psychosocial functioning the next day. To rule out the possibility that any lagged effect of stigma on functioning might be an artifact of previous functioning level, previous day's functioning level will be included in the model as a control variable. In such a model, the dependent variable can be interpreted as the change in functioning from day  $t$  to day  $t + 1$ . The generic analysis model for changes in psychosocial functioning for each individual can be expressed using the following Level 1 equation:

$$Functioning_{j,t+1} = a_{0,j} + a_{1,j}(Functioning_{j,t}) + a_{2,j}(Stigma_{j,t}) + r_{j,t+1}$$

where  $Functioning_{j,t+1}$  is the change in person  $j$ 's psychosocial functioning score between day  $t$  and day  $t + 1$ ;  $a_{0,j}$  is a regression intercept representing the mean change in daily psychosocial functioning;  $a_{1,j}$  is a partial regression slope representing an individual's level of a stigma variable on day  $t$ ; and  $r_{j,t+1}$  is a residual component of change in psychosocial functioning. This procedure involved dropping data for predicting Day 1 outcomes.

Each of the four daily psychosocial functioning variables (anxiety and depression symptoms, psychosocial impairment due to mental illness, and interpersonal self-esteem) were regressed on each of the three daily stigma variables (self-stigma, perceived public stigma,

severity of stigmatization experiences). To test the other direction of the bidirectional hypothesis, I ran the same model in reverse in the same analysis. For example, to test the bidirectional relationship between self-stigma and depression, I specified a single model regressing today's levels of self-stigma and depression on next day self-stigma and depression levels. I did not include frequency of stigmatization experiences in the analyses due to multicollinearity with the severity of stigmatization experiences variable and because there was not much variability in frequency of experiences. Further, due to the way the stigma experience severity variable was coded, it already reflects an element of experience frequency (see Section 2.1.4). Finally, even though most prior cross-sectional research has examined how the frequency of stigmatization experiences relates to psychosocial functioning, many suggest that it is not the amount or frequency but the severity of negative events that affects daily mood and functioning (Baker, 2003; David, Green, Martin, & Suls, 1997).

The top half of Table 2.6 displays the results for the models where stigma variables predict next day psychosocial functioning. Self-stigma significantly positively predicted next day anxiety symptoms and impairment, and negatively predicted interpersonal self-esteem, but was unrelated to next day depression symptoms. Perceived public stigma positively predicted next day anxiety symptoms, depression symptoms (trend), and impairment, and negatively predicted interpersonal self-esteem. Severity of stigmatization experiences only positively predicted next day anxiety symptoms and was unrelated to future levels of the other psychosocial functioning variables.

The bottom half of Table 2.6 displays the results for the models where psychosocial functioning variables predict next day stigma variables. The only psychosocial functioning variable that significantly predicted a next day stigma variable was anxiety symptoms, which was positively related to next day perceived public stigma. All other results were not statistically significant.

Table 2.6: Stigma and Psychosocial Functioning: Day-to-day Bidirectional Relations

Today levels (IV)	Next day levels (DV)	<i>n</i>	<i>Est.</i>	<i>SE</i>
Daily stigma variables (IV)				
Self-stigma	Anxiety symptoms	527	0.55**	0.09
	Depression symptoms	528	0.04	0.05
	Impairment	527	1.01**	0.02
	Interpersonal Self-esteem	528	-0.46**	0.08
Perceived public stigma	Anxiety symptoms	484	0.29**	0.04
	Depression symptoms	484	0.04 <sub>a</sub>	0.02
	Impairment	484	0.34**	0.04
	Interpersonal Self-esteem	485	-0.19**	0.04
Stigma experience severity	Anxiety symptoms	527	0.16*	0.08
	Depression symptoms	528	-0.01	0.03
	Impairment	527	0.10	0.14
	Interpersonal Self-esteem	528	-0.08	0.07
Daily psychosocial functioning variables (IV)				
Anxiety symptoms	Self-stigma	527	–	–
	Perceived public stigma	484	0.05*	0.02
	Stigma experience severity	527	0.06	0.04
Depression symptoms	Self-stigma	528	–	–
	Perceived public stigma	484	0.04	0.07
	Stigma experience severity	528	0.15	0.09
Impairment	Self-stigma	527	–	–
	Perceived public stigma	484	0.00	0.02
	Stigma experience severity	527	0.04	0.04

Today levels (IV)	Next day levels (DV)	<i>n</i>	<i>Est.</i>	<i>SE</i>
Interpersonal Self-esteem	Self-stigma	528	–	–
	Perceived public stigma	485	-0.01	0.06
	Stigma experience severity	528	0.08	0.07

*n* = number of observations; \*\* $p < .001$ ; \* $p < .05$ ;  $a_{trend} = p < .10$ .

*Note.* Parameters for self-stigma as a dependent variable were unable to be calculated due to an error in Mplus, probably due to very little within-person variability in next day self-stigma levels or a low correlation between next day self-stigma and each predictor.

### 2.2.3 Exploratory Analyses

#### Stigmatization experiences.

Of the 112 participants, 49 (43.75%) participants reported 102 stigmatization experiences during the daily diary phase. Participants reported a range from 0–7 experiences per day and 0–8 experiences per week, averaging 1.10 experiences per week per participant. 63 participants (56.2%) reported 0 experiences during the week, 26 (23.2%) reported 1, 11 (9.8%) reported 2, 5 (4.5%) reported 3, 5 (4.5%) reported 4, 1 (.9%) reported 7, and 1 (.9%) reported 8. Because some participants completed more daily surveys than others, this may be an underestimate of the number of person-level experiences per week. 15 participants reported having multiple experiences per day (actual range 2–7). Participants were divided on whether or not stigmatization experiences were a major part of their lives, with 34 reporting they were and 41 reporting they were not.

I created an “experience-level” dataset from the 112 participants that treated the 218 lifetime and 102 daily reported stigmatization experiences as separate cases. Each case, or

stigmatization experience, was coded for severity, target, source, and higher order source grouping. Among the most severe stigmatization experiences reported during the lifetime, most were directed towards participants, themselves (71%); however, the day-to-day experiences had stigmatization targets nearly evenly split among “myself” (34%), “someone else with mental illness” (23%), and “people with mental illness, in general” (43%).

Table 2.7 displays the frequency of the higher order sources of stigmatization in the current study (see M.1 for how specific sources during the coding were grouped into higher order stigmatization sources), comparing the lifetime to the daily sources at the experience-level. Work and family were among the most frequent stigmatization sources at the daily-level, but the media was by far the most frequent source of day-to-day stigmatization with 1 out of 3 daily stigmatization experiences from the media.

Table 2.7: Frequency of Stigmatization Sources

Source of stigmatization	Lifetime experiences		Daily experiences	
	<i>n</i>	%	<i>n</i>	%
Work	54	25.00	15	14.71
Family	40	18.52	17	16.67
Passerbys/General Public				
/Unknown Others	31	14.35	5	4.90
Friend	21	9.72	10	9.80
Medical Professionals	17	7.87	7	6.86
Other People	14	6.48	8	7.84
Romantic Partner	13	6.02	2	1.96
Mental Health Professionals	11	5.09	3	2.94
Media	8	3.70	34	33.33
School	7	3.24	1	0.98
Total	216	100.00	102	100.00

*Note.* *n* = number of reported stigmatization experiences. Results are based on the larger set of responses from 112 participants, but at the experience level.

