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# Psychosocial Functioning in Bipolar Disorder from a Social Justice Perspective

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## 1. Introduction

Previous research on psychosocial functioning in bipolar disorder (BD) has uncovered various factors that exacerbate disability over the course of illness, including illness severity (Burdick, Goldberg and Harrow, 2010; Haro et al., 2011; Mur, Portella, Martinez-Aran, Pifarre, & Vieta, 2009), anxiety (Boylan et al., 2004), substance use (Jaworski, Dubertret, Adès, & Gorwood, 2011), and cognitive impairment (Martino, Igoa, Marengo, Scapola, & Strejilevich, 2011). Accordingly, current efforts toward improving functional outcome in BD focus primarily on pharmacological and behavioral interventions that decrease mood symptoms (Fountoulakis & Vieta, 2008; Miklowitz, Goodwin, Bauer, & Geddes, 2008), attenuate anxiety (Rakofsky & Dunlop, 2011), reduce substance use (Weiss et al., 2009), and increase cognitive functioning (Deckersbach et al., 2010; Goldberg & Roy Chengappa, 2009). Whereas this approach addresses the neuro-psychological aspect of functional disability in BD, it largely ignores its social components.

Disability is inherently contextual, and is always defined by the interaction between the person and the environment. In other words, psychosocial functioning varies with the person's abilities, but also with the particular characteristics of the person's social environment. In theory, changes in any given society can shift the functional variability among its members, and therefore carry the potential to decrease the number of people who experience severe forms of psychosocial disability.

Applied to BD, this notion relates to removing social barriers to functioning in mainstream settings such as stigma and discrimination. Currently available therapies can reduce the symptoms of BD to some extent; however, the consequent potential for psychosocial growth remains latent in a social environment that limits the person's opportunities to obtain psychiatric care (Boyd, Linsenmeyer, Woolhandler, Himmelstein, & Nardin, 2011), medical care (Corrigan, 2004) and reputable social standing (Corrigan, Markowitz, & Watson, 2004; Corrigan & Wassel, 2008).

This chapter focuses on the contribution of stigma and discrimination to functional disability in BD. We explore the mechanisms of stigma's effects on functioning, which may involve increasing painful emotions (notably shame) and stress, reducing treatment seeking and adherence, and limiting social and vocational opportunities through both consumer avoidance and public exclusion.

We advance a two-pronged approach to treatment. The first involves therapy directly targeting the negative effects of internalized stigma on the psychological health of people with BD. The second requires providers to publicly align with federal and state governments, advocacy groups and consumers in making the issues of stigma and discrimination visible. These efforts should seek to reduce the ill effects of stigma and discrimination through educational programs, media campaigns, litigation, and reform of service systems.

These two prongs will likely have synergistic effects. With one alleviating internal distress and the other removing external obstacles, they may converge to attenuate the debilitating effects of stigma and discrimination on people with BD. This approach may even shift the functional trajectory of BD from psychosocial decline to growth over the course of illness despite the recurrence of mood symptoms.

## 2. Functional impairment in BD

Longitudinal, cross-sectional and qualitative studies, now summarized in multiple reviews, have documented substantial levels of social and occupational impairment in BD, even during euthymia (Bonnin et al., 2010; Burdick, Goldberg, & Harrow, 2010; Coryell et al., 1993; Dickerson et al., 2010; Huxley & Baldessarini, 2007; Latalova, Prasko, Diveky, & Velartova, 2011; Martino et al., 2011; McMorris, Downs, Panish, & Dirani, 2010; Michalak, Yatham, Maxwell, Hale, & Lam, 2007; Michalak et al., 2011; Montoya et al., 2010; Pope, Dudley, & Scott, 2007; Rosa et al., 2010). Longitudinal studies show that between 90 to 98% of people receiving treatment for an acute episode of BD achieve syndromal recovery within six months to two years (Bonnin et al., 2010; Dickerson et al., 2010; Huxley & Baldessarini, 2007; Tohen, Waternaux, & Tsuang, 1990; Tohen et al., 2000). However, only 30 to 40% of consumers demonstrate functional recovery after a significant decrease in acute symptoms (Huxley & Baldessarini, 2007; Montoya et al., 2010; Tohen et al., 2000). Even when full syndromal remission is achieved, only about 50% of people with BD recover premorbid functionality (Montoya et al., 2010; Tohen et al., 2000). Disability rates in euthymic BD are similarly high (Gutierrez-Rojas, Jurado, & Gurpegui, 2011; Huxley & Baldessarini, 2007; Montoya et al.; Rosa et al., 2010; Tohen et al., 1990), indicating that acute symptoms are only partially responsible for functional impairment.

This failure to return to premorbid levels of functioning is especially concerning given that while normal psychosocial functioning prior to a first episode is possible (Reichenberg et al., 2002), premorbid functioning in BD tends to be below average (Rietschel et al., 2009; Cannon et al., 1997). A vulnerable premorbid baseline suggests that further decline in functioning after illness onset can result in the type of severe life-long disability often observed in BD.

The effects of disability in BD pervade all areas of functioning (Coryell et al., 1993; Elgie & Morselli, 2007; Pope et al., 2007; Sanchez-Moreno et al., 2009; Sanchez-Moreno et al., 2010). People with BD have more familial conflict and fewer enjoyable social interactions or leisure activities than people without psychiatric diagnoses (Bauwens, Tracy, Pardoën, Vander Elst, & Mendlewicz, 1991; Bauwens, Pardoën, Staner, Dramaix, & Mendlewicz, 1998; Elgie & Morselli, 2007; Sanchez-Moreno et al., 2009; Shapira et al., 1999). In a five-year study following the outcome of an acute mood episode, people with BD were only half as likely as

the general population to be married (Coryell et al., 1993). People suffering from BD report significantly more illness-related obstruction of their social lives, even in comparison to people with chronic medical conditions including rheumatoid arthritis and renal failure (Robb, Cooke, Devins, Young, & Joffe, 1997). These studies further suggest that the disruption to social adjustment and development in BD may extend beyond the direct effects of acute symptoms on social engagement.

Beyond the challenges to social adjustment, limited occupational functioning is also widespread in BD, including during euthymia (Bonnin et al., 2010; Burdick et al., 2010; Dickerson et al., 2010; Zimmerman et al., 2010). Despite studies reporting people with BD to have more years of college and more B.A. degrees than is average in the general population of the U.S. (Kupfer et al., 2002), they demonstrate a much higher degree of unemployment, disability rates, workplace absenteeism, and other occupational impairments (Bowden, 2005; Latalova et al., 2011; Lloyd & Waghorn, 2007; McMorris et al., 2010; Reed, Goetz, Vieta, Bassi, & Haro, 2010; Rosa et al., 2010; Sanchez-Moreno et al., 2009). On average, about 60% of people with BD who are in syndromal remission and have either some college education or a college degree, are unemployed (compared to the average of 6% in the general population), and up to 88% suffer from reduced occupational functioning (Bearden et al., 2011; Elgie & Morselli, 2007; Hirschfeld, Lewis, & Vornick, 2003; Huxley & Baldessarini, 2007; Kessler et al., 2006). These studies indicate that in BD education and competency show much weaker correlations with professional or vocational development than expected in the general population.

Occupational impairment in BD is likely related to the difficulties in maintaining consistent engagement at work. For example, people with BD miss an average of up to 65.5 workdays a year due to absenteeism and presenteeism for illness-related reasons – up to more than one day per week (Gardner et al., 2006; Kessler et al., 2006). These problems can result in placement of people with BD in less skilled, entry-level, poorly paid positions despite superior education and intellectual abilities. Such placement may then lead to greater work dissatisfaction, which has a negative impact on achieving longer-term vocational goals (Baldwin & Marcus, 2011; Tse & Walsh, 2001).

Although work difficulties and underemployment in BD may be attributed to the direct effects of the illness, it is also quite possible that an inhospitable work environment contributes to absenteeism and the tendency to employ people with BD in capacities below their skill level. There is some evidence that despite the therapeutic advancements in BD, psychosocial functioning in this population may be declining. In a 2000 replication (Hirschfeld et al., 2003) of the 1992 National Depressive & Manic-Depressive Association survey (Lish, Dime-Meenan, Whybrow, Price, & Hirschfeld, 1994), people with BD reported that their illness had a more severe impact on their social, occupational and overall functioning than it had in 1992. These studies specifically indicated that rates of unemployment, underemployment and disability in BD had risen (Hirschfeld et al., 2003) during a period in which the stigmatization of people with mental illness (MI) also increased (Corrigan, Roe, & Tsang, 2011; Mehta, Kassam, Leese, Butler, & Thornicroft, 2009). Functional decline in the face of therapeutic progress suggests the presence of potentially important undetected factors that contribute to psychosocial disability in BD. Some of these factors may be external to the treated person, such as those related to social barriers rooted in discrimination.

### 3. Predictors of psychosocial functioning in BD

A volume of longitudinal studies has identified several predictors of poor psychosocial adjustment in BD. A more severe illness history – including a younger age at onset (Hays, Krishnan, George, & Blazer, 1998) and a greater number of mood episodes (MacQueen et al., 2000) and psychiatric hospitalizations (Altshuler et al., 2007) – yields reduced functioning even during euthymia (Martinez-Aran et al., 2004; Zubieta, Huguelet, O'Neil, & Giordani, 2001). In addition, common comorbidities of BD, such as anxiety (Boylan et al., 2004; Kauer-Sant Anna et al., 2007) and substance use disorders (SUD; Jaworski et al., 2011; Lagerberg et al., 2010), disrupt identity development (Michalak et al., 2011), increase symptoms and social avoidance (Jaworski et al., 2011; Otto et al., 2006), interfere with interpersonal engagement (Elgie & Morselli, 2007), exacerbate cognitive impairment (Latvala et al., 2009; Levy & Weiss, 2009; Silva & Leite, 2000), and generally reduce functioning (Goldstein & Levitt, 2008; Sanchez-Moreno et al., 2009). Finally, emotion dysregulation, sleep disturbances, and an elevated rate of medical comorbidities all predict reduced psychosocial functioning in BD (M.L. Phillips, Ladouceur, & Drevets, 2008 (Deckersbach, T., Hölzel, B. K., Eisner, L. R., Stange, J. P., Peckham, A. D., Dougherty, D. D., Nierenberg, A. A., 2011)).