### **Within- and between-person components.**

In a final set of exploratory analyses, I used multilevel modeling to decompose the associations between the stigma and psychosocial functioning variables into within-person and between-person components. In previous cross-sectional research, these two levels of analysis have been conflated. What is true of the association at the within-person level may well differ from the corresponding association at the between-person level (Fleeson, 2007).

Consider, for example, the association between self-stigma and depression. This association could be due to between-person variance (i.e., people who are generally higher in self-stigma tend to be generally more depressed) or within-person variance (i.e., days when a person experiences more self-stigma than usual tend to be days when the person is more depressed). I used Mplus Version 6.1 (Múthen & Múthen, 2010) to implement an analytic approach that decomposes relations into latent within- and between-person components, and may be especially useful when person-level means may have low reliability due to factors such as low numbers of observations per person (Lüdtke et al., 2008). To identify these within- and between person components, multilevel covariance models were investigated using robust maximum likelihood estimation. Each stigma variable was covaried with each psychosocial functioning variable. Pure between-person effects (i.e., “contextual” effects) were investigated by computing and testing the difference between the corresponding within-person and between-person associations. All between-person results presented below represent the between-person estimates with the within-person components subtracted out. These multilevel regression analyses also produced the ICCs found in Table 2.5.

Table 2.8 displays results from these analyses separating within- and between-person components. Most analyses were significant at the within-person but not at the between-person level. For example, when an individual had a day with higher levels than usual of self-stigma or perceived public stigma, that individual tended to report more anxiety and depression symptoms, more psychosocial impairment, and less interpersonal self-esteem. Daily severity of stigmatization experiences was also positively related to depression symptoms and negatively related to interpersonal self-esteem at the within-person level, but there was no significant relationship with anxiety symptoms or psychosocial impairment. At the between-person level, self-stigma was related to all psychosocial functioning variables in the expected directions; no other stigma variable was significantly related to psychosocial functioning variables at the between-person level. Though no formal analyses were conducted, estimates for relations with self-stigma and psychosocial functioning variables always appeared greater in magnitude than the estimates for perceived public stigma.

Table 2.8: Stigma and Psychosocial Functioning: Covariance Models Separating Within- and Between-Person Components

		Within		Between	
		<i>Est.</i>	<i>SE</i>	<i>Est.</i>	<i>SE</i>
Self-stigma	Anxiety symptoms	0.04***	0.01	0.18**	0.06
	Depression symptoms	0.07***	0.02	0.29***	0.07
	Impairment	0.12***	0.02	0.71***	0.15
	Interpersonal Self-esteem	-0.08***	0.02	-0.44***	0.08
Perceived public stigma	Anxiety symptoms	0.02*	0.01	0.03	0.04
	Depression symptoms	0.03***	0.01	0.06 <sub>a</sub>	0.04
	Impairment	0.06***	0.02	0.12	0.08
	Interpersonal Self-esteem	-0.03**	0.01	-0.02	0.04
Stigma experience severity	Anxiety symptoms	0.06	0.04	0.00	0.07
	Depression symptoms	0.10**	0.04	-0.02	0.06
	Impairment	0.04	0.05	0.19	0.15
	Interpersonal Self-esteem	-0.12**	0.04	0.10	0.08

\*\*\* $p < .001$ ; \*\* $p < .01$ ; \* $p < .05$ ; <sub>a</sub>trend =  $p < .10$ .

*Note.*  $n$  observations was 606 for self-stigma and perceived public stigma analyses, and 635 for stigma experience severity analyses.

## Chapter 3: General Discussion

The main goal of the current study was to investigate bidirectional relationships between mental illness stigmatization (i.e., self-stigma, perceived public stigma, severity of stigmatization experiences) and psychosocial functioning (anxiety and depression symptoms, impairment, self-esteem). Exploratory goals included examining (a) stigmatization experiences over the lifetime and from day-to-day, (b) the degree to which relations between stigmatization and psychosocial functioning are primarily due to differences within people versus between people over time, and (c) which mental illness stigma variables were more closely linked to psychosocial functioning. This study may be the first to investigate the impact of stigmatization experience severity on psychosocial functioning and to decompose relations between mental illness stigmatization and psychosocial functioning into within- and between-person components.

### 3.1 Bidirectional Analyses

This study addresses a limitation noted in the mental illness stigma literature (Livingston & Boyd, 2010) and the broad literature on stigma-related stress (Hatzenbuehler, 2009; Meyer, 2003): most prior research has been cross-sectional and unable to investigate the causal direction between stigmatization and stress. This study used a repeated-measures methodology to test the direction of the relationship between mental illness stigmatization and psychosocial functioning.

Does stigmatization predict future psychosocial functioning? In the current study, daily feelings of self-stigma and perceived public stigma predicted worse next day anxiety symptoms, more impairment due to mental illness, and less interpersonal self-esteem. Self-stigma and perceived public stigma thus have a “carryover” effect on people with mental illness,

affecting symptoms and functioning into *the next day*. The severity of stigmatization experiences may not be as powerful a predictor of next day psychosocial functioning as self-stigma or perceived public stigma, but it seems to influence next day anxiety symptoms. Stigma experience severity may not predict psychosocial functioning to the same degree as other stigma variables because it is simply an evaluation of external events that is a less proximal and less self-relevant (Hatzenbuehler, 2009; Meyer, 2003); its effects might just be limited to making people more anxious about possible future stigma experiences.

The findings support Link and Phelan (2006), and previous concurrent findings, suggesting stigmatization may impact the clinical course of the illness, itself: instances of stigma-related stress may be a risk factor for relapse. The current findings go on to suggest self-stigma and perceived public stigma, and stigmatization experience severity to a lesser extent, may impact one's illness within a much smaller, day-to-day, time frame.

Does psychosocial functioning predict stigmatization? From day-to-day, anxiety symptoms was the only psychosocial functioning variable to significantly predict a next day stigma variable (i.e., perceived public stigma), providing the lone piece of evidence for reverse causation. Anxiety symptoms can make a person more vigilant to perceived future environmental threats, including public stigma, and anxiety can make a person more on guard to such a threat. The current study does not provide much evidence for theories suggesting poorer psychosocial functioning causes people to report more stigmatization (Ertugrul & Ulug, 2004; Gaebel et al., 2006; Hatzenbuehler, 2009; Lyons et al., 2009; Switaj et al., 2009), at least at the within-person level within this one week time frame.

### **3.2 Within- and Between-person Components**

Analyses separating relations between stigma and psychosocial functioning variables into within- and between-person components suggest that when a person experiences more self-stigma and perceived public stigma than usual, the person also tends to struggle with worse anxiety, depression, impairment, and social insecurity. When a person experiences more

severe stigmatization experiences than usual, that person tends to feel more socially insecure and more depressed but no change in anxiety symptoms or impairment. People who generally have the highest levels of self-stigma also tend to be the people with the highest levels of anxiety, depression, impairment, and social insecurity. Although self-stigma was strongly related to psychosocial functioning variables at both levels, relationships between perceived public stigma and stigmatization experiences with psychosocial functioning appeared to be more consistently related at the within- compared to the between-person level. Generally, people with higher levels of stigmatization may not be worse off than those with lower levels except in the case of higher self-stigma; however, when self-stigma, perceived public stigma, and in some cases stigmatization experience severity are worse than usual for that individual, a host of psychosocial problems may follow.