In euthymic BD, two of the strongest predictors of social and occupational functioning are subsyndromal depressive symptoms and cognitive impairment (Bearden et al., 2011; Bonnin et al., 2010; Dickerson et al., 2010; Martínez-Arán et al., 2011; Martino et al., 2009; Tabares-Seisdedos et al., 2008). Even very mild subsyndromal depression leads to reduced functioning including poorer vocational performance (Bearden et al., 2011; Gitlin, Mintz, Sokolski, Hammen, & Altshuler, 2010). Likewise, cognitive deficits (notably in verbal memory, processing speed and executive functioning) are significantly associated with worse social and occupational functioning (Bearden et al., 2011; Dickerson et al., 2010).

These findings focused current efforts for improving psychosocial functioning in BD on reducing subsyndromal depressive symptoms (M. Bauer et al., 2009) and cognitive dysfunction (Bearden et al., 2011; Deckersbach et al., 2010; Martínez-Arán et al., 2011), as well as enhancing stress management and interpersonal skills (Frank et al., 2000; Martínez-Arán et al., 2011). The bulk of this research emphasizes pharmacological interventions (Nivoli et al., 2011), followed by psychosocial treatments, such as psychotherapy (Ball et al., 2006; Hollon & Ponniah, 2010; Miklowitz, George, Richards, Simoneau, & Suddath, 2003; Miklowitz et al., 2008) and psychoeducation (Colom et al., 2009), as well as cognitive (Deckersbach et al., 2010) and functional remediation (Martínez-Arán et al., 2011). More broadly, the current overall approach to improving psychosocial adjustment in BD focuses on changing internal factors, with less consideration given to reducing environmental barriers to functioning.

The view that functioning can be fully restored in BD by treating internal factors such as depressive symptoms and cognitive dysfunction may be restrictive. Even if all internal factors that predict lower functioning were identified and successfully treated, people with BD may still not achieve functional recovery due to environmental influences that include level of expressed emotion (i.e., criticism or stigmatization of person with BD) in families (Elgie & Morselli, 2007; McMurrich & Johnson, 2009), stigma (Michalak et al., 2011; Perlick et



al., 2001; Vazquez et al., 2011), discrimination (Corrigan et al., 2004; Elgie & Morselli, 2007; Michalak et al., 2007; Tse & Yeats, 2002), and lack of social support (Elgie & Morselli, 2007; Michalak, Yatham, Kolesar, & Lam, 2006; Michalak et al., 2011).

This notion is consistent with qualitative studies showing people with BD describing stigma, discrimination, reduction in social (especially family) support, shame and identity loss as the greatest challenges they face in dealing with their illness and functional recovery (Elgie & Morselli, 2007; Michalak et al., 2006; Michalak et al., 2007; Michalak et al., 2011; Proudfoot et al., 2009). People with BD describe social validation and support as the most important components that determine their quality of life (QOL; Michalak et al., 2006; Michalak et al., 2007; Michalak et al., 2011). In fact, many people with BD consider social inclusion to be more important than symptom resolution or clinical remission (Michalak et al., 2006).

Given the importance of social inclusion to recovery in BD, as well as the role of stigma in reducing treatment seeking and adherence (Berk et al., 2010; N. Rusch, Corrigan, Wassel, et al., 2009), a more effective investment in treatment may involve a distribution of resources that extends to both sides of the psychosocial equation. Improving functioning in BD may require the simultaneous development and implementation of interventions that target both internal consumer characteristics and external societal barriers to functioning.

#### 4. The stigma of mental illness

“Stigma” comes from a sixteenth-century Greek word meaning a mark that was branded or tattooed onto people to denote a devalued social status – for example, that of a criminal or a slave (Hinshaw, 2007). Likewise, in most countries, MI is associated with harmful social devaluation (Brohan, Gauci, Sartorius, & Thornicroft, 2011). In the U.S., both the Surgeon General and the Department of Defense have identified current stigma against people with MI as one of the most serious barriers to the nation’s mental health (Department of Defense Task Force on Mental Health, 2007; Surgeon General, 1999). There is also evidence that stigma against people with MI has grown since 1950, despite greater scientific insights into the phenomenon of MI and the relatively widespread acceptance of these insights by the public (Australian Journal of Pharmacy, 2011; Corrigan & Wassel, 2008; Corrigan et al., 2011; Mehta et al., 2009; Pescosolido, Martin, Lang, & Olafsdottir, 2008; Siltan, Flannelly, Milstein, & Vaaler, 2011; Star, 1952, 1955). Recent surveys finding an upward trend in stigmatizing people with MI have inspired large-scale investigations of this stigma and its consequences.

The scientific inquiry into stigma and related constructs, however, is quite complex. While the word “stigma” has grown to be colloquially associated with prejudicial attitudes and discriminatory conduct, it remains a challenging construct to isolate, define and measure for the purpose of scientific research (Corrigan et al., 2011; B. G. Link, Yang, Phelan, & Collins, 2004). Despite these challenges, stigma instruments have been developed and validated for use with people who suffer from depression (Gabriel & Violato, 2010; Interian et al., 2010; Kanter, Rusch, & Brondino, 2008), psychotic disorders (B. G. Link et al., 2004), and SUD (Luoma, O’Hair, Kohlenberg, Hayes, & Fletcher, 2010). In BD, important progress in this area has been made with the development of qualitative literature describing widespread consumer experiences of stigma (Michalak et al., 2006; Michalak et al., 2011; Proudfoot et al., 2009).

Theoretical progress in stigma research has advanced several models that describe its impact on people with MI (Corrigan, 2004; Goffman, 1963; Jones et al., 1984; B. G. Link, Mirotznik, & Cullen, 1991). In the last fifteen years, research has generally converged to support a cognitive-behavioral model of stigma's operation (Corrigan et al., 2011; Crocker, Major, & Steele, 1998; Goffman, 1963; Jones et al., 1984; B. G. Link et al., 1991).

According to the model delineated by Corrigan and colleagues (Corrigan, 2004; Corrigan & Wassel, 2008), stigma is a contextual and relational psychosocial phenomenon whose impact on people suffering from MI can be described using three primary constructs: structural, or institutional, stigma (macro level), public, or enacted, stigma (meso level), and internalized, or self, stigma (micro level) (Corrigan, 2004). This model also describes a fourth construct known as perceived stigma that refers to an individual's perception of structural and public stigma (Corrigan & Watson, 2002).

#### 4.1 Structural stigma

Institutional or structural stigma includes policies and practices of private and governmental institutions that intentionally or unintentionally restrict rights or limit opportunities for people with MI (Corrigan et al., 2004; Corrigan & Wassel, 2008; Michalak et al., 2011). Laws that directly restrict the rights of people with MI are examples of intentional structural discrimination that inhibits functioning (Corrigan et al., 2004; Corrigan, Watson, Heyrman, et al., 2005). In the private sector, lack of equal insurance coverage for mental health treatment (compared to non-psychiatric treatment) and the increasingly negative portrayals of MI in the media are both examples of intentional structural stigma (Corrigan et al., 2004). An example of unintentional structural stigma includes workplace rules that do not allow for scheduling flexibility (even in the absence of a clear need for rigid schedules) such that a person with BD's need for maintenance treatment appointments during business hours is not accommodated (Schultz et al., 2011; Michalak et al., 2007).

In the U.S., private and public institutions play critical roles in perpetuating stigma against people with MI across multiple domains (Krupa, Kirsh, Cockburn, & Gewurtz, 2009; Krupa, 2011a, 2011b). In the legal realm, the Americans with Disabilities Act (Americans with Disabilities Act, 1990) and Fair Housing Act (Fair Housing Amendments Act, 1988) have largely failed to protect people with MI, as indicated by judicial rulings over many years that greatly favored employers (Petrila, 2009) and landlords (Carter, 2010; Swanson, Burris, Moss, Ullman, & Ranney, 2006). In the area of health care, current government policies allow extensive discrimination against people with MI by health insurance companies (Boyd et al., 2011), fail to support deinstitutionalization of psychiatric patients with adequate community alternatives (Corrigan, Watson, Gracia, et al., 2005; Heginbotham, 1998; Phelan & Link, 1998), and provide insufficient funding for effective dissemination of evidence-based psychiatric practices (McHugh, K.R., & Barlow, D.H., 2010). With respect to civil rights, people with MI experience restrictions in obtaining firearms, voting, holding elective office, serving on juries, or gaining full parental rights over their children (Burton, 1990; Corrigan, Watson, Heyrman, et al., 2005; Hemmens, Miller, Burton, & Milner, 2002). People with MI also suffer a great deal of harm from the media (Corrigan, Watson, Gracia, et al., 2005). Currently, the government provides only limited support for anti-MI-discrimination campaigns, and allows the national media to portray people with MI as violent and immoral without penalty (Corrigan, Watson, Gracia, et al., 2005; Corrigan et al., 2011; Heginbotham,

1998; Krupa et al., 2009; Phelan & Link, 1998). Finally, even Social Security Administration (SSA) disability benefits may be structured in a way that incentivizes disability rather than rehabilitation for people who suffer from MI (Drake, Skinner, Bond, & Goldman, 2009; Elinson, Houck, & Pincus, 2007). All of these forms of structural stigma may compromise the psychosocial adjustment of people with MI, beyond the functional limitations imposed by psychiatric symptoms.

#### 4.2 Public stigma

Public stigma operates at the level of interpersonal interactions through a three-part cognitive-behavioral process (Corrigan et al., 2011). First, contextual cues known as “marks” associated with a given person signal to a perceiver (who is in a position of power via the marked person) that a larger group stereotype may be a relevant cognitive response to the marked person. Second, a stereotype is invoked as a cognitive short-cut to allow the perceiver to quickly access a summary of characteristics of that larger group. Finally, the perceiver responds with behavior based on the assumption that these stereotypical group characteristics are true with respect to the marked person (Corrigan, 2004; Corrigan & Wassel, 2008; B. G. Link et al., 2004; Pescosolido et al., 2008).

In this context, the term “prejudice” refers to the adoption of a stereotype as truth with respect to individual members of a stigmatized group, as in step two of the model (Pescosolido et al., 2008). “Discrimination” is defined as a behavior resulting from prejudice that negatively impacts members of the stigmatized group, or step three in the model (Corrigan, 2004 (*American Psychologist*)). The three most common relevant stereotypes found in research literature are that people with MI are dangerous and incompetent, as well as blameworthy with respect to their illness (Corrigan & Wassel, 2008).