Because concurrent relations between mental illness stigma and psychosocial functioning appear to be primarily within-persons as opposed to between-persons, this may explain why some studies have failed to find significant relationships. Previous work has conflated these levels of analysis, ignoring important within-person results and perhaps underestimating the overall impact of stigmatization on people with mental illness. Further, stigma variables appear to influence functioning differently depending on the measurement time frame and level of analysis; these nuances were not captured in past concurrent or “pre-post” designs. For example, the current findings suggest stigmatization perhaps initially increases depression within-persons on the same day (as in the analyses separating within- and between-person components) and then increases anxiety and impairment on the next day (as in the day-to-day analyses). Focusing on the within-person relations between stigmatization and psychosocial functioning at different measurement time frames may provide a more accurate and nuanced picture of the effects of mental illness stigmatization.

### **3.3 Treatment Implications**

The day-to-day within-persons analyses suggest improving an individual’s symptoms, self-esteem, or level of functioning may not translate into less self-stigma, perceived public

stigma, or less severe stigmatization experiences—except that improving anxiety may help reduce next day perceived public stigma. Thus, mental health treatment that reduces symptoms may not necessarily lead to less problems with stigmatization in the future, at least not at the day-to-day level. Given that stigmatization is a powerful predictor of future functioning and possibly relapse, it may be useful for clinicians and treatment programs to consider addressing stigmatization their patients feel, directly, in addition to symptom management.

Which facets of stigmatization should such treatments focus on to improve psychosocial outcomes? This conclusion is made with caution because I did not conduct statistical analyses comparing the relative strength of the stigma variables, but in viewing the overall results, self-stigma appears to be more closely linked to psychosocial outcomes, day-to-day, at the within- and especially between-persons levels. These findings are in line with a previous result (Kendra & Mohr, under review) and theory (Corrigan et al., 2006) suggesting self-stigma is more harmful than perceived public stigma. The more proximal nature of self-stigma may explain why self-stigma appeared more harmful to mental health than perceived public stigma or stigmatization experiences, and may also make self-stigma more amenable to change and clinical intervention (Hatzenbuehler, 2009; Meyer, 2003). Taken together, the findings suggest that to produce psychosocial change, it may be especially valuable to develop stigma reduction treatments that specifically target self-stigma.

In contrast, treatments designed to reduce stigmatization often ignore self-stigma as an outcome. For example, at least a few treatment programs designed to reduce perceived public stigma have not obtained such desired effects (Griffiths & Christensen, 2007; Knight, Wykes, & Hayward, 2006). The relevance of these studies is dampened because of the sole focus on perceived public stigma as an outcome. Might the same treatment programs with different outcome variables such as self-stigma produce different results? Recent work is beginning to highlight the role of self-stigma as a target of such treatment programs in people with severe mental illness (Lucksted et al., 2011). The current study suggests such treatment programs may also be helpful for people with less severe mental illness.

### 3.4 Overlooked Variables

While mental illness self-stigma is now becoming more frequently studied, researchers and clinicians may be continuing to neglect the role of anxiety in stigmatization. There is ample theory to suggest anxiety symptoms may be an outcome or predictor of stigma-related stress (especially perceived public stigma), but little empirical evidence linking mental illness stigma variables to anxiety symptoms (or vice versa). The current findings coincide with the lone study examining mental illness stigma and anxiety symptoms (Markowitz, 1998) and ample stigma theory (Hatzenbuehler, 2009; Pachankis, 2007; Smart & Wegner, 2000), suggesting that anxiety may be among the most important symptoms to study in the context of mental illness stigmatization. Despite the fact most of the sample reported a mood disorder diagnosis, depression symptoms actually appear less strongly linked to stigma-related outcomes than anxiety. Further, stigmatization experience severity only predicted next day anxiety symptoms out of all psychosocial outcomes, and anxiety symptoms provided the only support for reverse causation, predicting next day perceived public stigma.

The current findings also identify impairment due to mental illness as an overlooked outcome of stigmatization. Although this statement is made with caution because no significance tests were conducted, the overall pattern across all results suggests out of all psychosocial functioning variables, psychosocial impairment had the highest estimates for relations with self-stigma or perceived public stigma. Most previous research has studied relations with stigmatization, self-esteem, and symptoms, overlooking the stronger, or, at least equal the effects that stigmatization has on daily psychosocial impairment including the ability to work, take care of family, and participate in social activities.

Overlooking anxiety and impairment due to mental illness may underestimate the effects of stigmatization and the success of interventions to reduce stigmatization as currently documented in the literature. For example, some studies may conclude that anti-stigma treatment programs do not improve patient depression symptoms or self-esteem, but such interventions may actually have improved omitted but important effects of stigmatization,

including anxiety and impairment. When evaluating anti-stigma interventions, or the broad effects of stigma on people with mental illness, it is important to look beyond the commonly investigated outcomes (e.g., depression, self-esteem, well-being) to other theoretically relevant outcomes such as anxiety and impairment in order to better estimate the overall effect of stigmatization on the person.

### **3.5 Stigmatization Experiences**

The role of stigmatization experiences in the daily lives of people with mental illness have also received little attention in the literature. The current study highlights the importance of describing stigmatization experiences encountered day-to-day and over the lifetime. Participants reported the three most severe experiences over their lifetime and any that occurred during the week. Stigmatization at work and within the family are the most frequent experiences over the lifetime. Stigmatization from the media emerged as the most common source from day-to-day, but the media was rarely identified as one of the three most severe lifetime experiences.

How do the current stigmatization experience results compare with previous work? First, the current sample is quite different in terms of size and demographics. Compared to a U.S. sample of 1301 mental health consumers (Wahl, 1999) and an international sample of 732 patients with schizophrenia (Thorncroft et al., 2009), the current sample is smaller, has less psychotic disorder diagnoses but more disorders represented, many more females, and higher employment rates. Compared to Wahl's (1999) sample, the current sample is similar in cultural diversity and marital status, but has been less frequently hospitalized over the lifetime. Compared to Thorncroft et al.'s (2009) sample, the current sample is similar in the time since first contact with mental health services, but is less culturally diverse, much more educated, and excludes psychiatric inpatients.

Although the current sample has less severe psychopathology and more diverse disorders compared to previous studies, the most common sources of stigmatization remained similar: all three studies cited family, general community/passerbys/general public/unknown others,

friends, and work as among the most common sources of stigmatization. These findings support Angermeyer and Dietrich's (2006) review suggesting that people with less severe mental illness such as depression appear to experience stigmatization from similar sources as people with more severe mental illness such as schizophrenia, but it remains to be seen if they experience stigmatization less frequently and to a lesser degree of severity.

### **3.6 Limitations**

Recruiting from NAMI, FDA, and their contacts sampled from a population interested in stigmatization, advocacy, and mental health issues and might have influenced the study results. Such individuals may be more prone to experience stigmatization than others because frequently experiencing stigmatization may motivate someone to join a community advocacy organization. In addition, members likely identify more with their social group of mental illness and may thus be more likely to perceive public stigma and experience stigmatization (Major & O'Brien, 2005); however, the solidarity and cohesiveness provided by group membership with stigmatized others may protect members from stigma-related stress (Crocker & Major, 1989; Miller & Major, 2000). Thus, mental health organization members may experience stigmatization more frequently and severely than a random sample from the population of people with mental illness, but stigmatization may not have as powerful an impact on their psychosocial functioning.

The goal of this study was to sample from a population that is much more diagnostically diverse and less functionally impaired than participants in most other mental illness stigma studies, but it remains unclear how this variability impacted results. The current study shows that mental illness stigma impacts people with less severe mental illness, but it is unclear if the observed relationships at the different levels of analysis are generalizable to a sample with more severe mental illness (e.g., schizophrenia), or to a sample that is less educated, has lower employment rates, better represents both genders, and is more culturally diverse.

Although daily report was a better method to use than long-term retrospective report to

address the current study goals, daily report has its limitations. Recording inner experiences that fluctuate often during the day such as mood may produce different results if assessed at the moment instead of at the end of the day when subject to recall bias (Cohen et al., 1997). By the end of the day, memories may have faded or the impact of stigmatization may not be as accurately estimated. Also, momentary assessment of actual events such as stigmatization experiences may be a better way to classify and capture the effects of stigmatization experiences as they occur.

Results could change if the sampling time frame was at more frequent or specified moments throughout the day, or less frequent such as once weekly for several weeks (Cohen et al., 1997; Mroczek et al., 2003). For example, it is possible that the null day-to-day results for stigmatization and depression could be significant if variables were sampled at even shorter time intervals within-days (e.g., three times per day) or with sampling spread out over a greater time frame (e.g., weekly, monthly). Lengthening the sampling time frame may capture more extreme relative levels of depression than observed in the current study, and this added variability may be needed for stigmatization to predict future depression. Also, observing participants over the course of weeks or months may capture times when participants are of relatively low or high functioning, which may produce stronger effects, generally, and more support for reverse causation (i.e., psychosocial functioning predicting future stigmatization).

Results may also differ if slightly different stigmatization variables were examined. For example, although perceived public stigma and the severity of stigmatization experiences were unrelated to psychosocial functioning at the between-person level, other unexamined yet important variables such as expectations of stigmatization, fear of stigmatization, and self-efficacy for coping with stigmatization may be more closely linked to psychosocial outcomes. This suggests researchers and clinicians need to carefully construct measures that tease out the specific stigma-related variables, and select variables to include in studies that clearly separate the different components of stigmatization.

The self-report nature of the study was a limitation. Participants self-reported their

diagnosis and the diagnosis was not confirmed; however, the participant's perception that they have a mental illness and thus belong to that social group may matter more than whether or not they actually currently meet diagnostic criteria. Participants also self-reported *perceived* stigmatization experiences; it is possible that participant's perceptions of an event were clouded by their own subjective bias. Although the coding helped eliminate experiences that were clearly unrelated to stigmatization, it is possible that some reported experiences, in reality, were misinterpreted by participants. A similar limitation was noted by Thornicroft et al. (2009): it is difficult to tell if the reported stigmatization experiences were legitimate. For example, an employer could fire a person with mental illness for reasons unrelated to their illness, but the person with mental illness may still interpret this as unjust discrimination. One may never be able to definitely determine whether stigmatizing events objectively reflect *unjust* discrimination, prejudice, and stereotyping.

Finally, it is unclear if the act of measuring stigmatization influenced participants' frequency and severity ratings of stigmatization throughout the week. Asking participants to self-report their stigmatization experiences from day-to-day actually may have caused them to be more aware of stigmatization. For example, in a study of workplace LGB identity management (Mohr, King, Peddie, Jones, & Kendra, under review), many participants said they were unaware of how often they have to manage their identity and that doing the study made them more aware of how they had previously underestimated the frequency of identity management events. Further, 80% of participants in a study of gender discrimination reported that being in the study increased the likelihood that they noticed such events (Swim et al., 2001). Similarly, it may be possible for individuals with mental illness to be underestimating the frequency and severity of stigmatization experiences during their daily lives until they are consciously attending to them. However, asking participants to report on stigmatization may make them more prone to see stigmatization where it might not usually be noticed, thus compromising external validity. One reason to believe that reactivity may not have been a major problem is because the current study observed but did not attempt to influence any variables; reactivity tends to be low when the behaviors under study are

not targets of change (Shiffman, Stone, & Hufford, 2008). Also, many participants reported zero experiences during most days of the week, and some even reported none throughout the entire week.

### **3.7 Future Research**

More investigation into the causal relationship between stigmatization and psychosocial functioning is needed. To provide a bridge between the current study and previous research, future work may wish to examine these relationships over a much longer time frame (e.g., weeks, months, years) but more frequently repeat measures, rather than conducting pre-post designs which may not effectively capture within-person change over time (Singer & Willett, 2003).

This study investigated stigmatization experiences, but not how people with mental illness cope with them. Are some stigma coping orientations (e.g., secrecy, withdrawal, education, challenging, cognitive distancing) better than others, and for what experiences in which contexts? Using a momentary assessment methodology, capturing the coping responses to anticipated or actual stigmatization could help determine what types of responses are most effective in which situations. Future work in this area might refer to a similar, forthcoming study on LGB stigmatized identity management in the workplace (Mohr et al., under review).

Future work can also examine potential mediators and moderators underlying the relationship between stigma and psychosocial functioning. Some factors may protect individuals from harmful psychosocial effects of self-stigma, perceived public stigma, and stigmatization experiences, but such interaction hypotheses have rarely been examined at the within- or between-person level in the general stigma-related stress literature (Hatzenbuehler, 2009) or the mental illness stigma literature. Clinicians can thus address stigmatization—especially self-stigma—directly with their patients, but also identify and target specific cognitive variables that may make their patients more prone to experience ill effects when stigmatization

does occur.

Finally, it remains unclear *how* stigmatization worsens psychosocial functioning. For example, does stigmatization contribute to impairment by exacerbating existing symptoms (e.g., problems with depression, psychotic symptoms) or by creating new symptoms where they did not previously exist (e.g., problems with social anxiety in an individual previously without social anxiety disorder). In the former pathway, stigma could represent a generalized source of stress that worsens existing problems. In the latter pathway, stigmatization could increase the chances of experiencing specific types of psychological problems (e.g., anxiety, panic, depression). Stigmatization may also affect psychosocial functioning through both pathways.