The four major categories of cues or “marks” that trigger the use of MI stereotypes are labels, psychiatric symptoms, social skill deficits, and physical appearance (Corrigan, 2004). Several studies demonstrated that a person labeled mentally ill is likely to face prejudiced and discriminatory responses even in the absence of visible psychiatric symptoms or atypical behavior (Link, Cullen, Frank, & Wozniak, 1987; Link, Phelan, Bresnahan, Stueve, & Pescosolido, 1999; Martinez et al., 2011). Additional studies have found that even if a potential stigmatizer or stigmatized person does not endorse negative societal stereotypes of people with MI, either party’s knowledge of these stereotypes may increase anxiety and discomfort during an interaction (Hinshaw, 2007; B. G. Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001). This discomfort, in turn, may raise anxiety levels and future interactional avoidance for people with MI, even when they are not aware that the other party has knowledge of their illness (Hinshaw, 2007). Thus, the pervasive and harmful nature of public stigma can negatively impact interpersonal relationships even in the absence of individual prejudice.

#### 4.3 Perceived and internalized stigma

Perceived stigma refers to the degree to which a person with MI is aware of structural and public stigma, whether through personal experience, the media, or other means (Corrigan & Wassel, 2008; Livingston & Boyd, 2010). Perceived stigma describes people’s awareness that stigma exists, but not their reaction to it, and is thus deemed a separate construct from



internalized stigma (Livingston & Boyd, 2010; N. Rusch, Corrigan, Wassel, et al., 2009; N. Rusch, Todd, Bodenhausen, Olschewski, & Corrigan, 2010). Internalized stigma is broadly defined by feelings of shame, self-criticism, identity changes and maladaptive (most notably avoidant) behavior that may develop in response to perceived stigma (Brohan et al., 2011; Corrigan & Wassel, 2008; Livingston & Boyd, 2010; Manos, Rusch, Kanter, & Clifford, 2009; Michalak et al., 2011; N. Rusch, Lieb, Bohus, & Corrigan, 2006).

## **5. The impact of stigma on psychosocial functioning in BD**

These four forms of stigma – structural, public, perceived and internalized – interact with each other in complex ways to decrease psychosocial functioning in BD. Understanding their individual and combined contributions to these negative outcomes among people with BD is a vital step towards promoting functional adjustment in this population.

On a macro level, structural stigma probably affects functioning in BD through the same mechanisms that limit psychosocial adjustment in MI more generally. In the absence of institutional protection, funding and support, structural stigma directly circumscribes the opportunities of people with BD to improve their clinical, social and vocational functioning (Baldwin & Marcus, 2011; Boyd et al., 2011; Corrigan, Watson, Heyrman, et al., 2005; Krupa, 2007; Michalak et al., 2007; Michalak et al., 2011). Thus, people with BD may struggle to function in part because they attempt to negotiate a social environment that is not designed to accommodate their limitations (e.g. cognitive impairment) and special needs (e.g. flexible work schedules and occupational supports), and thus deprives them of opportunities that are available to others.

On the meso level, people with BD encounter functional challenges that emanate from public discrimination. Studies suggest that public stigma against people with BD is prevalent and intense (Australian Journal of Pharmacy, 2011). A 2004 survey of 1200 American adults by the Depression and Bipolar Support Alliance (DBSA) found that a large number of respondents reported serious doubts about the ability of people with BD to keep responsible jobs, hold public office, and maintain positive relationships (Depression and Bipolar Support Alliance, 2008). Employers reported particular concerns as to the potential effects of emotional instability and atypical behavior on clients and co-workers, in addition to absenteeism, poor work performance, and an inability to tolerate stress (Schultz, Milner, Hanson, & Winter, 2011). People with BD therefore appear to suffer unemployment at least partly because employers refuse to hire or retain them (Michalak et al., 2007; Michalak et al., 2011). This notion is consistent with research findings in BD and MI generally indicating that stigma-related constructs are stronger predictors of employment outcomes than diagnosis, employment history or symptoms (Baldwin & Marcus, 2011; Krupa, 2011b; Larson et al., 2011; Michalak et al., 2007; Tse & Walsh, 2001; Tse, 2002; Tse & Yeats, 2002). Unemployment and underemployment in BD therefore may not emanate solely or even primarily from the limiting effects of psychiatric symptoms. Instead, occupational difficulties in BD may be compounded to a considerable degree by social barriers rooted in stigma and discrimination.

Public stigma may also hinder psychosocial adjustment in BD within the close family circle. There is evidence that “expressed emotion” – which consists of emotional over-involvement, as well as hostile, critical, and blaming attitudes of a family toward its members with MI –

is high in families of people with BD (McMurrich & Johnson, 2009). Studies further show that expressed emotion predicts depression and relapse in people with BD (Eisner & Johnson, 2008; McMurrich & Johnson, 2009), which independently correlate with each other and with poor overall functional outcomes (M. Bauer et al., 2009; Bonnin et al., 2010). Conversely, greater social support predicts better social (Perlick et al., 2001) and occupational adjustment in BD (Gutierrez-Rojas et al., 2011). Changes in public stigma within the family therefore may help to improve psychosocial adjustment in BD.

On a micro level, studies consistently show that people with BD suffer from high levels of perceived and internalized stigma (Brohan et al., 2011). Research indicates that many people with BD report experiencing shame about their diagnosis (Michalak et al., 2011) as well as illness-related social and occupational rejection or exclusion (Michalak et al., 2006; Michalak et al., 2007; Michalak et al., 2011; Proudfoot et al., 2009; Ward, 2011).