### **3.8 Conclusion**

The study is among the first to examine day-to-day bidirectional relations between mental illness stigmatization and psychosocial functioning. Mental illness stigma research has rarely examined the effects of stigmatization within-persons, focusing primarily on concurrent, between-person effects. The relationship between stigmatization and psychosocial functioning depends on the level of analysis (i.e., day-to-day, within-persons, between-persons), although self-stigma appears to have negative effects on psychosocial functioning at all levels. The study also highlighted the importance of studying two outcomes of stigmatization neglected in the literature: anxiety symptoms and impairment due to mental illness. Finally, the study brought much needed attention to the day-to-day effects not only of self-stigma and perceived public stigma, but also to the role that stigmatization experiences play in the lives of people with mental illness.

## **Appendix A: Recruitment Flyer**

**Are you interested in combating stigma? Help researchers understand how mental illness stigma impacts your life.**

Mental illness can affect our daily lives, but so can stigma. Little is known about the day-to-day effects of stigma on the lives of people with mental illness. Become a part of a research study designed to understand how stigma impacts the lives of people with mental illness! You could be paid up to \$15 for your participation.

**We are looking for participants who are:**

- Over 18 years of age
- Currently diagnosed with mental illness
- Able to access email/Internet nightly
- Willing to complete daily surveys about mental illness and stigma for one week
- Currently be receiving mental health treatment

**Interested in being a participant in the study?**

Visit our website at <https://sites.google.com/site/mentalillnesstigma/> OR e-mail the graduate student, Matthew Kendra, M. A., at [mkendra@gmu.edu](mailto:mkendra@gmu.edu), for more information.

## Appendix B: Study Website

### **Welcome to the Mental Illness Stigma Study!**

Thank you for your interest in our study on everyday experiences with stigma in the lives of people with a mental illness. This website is designed to give you some more detailed information about the study to see if you are still interested in participating.

**Who are the researchers?** The primary researcher is Matthew Kendra, M.A., who is conducting this research for his dissertation at George Mason University under the supervision of Jonathan Mohr, Ph.D. We both strive to conduct research that can lead to positive social change and increase awareness of the negative effects of discrimination on individuals, family, and society.

**What is the purpose of the study?** People with mental illness still encounter negative social attitudes and stereotypes, despite some positive changes over the past decades. Surprisingly little is known about the role of those attitudes and stereotypes in the everyday experiences of people with mental illness. Our goal is to learn more about those experiences by gathering data from our participants every day for 7 days. By using this research method, this study will contribute to a greater understanding of the unique experiences of people with mental illness.

**Who can participate?** To participate, you must be:

- At least 18 years of age
- Currently diagnosed with a mental illness (any mental illness other than, or in addition to, substance use and personality disorders)
- Able to access the Internet 7 consecutive evenings to complete electronic surveys
- Willing to share your email address
- Receiving mental health treatment (e.g., seeing a psychiatrist, psychologist, or other mental health provider)

If you meet the criteria, we would be glad to have you in the study!

**Why participate?** With your help, we can improve our understanding of what it means to be a person living with a mental illness in today's society. Participants who complete the study will receive \$15. Participants can also elect to contribute their \$15 to the National Alliance on Mental Illness (NAMI) or to Families for Depression Awareness.

**How to participate** If you would like to participate, click the link below to an electronic survey where you can read more about the study, complete an informed consent form, and complete questionnaires asking about mental illness stigma and your mood. Then you will be asked to complete 5-10 minute surveys about mental illness stigma and your mood every night for the next 7 days. At the end of the final survey, we will ask about stigma and what it was like participating in the study. You will then be paid \$5 for your participation and an additional \$10 if you completed at least 6 out of 7 surveys.

If you ever have questions during the study, you can always email me. I will also help you complete the surveys by sending you an email reminder to do so; you would simply click on a weblink in the email to take you to the next survey you need to complete. If you are still interested in participating, please open the survey and read more about the study. We suggest doing this when you have about 10 minutes to read through the information and, if you decide to participate, another 15-20 minutes to complete the questionnaires.

**Click here to take the Mental Illness Stigma survey!**

Thank you for your interest. If you know anyone else who may be interested in the study and meet the above criteria, please have them email me, or give them the link to this website.

Thanks again!

Matthew Kendra, M. A.

Graduate Student

George Mason University

mkendra@gmu.edu

## Appendix C: Screening Questions

Thank you for your interest in participating in this study. An important first step is determining if you are eligible to participate. Please answer the following three questions:

Are you currently diagnosed with a mental illness? In order to participate, you must identify as a person with mental illness. You can also have a substance use disorder or personality disorder, but you must also have another mental illness besides substance use or personality disorder to qualify for this study.

Yes

No

Are you willing to share your e-mail address with us? We will delete this information from our files when the study is complete.

Yes

No

Are you at least 18 years old?

Yes

No

Do you have regular access to the Internet for a week? Would you be able to complete short surveys each night for a week?

Yes

No

## Appendix D: Informed Consent

Thank you for your interest in this study on mental illness stigma. This webpage and the next page provide you with information about the study. This may seem like a lot to read, but we want to help you understand what participation involves so you can make an educated decision about whether to participate. After reading each of the short paragraphs below, please click the box to indicate that you have read the information. The link at the bottom of this webpage will enable you to take the first questionnaire, if you so choose. You will not have to read this information again on the daily surveys. At the end of this webpage, you will be given an opportunity to print out or save the information on this and the next page.

### **INFORMED CONSENT FORM**

**RESEARCH PROCEDURES** This research is being conducted to learn about the experiences people with mental illness have with stigmatization, including factors that may influence their well being. In particular, we are interested in how mental illness stigma affects your everyday life.

If you agree to participate, you will take the first questionnaire which will take about 15-20 minutes. The first questionnaire will gather some information about your background, your mental illness, experiences you have had with stigma in the past, and your well-being. After the first questionnaire, you will complete short Internet surveys for 7 consecutive days. Daily surveys take approximately 5-10 minutes to complete. The surveys contain a variety of questions, including ones related to your mood and stigmatization experiences. We ask that you complete the surveys every night, but you can complete them first thing in the morning (with your answers reflecting on the previous day) if you forget one night.

- *I have read the above information.*

**RISKS** A foreseeable risk of participating in this study includes feelings of discomfort associated with revealing private information about oneself. Sometimes answering questions

about personal topics such as emotional difficulties can cause individuals to feel uncomfortable, but we expect for participation in this research to involve no more risk of serious harm than that encountered in everyday activities. If you experience feelings of discomfort and wish to discuss them, then we encourage you to contact the principal investigator for this study—Dr. Jonathan Mohr (301-405-5907; jmohr@umd.edu). You may also find it useful to discuss feelings of discomfort with your mental health provider.

A possible risk of participating in the study is that others may view your responses to the survey if you do not take the survey in a private location. We encourage you to take the survey in a private environment where you feel comfortable responding to questions about your emotional distress and stigmatization. If you have privacy concerns while taking a survey, you can always close the Internet browser.

- *I have read the above information*

**BENEFITS** There are no benefits to you as a participant other than to further research on issues that may be important to you. By participating, you can contribute to the growing effort to learn more about your everyday experiences with mental illness stigma in today's society. Your participation may also help raise awareness about mental health issues.

- *I have read the above information.*

**CONFIDENTIALITY: Part 1** The information you provide will be confidential. An important confidentiality issue in this study is that your responses to this survey will be transmitted over the Internet. While it is understood that no computer transmission can be perfectly secure, reasonable efforts will be made to protect the confidentiality of your transmission. In particular, your responses will be sent over the Internet in an encrypted form that would be very difficult for others to interpret. All survey responses will be kept in a secure computer environment. Data will be stored in a secure format on a password protected computer once they are received by the research team.