Both internalized and perceived stigma have been shown to be associated with functional outcome in BD (Brohan et al., 2011; Vasquez et al., 2011). The presence of significant internalized stigma is associated with reduced self-esteem, and lower self-efficacy (Brohan et al., 2011). Internalized stigma is also related to an overall reduction in QOL (Alonso et al., 2009; Brohan et al., 2011), delayed treatment seeking, poor treatment adherence, and greater depressive symptoms (Brohan et al., 2011; Sirey et al., 2001).

Micro-level stigma may play an important role in the mechanisms that decrease psychosocial functioning in BD. As qualitative findings imply, perceived and internalized stigma evoke marked distress in people with a BD diagnosis (Michalak et al., 2006; Michalak et al., 2011; Ward, 2011). More specifically, recent studies found that heightened stress from stigma was associated with increased social anxiety and shame (N. Rusch, Corrigan, Powell, et al., 2009). While anxiety has been shown to predict worse outcomes in BD (Boylan et al., 2004), shame predicts depression, avoidance and psychopathology generally (Andrews, Qian, & Valentine, 2002; Highfield, Markham, Skinner, & Neal, 2010; J.P. Tangney, 1995), which also decrease functional adjustment.

The automatic nature of internalized stigma makes it particularly destructive. There is evidence that the primary response to stigma is an involuntary aversive emotional experience rather than a conscious cognitive reaction (N. Rusch, Corrigan, Powell, et al., 2009). Thus, the impact of internalized stigma on functional adjustment in BD may operate primarily through the mediating factors of shame and social anxiety (Andrews et al., 2002; Brohan et al., 2011; Cheung, Gilbert, & Irons, 2004; B. Link et al., 1987; B. G. Link, 1987; Michalak et al., 2011; Vasquez et al., 2011), rather than through maladaptive cognitions such as endorsed stereotypes (N. Rusch et al., 2010; N. Rusch, Corrigan, Todd, & Bodenhausen, 2011). Shame, avoidance, social isolation and depressive symptoms all contribute to lower QOL in BD and heightened risk of relapse (Cohen et al., 2004; Bonnin et al., 2010; Michalak et al., 2011; Perlick et al., 2001). Collectively, these stigma-related factors probably decrease psychosocial development in BD.

In broader conceptualization, it may be useful to understand the debilitating roles that shame and social anxiety play in stigma's operation across its various levels. More specifically, the different levels of stigma are probably looped together in detrimental ways that exacerbate their individual effects. In this respect, insight into the connection between public and internalized stigma might be particularly informative, with the leading

hypothesis being that public stigma and discrimination often create internalized stigma, which manifests as shame and social anxiety.

In support of this line of reasoning, shame and social anxiety are known as key outcomes of social devaluation by the public (L. C. Rusch, Kanter, Angelone, & Ridley, 2008; N. Rusch, Corrigan, Powell, et al., 2009; N. Rusch et al., 2010). These emotions may be triggered when people perceive themselves to be at risk of social exclusion due to not meeting societal norms or losing social rank (Cheung et al., 2004; Gilbert & Procter, 2006). Further, ongoing criticism or stigmatization of a person may result in the internalization of these devaluations as trait or internal shame, key elements of which are chronic self-invalidation, self-criticism and self-blame (Cheung et al., 2004; Gilbert, 1992, 2002; Gilbert & Procter, 2006; Gilbert et al., 2010; Miklowitz & Johnson, 2009). Trait shame is strongly associated with avoidance (J. P. Tangney & Dearing, 2002) and social anxiety (Gilbert & Irons, 2004), and all three are known as core emotional and behavioral components of internalized stigma (Birchwood et al., 2007; Perlick et al., 2001; N. Rusch et al., 2006; N. Rusch et al., 2010). Internalized stigma therefore may emerge as a function of public stigma (Livingston & Boyd, 2010; Schneider, Beeley, & Repper, 2011) in a manner that compromises psychosocial adjustment (Brohan et al., 2011; Vasquez et al., 2011). Interventions aimed at improving psychosocial functioning in BD thus need to address all levels of stigma to be effective.

## 6. Implications for care

The conventional approach to improving functional adjustment in BD focuses primarily on pharmacological interventions to decrease symptoms (Balanza-Martinez et al., 2010). These efforts have been traditionally supported by psychosocial treatments that are designed to increase practical knowledge about the illness and its management (e.g., group psychoeducation; Colom et al., 2009), as well as to improve interpersonal and coping skills (Frank et al., 2005). Although studies support the efficacy of these interventions, they are clearly insufficient in fully addressing the problem of psychosocial impairment in BD. Further improvement to functional outcome in BD may therefore come from addressing factors such as stigma and discrimination that originate in the larger social milieu rather than within the individual consumer.

### 6.1 Bringing about structural changes

On a structural level, treatment providers and mental health care administrators need to advocate for affirmative litigation, proper funding of services, effective dissemination of evidence-based practices, and incentives for work that do not, in the near term, jeopardize the financial support and stability derived from maintaining disability status. These efforts may reduce discrimination in housing and employment. They may also equalize health insurance coverage and access to care for people with BD compared to those with non-psychiatric diagnoses. People with BD need major structural changes in the larger social context to create environments that accommodate their special needs. The absence of these changes currently limits their ability to participate in mainstream social functions.