In the first Internet questionnaire, we collect some information that could be used to contact or identify you. For example, you will be asked to provide your e-mail address so we

can send you the survey Internet links and so we can connect information from the different surveys you complete. In addition, if you wish to be paid for your participation, we will need your name and mailing address so that we can write and send you a check. However, we take several precautions to prevent this personal information from being linked to your survey responses.

- We gather your name and mailing address through a completely separate survey from the main survey. Because of this, your name and mailing address will never appear in the same dataset as your main survey responses.
- At first, your e-mail address will be associated with your main survey responses. This will enable us to link your survey responses with your name and mailing address (if you choose to share your name and address with us). However, once we complete data collection, we will remove your e-mail address from the dataset. At that point, we will be unable to link your survey responses to your identity or contact information.
- *I have read the above information.*

**PARTICIPATION** Your participation is voluntary, and you may withdraw from the study at any time and for any reason. If you decide not to participate or if you withdraw from the study, there is no penalty or loss of benefits to which you are otherwise entitled. There are no costs to you or any other party.

You will receive \$5 if you complete the baseline questionnaire and at least one daily survey, and an additional \$10 if you complete 6/7 daily surveys. So you can earn up to \$15 for participating. If you provide us with your name and mailing address, we will send you a check. Another option you have is to have the research team donate your payment for participation directly to the National Alliance on Mental Illness (NAMI) or Families for Depression Awareness, and you would not have to provide your name or mailing address to make this donation.

- *I have read the above information.*

**CONTACT** This doctoral dissertation research is being conducted by Matthew Kendra, a graduate student at George Mason University, under the supervision of Dr. Jonathan Mohr at the University of Maryland. Dr. Mohr may be reached at 301-405-5907 or [jmohr@umd.edu](mailto:jmohr@umd.edu) for questions or to report a research-related problem. Questions regarding details of participation can be addressed to Matthew Kendra ([mkendra@gmu.edu](mailto:mkendra@gmu.edu)). You may contact the George Mason University Office of Research Subject Protections at 703-993-4121 if you have questions or comments regarding your rights as a participant in the research.

This research has been reviewed according to George Mason University procedures governing your participation in this research.

- *I have read the above information.*

**CONSENT** If you have read all of the above points, are at least 18 years old, and wish to participate, then make sure you have clicked all of the checkboxes above and the appropriate button below.

- *I have read the above points and I wish to participate*
- *I have read the above points and I do NOT wish to participate*

The George Mason University Human Subjects Review Board has waived the requirement for a signature on this consent form. However, if you wish to sign a consent, please contact Dr. Mohr's research assistant, Matthew Kendra ([mkendra@gmu.edu](mailto:mkendra@gmu.edu)).

If you would like a copy of the study description you have just read (for your records), click the following link:

**Study Description**

## Appendix E: Demographics and Baseline Items

### Demographics

On this page we ask for some general information about your background. We only ask for this information on this first survey. We will not ask for it on the daily surveys.

What is your age?

- Age:

Your sex/gender identity

- Male
- Female
- Transgender (Male to Female)
- Transgender (Female to Male)
- Intersex
- Other (please specify)

Your race/ethnicity (choose all that apply)

- African American/Black
- Asian American/Pacific Islander
- Latina/Latino/Hispanic
- Native American/American Indian
- White/Caucasian/European American
- Middle Eastern

- Other (please specify)

Your marital status

- Married
- Separated
- Divorced
- Widowed
- Single (never married)

Your employment status

- Employed full-time
- Employed part-time
- Self-employed
- Unemployed
- Retired
- Student
- Homemaker

Your current living situation (check all that apply)

- Alone
- With parents
- With children
- With partner/spouse
- In a group home/residential living facility

- Shelter
- With others (friends/housemates)
- Other (please specify)

Your education level

- Never attended high school
- Some high school
- High school degree
- Some college
- College degree (B.A. or B.S.)
- Some graduate school
- Post-graduate degree (M.A., Ph.D., etc.)

The following questions are about your mental illness. You will not be asked these questions on the daily surveys.

What is your current diagnosis? Check all that apply. If you have other diagnoses, please specify below:

- Schizophrenia
- Schizoaffective disorder
- Bipolar disorder/manic depression
- Depressive disorders (major depressive disorder, dysthymia)
- Generalized anxiety disorder
- Panic disorder
- Specific phobia
- Social phobia
- Post-traumatic stress disorder
- Obsessive-compulsive disorder
- Eating disorder (anorexia nervosa, bulimia nervosa)
- Personality disorder (e.g., antisocial personality disorder, borderline personality disorder, paranoid personality disorder, etc.)
- Attention disorder or learning disability (e.g., attention deficit disorder, attention deficit hyperactivity disorder, learning disability)
- Don't know
- Other (please specify)

At what age did your mental illness begin? That is, how old were you when you had your first occurrence of mental illness? If you have more than one mental illness, indicate your age for the mental illness that was the earliest onset.

- Age:

At what age were you first diagnosed with a mental illness?

- Age:

What is the duration of your illness? That is, how long have you had mental illness for?

- < 6 months
- 6 months to 1 year
- 1-2 years
- 2-3 years
- 3-4 years
- 4-5 years
- > 5 years

How many times have you been admitted as an inpatient to a hospital for psychiatric treatment?

- Never hospitalized
- 1 time
- 2-5 times
- 6-10 times
- > 10 times

Do not answer this question; leave this question blank. This question is for test security purposes. Continue on to the next page of the survey.

- Strongly Disagree
- Disagree
- Agree
- Strongly Agree

Thinking back over your lifetime, about how many years total have you received mental health treatment?

- Number of years:

What types of mental health providers are you currently seeing for your mental illness? Select all that apply (or select "Not currently seeing"), and tell us how often you see each of them:

Not currently seeing; Daily; Twice per week; Weekly; Every 1-4 weeks; Monthly; Every 1-6 months; Once per year

- Psychologist
- Social worker
- Psychiatric/mental health nurse
- Licensed professional counselor
- Peer counselor
- Psychiatrist
- General practitioner or other physician for mental health treatment such as medication

What types of mental health services do you currently use? Select all that apply (or select "Not currently seeing"), and tell us how often you do or use each of them:

Not currently doing/using; Daily; Twice per week; Weekly; Every 1-4 weeks; Monthly; Every 1-6 months; Once per year

- Individual psychotherapy/counseling
- Group psychotherapy/counseling
- Consumer-led support groups, or other groups not led by a mental health professional
- Case management
- Psychiatric medication

Do you currently take medication for your mental illness?

- Yes
- No

Thinking back over your lifetime, about how many years (total) have you been on medication for your mental illness?

- Number of years:

How severe are the side effects of your medication?

- Not at all severe side effects
- A little severe side effects
- Somewhat severe side effects
- Severe side effects
- Very severe side effects

## Work and Social Adjustment Scale

Rate each of the following questions on a 0 to 8 scale: 0 indicates no impairment at all and 8 indicates very severe impairment.

- Because of my mental illness, my ability to work is impaired. 0 means not at all impaired and 8 means very severely impaired to the point I can't work.
- Because of my mental illness, my home management (cleaning, tidying, shopping, cooking, looking after home or children, paying bills) is impaired. 0 means not at all impaired and 8 means very severely impaired.
- Because of my mental illness, my social leisure activities (with other people, such as parties, bars, clubs, outings, visits, dating, home entertainment) are impaired. 0 means not at all impaired and 8 means very severely impaired.
- Because of my mental illness, my private leisure activities (done alone, such as reading, gardening, collecting, sewing, walking alone) are impaired. 0 means not at all impaired and 8 means very severely impaired.
- Because of my mental illness, my ability to form and maintain close relationships with others, including those I live with, is impaired. 0 means not at all impaired and 8 means very severely impaired.

## Significant Lifetime Stigmatization Experiences

People sometimes have experiences that make them aware of others' negative attitudes or stereotypes about people with mental illness. Some examples of these experiences include:

- Witnessing hurtful or offensive things about people with mental illness in the media (e.g., television, movies, books);
- Being rejected, insulted, or ignored because of having a mental illness;
- Noticing others feeling uncomfortable around you because you have a mental illness;
- Experiencing unjust discrimination and being excluded from opportunities (e.g., in housing, employment, education, medical care) because of having a mental illness;
- Hearing about another person being treated poorly because she or he has a mental illness.

Has anything happened in your lifetime to make you aware of others negative attitudes or stereotypes about people with mental illness? This could involve prejudice, negative stereotyping, or discrimination directed (a) toward you, (b) toward someone else, or (c) toward all people with mental illness.

Have you had such a mental illness stigmatization experience in your lifetime?

- Yes
- No

### **The #1 most severe mental illness stigmatization experience.**

Please write about your experience in the space below. Then rate the degree to which stigmatization (prejudice, negative stereotyping, or discrimination) was present in the situation. In other words, how bad of a stigmatization experience was it? For example, an experience of overhearing an insensitive joke about someone with mental illness would likely

be rated as less severe (or less stigmatizing) than being told you weren't hired for a job because of your mental illness. Also, tell us about who was the target of the stigmatization experience.

Can you tell us about the MOST severe or extreme mental illness stigmatization experience you have had? Please describe in detail: Who was involved, what happened, what was said and done, where did it happen, how did you respond to it, etc.

Indicate the degree of stigmatization present in the experience:

1 = almost none

2

3 = some

4

5 = extreme

Who was the target of the stigmatization?

1 = myself (personally experienced direct stigmatization)

2 = someone else with mental illness (witnessed stigmatization that was not directed at me, personally)

3 = people with mental illness, in general (overheard stigmatization not directed at any individual in particular, but against a broad group of people with mental illness)

Have you had another mental illness stigmatization experience in your lifetime?

- Yes

- No

**The #2 most severe mental illness stigmatization experience.**

Please write about your experience in the space below. Then rate the degree to which stigmatization (prejudice, negative stereotyping, or discrimination) was present in the situation. In other words, how bad of a stigmatization experience was it? For example, an experience of overhearing an insensitive joke about someone with mental illness would likely

be rated as less severe (less stigmatizing) than being told you weren't hired for a job because of your mental illness. Also, tell us about who was the target of the stigmatization experience.

Can you tell us about the SECOND most severe or extreme mental illness stigmatization experience you have had? Please describe in detail: Who was involved, what happened, what was said and done, where did it happen, how did you respond to it, etc.

Indicate the degree of stigmatization present in the experience:

1 = almost none

2

3 = some

4

5 = extreme

Who was the target of the stigmatization?

1 = myself (personally experienced direct stigmatization)

2 = someone else with mental illness (witnessed stigmatization that was not directed at me, personally)

3 = people with mental illness, in general (overheard stigmatization not directed at any individual in particular, but against a broad group of people with mental illness)

Have you had another mental illness stigmatizing experience in your lifetime?

- Yes

- No

**The #3 most severe mental illness stigmatization experience**

Please write about your experience in the space below. Then rate the degree to which stigmatization (prejudice, negative stereotyping, or discrimination) was present in the situation. In other words, how bad of a stigmatization experience was it? For example, an experience of overhearing an insensitive joke about someone with mental illness would likely

be rated as less severe (less stigmatizing) than being told you weren't hired for a job because of your mental illness. Also, tell us about who was the target of the stigmatization experience.

Can you tell us about the THIRD most severe or extreme mental illness stigmatization experience you have had? Please describe in detail: Who was involved, what happened, what was said and done, where did it happen, how did you respond to it, etc.

Who was the target of the stigmatization?

1 = myself (personally experienced direct stigmatization)

2 = someone else with mental illness (witnessed stigmatization that was not directed at me, personally)

3 = people with mental illness, in general (overheard stigmatization not directed at any individual in particular, but against a broad group of people with mental illness)

Indicate the degree of stigmatization present in the experience:

1 = almost none

2

3 = some

4

5 = extreme

## Appendix F: Security

Do not answer this question; leave this question blank. This question is for test security purposes. Continue on to the next page of the survey.

- Strongly Disagree
- Disagree
- Agree
- Strongly Agree

## Appendix G: Daily Stigmatization Experiences

You indicated that you have had at least one stigmatizing experience related to mental illness, today. How many such experiences have you had, in total, today?

In the space below, please write about the ONE mental illness stigmatization experience that had the most impact on your day. Also, rate the degree to which stigmatization (prejudice, negative stereotyping, or discrimination) was present in the situation. In other words, how bad of a stigmatization experience was it? For example, an experience of overhearing an insensitive joke about someone with mental illness would likely be rated as less severe (less stigmatizing) than being told you weren't hired for a job because of your mental illness. Also, tell us about who was the target of the stigmatization experience.

Please describe in detail: Who was involved, what happened, what was said and done, where did it happen, how did you respond to it, etc.

Indicate the degree of stigmatization present in the experience:

1 = almost none

2

3 = some

4

5 = extreme

Who was the target of the stigmatization?

1 = myself (personally experienced direct stigmatization)

2 = someone else with mental illness (witnessed stigmatization that was not directed at me, personally)

3 = people with mental illness, in general (overheard stigmatization not directed at any individual in particular, but against a broad group of people with mental illness)

If you had other stigmatizing experiences related to your mental illness today that you would like to tell us about, please write about them in the space below.

## Appendix H: Self-stigma and Perceived Public Stigma

Please read all of these items carefully and click on the circle that best reflects how you think about yourself as a person with mental illness today.

1 = Strongly Disagree

2 = Disagree

3 = Agree

4 = Strongly Agree

1. I feel ashamed of myself for having a mental illness.
2. I feel inferior to others who don't have a mental illness.
3. (R) My self-confidence is NOT threatened because I have a mental illness.
4. Because I have a mental illness, I cannot live a good, rewarding life.
5. I am disappointed in myself for having a mental illness.
6. (R) I feel okay about myself for having a mental illness.
7. I feel that having a mental illness is a personal shortcoming for me.
8. (R) Most people would treat a person who has a mental illness just as they would treat anyone.
9. In general, others believe that having a mental illness is a sign of personal weakness or inadequacy.
10. In general, others think that people with a mental illness are unworthy.
11. It is advisable for a person to hide from people that he/she has a mental illness.
12. (R) Most employers will hire a person who has had a mental illness if he or she is qualified for the job.