Accommodations in the workplace should rank high in priorities for reform, due to the pernicious effects of stigma on employment in BD, and the drastic effects of unemployment on mental and physical health generally (Bambra, 2010; Bowden, 2005; Bush, Drake, Xie,

McHugo, & Haslett, 2009; Michalak et al., 2007). Qualitative studies (Michalak et al., 2007; Tse & Yeats, 2002) indicate that augmenting employment in BD requires interventions in four key areas: illness management, social support, and employer-employee relations, as well as in combating broader societal barriers such as stigma and disincentives to working embedded in disability regulations (Elinson et al., 2007; Tse & Yeats, 2002). Evidence-based supported employment (SE) programs that include early intervention after diagnosis, integrated clinical care and vocational services (Cook et al., 2005; Cook et al., 2008), training in goal-setting, cognitive and social skills (Arbesman & Logsdon, 2011; Cook, 2006; Cook et al., 2008; Krupa, 2007; Krupa et al., 2009), a collaborative and individualized approach to rapid employment placement without lengthy pre-placement training, and especially, high-intensity on-the-job support of unlimited duration (G. R. Bond & Kukla, 2011; Cook et al., 2005; Evans & Bond, 2008; McHugo, Drake, & Becker, 1998), address the first three of these areas.

SE programs have been found to be highly effective in improving employment outcomes for people with severe MI, including BD (Arbesman & Logsdon, 2011; Tse & Yeats, 2002). Importantly, as Tse & Yeats (2002) note, the absence of time limits in SE programs is likely critical in helping people with BD achieve their long-term vocational goals. People with BD may need to be guided from working in low-level positions as they initially adjust to employment, towards taking on increasingly challenging work or education over time (Drake et al., 2009; Tse & Yeats, 2002). From a broader structural viewpoint, a widespread implementation of supportive programs and workplace accommodations for people with BD will require affirmative litigation, adequate funding and a change in the social climate.

Beyond the wide-scale implementation of SE, further structural reforms that may increase employment in BD should address the process of shifting consumers from the protective service of disability benefits towards enrollment in SE programs. Even if SE programs were sufficiently funded and disseminated, a remaining obstacle to this shift involves SSA disability benefits recipients' concerns about the loss of income and health insurance benefits in the short and long-term were they to begin working (Drake et al., 2009; Elinson et al., 2007; Tse & Yeats, 2002). In 2011, SSA disability beneficiaries face powerful disincentives to employment as, after a brief trial work period, they risk losing their cash benefits immediately and public health insurance several months thereafter, if they gross over 1000 dollars per month (Drake et al., 2009; Elinson et al., 2007). Not surprisingly, in BD, very few employed people receive disability benefits, and most experience reduced health insurance coverage and access to mental health care compared to those receiving benefits (Elinson et al., 2007).

The vocational reform under discussion is guided by the notion that BD is a form of major mental illness, with recurrent mood and/or psychotic episodes that periodically preclude continuous attendance at work. The instability that inheres in this condition necessitates external supports to assure even minimal long-term financial security. In the absence of such security, the decision to forego the benefits of disability for employment opportunities seems unreasonably risky. For this reason, allowing people with BD to reap the health and economic benefits of employment while reducing the tremendous cost to the nation of lost productivity due to BD, requires a structural mechanism that ensures consumers larger rewards from working without the risk of losing financial security due to relapse.



## 6.2 Reducing public stigma

Attenuating the detrimental effects of public stigma may also be important for improving functional adjustment in BD. In this regard, there is evidence that family-focused therapy (FFT; Miklowitz et al., 2003), which aims to mitigate expressed emotion and augment social support from family members, can be highly beneficial. Studies suggest that FFT improves clinical outcomes in BD even over long periods of time (Rea et al., 2003), including by delaying time to relapse and lessening residual symptoms (Miklowitz et al., 2003), which are highly correlated with functional adjustment (M. Bauer et al., 2009).

While the focus on family members is essential, the efforts to reduce the ill effects of public stigma should also include larger social circles. In this realm, advocates have traditionally supported the use of protests (Corrigan et al., 2011), anti-stigma mass media campaigns (Schneider et al., 2011), and educational programs that contradict negative stereotypes (Corrigan et al., 2011). However, there is no evidence that these interventions lead to lasting reductions in stigma, and they sometimes may have opposite effects (Corrigan & Wassel, 2008; Masuda, Hayes, et al., 2009). As with internalized stigma, the stigmatization of people with MI by others appears to be an automatic emotional process occurring outside awareness, which then triggers stereotypical cognitions (N. Rusch et al., 2011). Further efforts to alter or suppress these unwanted cognitions often paradoxically result in reinforcing them (Masuda, Hayes, et al., 2009). Thus, educational interventions that aim to decrease the frequency of stereotypical cognitions without addressing the underlying emotional process that produces stigma, may in fact trigger an intensified emotional reaction of heightened stigma. This reaction may then unintentionally increase the occurrence of stereotypical thoughts (Masuda, Hayes, et al., 2009; Masuda, Price, Anderson, Schmertz, & Calamaras, 2009). The same type of resistance to change was observed in educational interventions aimed at altering racial prejudice (McKown, 2005; Paluck & Green, 2009). At the same time, extensive research in social psychology has developed models and programs involving advocacy and education to combat public stigmatization of historically oppressed groups that have had some success (Buhin & Vera, 2009). These models may inform the development of interventions to reduce public stigma in BD.