13. (R) In general, others respect people with a mental illness.

14. Having a mental illness carries social stigma.

Items 1-7 are self-stigma, items 8-14 are perceived public stigma. (R) indicates reverse scoring.

## Appendix I: State Self-esteem Scale (Social Subscale)

Instructions: This questionnaire is designed to measure what you are thinking reflecting back on today. There is no right answer for any statement. The best answer is what you feel is true of yourself today.

Not at all; A little bit; Somewhat; Very much; Extremely

- I have been worried about whether or not I am regarded as a success or a failure.
- I have felt inferior to others today.
- I have been worried about what other people think of me.
- I have been worried about looking foolish.
- I have felt concerned about the impression I have been making.
- I have felt self-conscious.
- I have felt displeased with myself.

## Appendix J: Positive and Negative Affect Scale

This scale consists of a number of words and phrases that describe different feelings and emotions. Read each item and then mark the appropriate answer in the space next to that word. Indicate to what extent you have felt this way today.

1 = Very Slightly or Not At All

2 = A Little

3 = Moderately

4 = Quite A Bit

5 = Extremely

1. Sad
2. Blue
3. Downhearted
4. Alone
5. Lonely
6. Afraid
7. Scared
8. Frightened
9. Nervous
10. Jittery
11. Shaky

Items 1-5 are the “Sadness” subscale, and items 6-11 are the “Fear” subscale

## Appendix K: Debriefing Survey

What did you learn from doing the study?

Are experiences with stigmatization a major part of your life?

Are they a larger part of your life than you used to think before completing the study?

For example, were you aware of how often you had to manage your identity as a person with mental health problems before taking part in the study?

Did you underestimate, overestimate, or estimate correctly the frequency of stigmatizing experiences and their effects on your daily life?

1 = very much underestimated

2 = somewhat underestimated

3 = correctly estimated

4 = somewhat overestimated

5 = overestimated very much

Would you like to receive a summary of the research findings?

Yes

No

Any other questions or comments?

## Appendix L: Coding

How can you decide between whether each response is a YES, MAYBE, or NO?

**YES:** The experience \*MUST\* involve the perception that someone else may hold negative views of people with mental illness, expressed either by a specific person or in some other way (e.g., TV show, organization). It is okay if the participant is not completely certain whether the experience involves negative perceptions of people with mental illness. The key is that the person is at least wondering if negative attitudes or stereotypes may be involved. The negative attitudes or stereotypes do not need to be directed toward the participant.

**MAYBE:** There is good reason to believe that the experience may involve the perception that someone else holds negative views of people with mental illness. However, there is not enough information provided to code the response as a definite YES.

**NO:** Anything that does not constitute a YES or MAYBE should be coded as a NO. For example, code a response as a NO if the person describes...

- A difficult experience not clearly related to negative attitudes or stereotypes about people with mental illness
- An experience involving the participant's own negative attitudes or stereotypes about people with mental illness
- Difficulty managing symptoms of mental illness (e.g., "I have had to take a lot of time off work because I feel too depressed")
- The need to keep their mental illness secret from others, for fear of stigmatization (there needs to be an actual experience, not just the fear of one happening)

When deciding between a YES and a MAYBE - don't spend too much time on the item. Really, we are looking to eliminate items that are very clearly a NO. If you are deciding between a NO and a MAYBE, then take a lot of time to think about it.

So, how to tell between a YES/MAYBE and a NO?

- There MUST be an actual stigma EVENT that day.
- If you find yourself questioning A LOT between a NO and a MAYBE, opt for MAYBE.
- Give the participant the benefit of the doubt: If you have an item where all that is needed is a little more context or information, opt for a MAYBE

(Coders then read examples of YES, NO, and MAYBE experiences with an explanation for each example)

## Appendix M: Coding Sources of Stigmatization

Who/what is the stigmatizer? (if you selected NO, leave this blank)

- TV show
- Radio
- Movie
- Music
- Newspaper/magazine
- Website/blog
- Billboard/signs/advertising
- Other media (specify at bottom)
- Romantic partner
- Less serious romantic partner (e.g., date)
- Unfamiliar, online dating contact
- Parent
- Sibling
- Other family member
- Coworker
- Boss/supervisor
- Client (at work)
- Other person at work

- Friend
- Churchgoers
- Classmates
- Professor/teacher
- Another person with mental illness
- Psychiatrist
- Mental health nurse
- Other nurse
- Case manager
- Therapist
- Other mental health service provider (please specify)
- Other physician (non-mental health, such as a primary care/general practitioner)  
(please specify)
- Other medical professional (please specify)
- Unknown others/vague/general public
- Random passerbys (e.g., overheard random people talking walking down the street)
- Political figures
- Mental health system, generally (stigmatizing/discriminatory rules/practices)
- I just can't tell where the stigma is coming from!
- Other (please specify)

<u>Media</u>	<ul style="list-style-type: none"> <li>• TV Show, TV Commercial, TV News, Radio, Movie, Music, Newspaper/Magazine, Website/Blog, Billboard/Signs/Advertising, Musical/Play, Book, Media (generally)</li> </ul>
<u>Romantic partner</u>	<ul style="list-style-type: none"> <li>• Spouse, Less Serious Romantic Partner (e.g., Date)</li> </ul>
<u>Family</u>	<ul style="list-style-type: none"> <li>• Parent, Parent in-law, Sibling, Sibling in-law, Niece/Nephew, Child, Grandparent, Other/Unspecified family</li> </ul>
<u>Work</u>	<ul style="list-style-type: none"> <li>• Coworker, Boss/Supervisor, Client (at work), Job Interviewer/Potential Employer, Other/Unspecified Person at Work</li> </ul>
<u>School</u>	<ul style="list-style-type: none"> <li>• Professor/Teacher, Classmates</li> </ul>
<u>Friend</u>	<ul style="list-style-type: none"> <li>• Friend</li> </ul>
<u>Other People</u>	<ul style="list-style-type: none"> <li>• Churchgoer, Roommate, Lawyer/Judge, Police, Political Figures, Administrator, Students, Another Person with Mental Illness, Other Person/Acquaintance</li> </ul>
<u>Mental Health Professionals</u>	<ul style="list-style-type: none"> <li>• Psychiatrist, Case Manager, Therapist, Psychologist (not currently seeing), Mental Health System (generally), Social Worker, Mental Health Nurse</li> </ul>
<u>Medical Professionals</u>	<ul style="list-style-type: none"> <li>• General Practitioner, Other Nurse, EMT, Intake Staff, ER Doctor, Other Doctor</li> </ul>
<u>Passerbys/General Public/Unknown Others</u>	<ul style="list-style-type: none"> <li>• Random Passerbys, Unknown Others/Vague/General Public, Unclear Source</li> </ul>

Figure M.1: Further grouping of stigmatization experience sources.

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## Curriculum Vitae

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