Models that come from the field of clinical psychology may also be helpful in reducing public stigma. There is some evidence that mindfulness-based interventions can decrease the stigmatizing of people with MI by college students (Masuda, Hayes, et al., 2009). In this study, after an acceptance and commitment therapy (ACT) intervention of only 2.5 hours, stigmatization of MI was reduced even at a one-month follow-up, compared to an educational control intervention. Mindfulness-based interventions may be practical to implement in educational settings, as part of a curriculum that aims to promote social justice.

## 6.3 Individual counseling

Addressing the broader social context of stigma, with its structural and public components, should be accompanied by counseling methods that reduce the effects of stigma at an individual level. One potentially useful approach to alleviating the shame, social anxiety and avoidance that result from stigma in BD may be based on mindfulness- (Luoma, Kohlenberg, Hayes, Bunting, & Rye, 2008) and compassion-focused (Gilbert & Procter, 2006) therapies. Mindfulness-based interventions increase nonjudgmental awareness and acceptance of thoughts and feelings, which allow people to better regulate these internal



experiences (Luoma et al., 2008). Thus, these therapies may be suitable for decreasing the chronic, automatic self-criticism that emanates from internalized stigma and impedes functioning (Gilbert et al., 2010). Some studies show that mindfulness-based cognitive therapy (MBCT; Weber et al., 2010; Williams et al., 2008) raised levels of treatment adherence while diminishing stress, anxiety, depression and relapse in BD, all of which improved functioning (Bonvalot et al., 2010; Miklowitz & Johnson, 2009; Richardson, 2010). ACT has been found to diminish internalized stigma in SUD, a common comorbidity of BD (Luoma et al., 2008), warranting research to examine the effects of this intervention on stigma-related thoughts and feelings in BD.

Recent research also points to the potential usefulness of compassion-focused therapy (CFT; Gilbert & Procter, 2006; Highfield et al., 2010) in improving functioning in BD. CFT trains people in countering chronic self-criticism by practicing self-compassion (Gilbert & Procter, 2006). Studies show that CFT can promote self-soothing and decrease shame, social anxiety, depression and self-criticism in personality as well as mood disorders (Gilbert & Procter, 2006; Pauley & McPherson, 2010; Van Dam, Sheppard, Forsyth, & Earleywine, 2010). In BD, it may also promote affect regulation (Galvez et al., 2011; Gruber et al., 2009; Lowens, 2010). Given CFT's potential to diminish shame and self-criticism, future research may therefore wish to examine the effects of CFT on internalized stigma in BD.

Use of empowerment-based interventions to counter internalized stigma also deserves consideration (Brohan et al., 2011; Corrigan et al., 2011). Broadly defined, empowerment refers to perceived and actual control over the central domains of life, such as personal security, financial stability, social networks, employment and health (Corrigan et al., 2011). To empower people with BD in the face of heavy internal and public stigma, treatment providers and researchers need to give greater weight and attention to consumer experiences including self-management strategies (Ilic et al., 2011), as well as to the potential use of consumer-led support services (Repper & Carter, 2011) and a strengths-based collaborative care treatment model (M. S. Bauer et al., 2006). While research on empowerment in BD remains scarce, Brohan et al. (2011) found that empowerment was negatively correlated with internalized stigma in BD. Empowerment interventions may therefore carry the potential to decrease the ill effects of stigma and improve functioning in BD.

Finally, psychoeducation for consumers with BD that explicitly acknowledges the realities of stigma and discrimination and helps consumers share experiences and improve strategies for navigating and coping with stigma, may serve a three-part function. First, such psychoeducation may reduce individual shame with respect to stigma by naming it as part of unjust systemic inequalities. Second, helping people with BD learn strategies for negotiating stigma may be of practical value to them. Third, such psychoeducational programs could provide a mechanism for people with BD who are managing their illness and related stigma successfully to impart their experiences to others with BD, in a way that empowers the community of people with BD as a whole. Such consumer-led psychoeducation and empowerment is taking place in some psychiatric rehabilitation programs, as well as in consumer support centers known as "recovery learning centers," that are being created in growing numbers. However, significantly increased resources must be devoted to the peer-led recovery movement if it going to play a dominant role in combating stigma and improving functioning in BD.

In sum, diminishing the effects of stigma on functioning in BD requires efforts on multiple levels. Treatment providers, researchers and mental health care administrators need to join with consumers and others in advocating for equality, support and accommodation in employment, housing and social opportunities, as well as in health insurance coverage for people with BD. To reduce public and internalized stigma, mindfulness- and compassion-based therapies might be considered along with more traditional empirically validated psychosocial interventions.

## 7. Conclusions

Tremendous advances in pharmacological and psychosocial treatments now allow many people with BD to achieve syndromal remission within two years of an acute episode, and sometimes much sooner (Huxley & Baldessarini, 2007; Tohen et al., 2000). However, the reduction in symptoms is often not accompanied by functional recovery (Montoya et al., 2010; Tohen et al., 2000). Given the limited ability of identified predictors of functioning in euthymic BD to account for the variance in functional outcomes, researchers have begun to look more closely at contextual factors that may restrict functioning. Stigma and discrimination have been identified as important contextual factors that contribute to psychosocial disability in BD (Vazquez et al., 2011).

Different forms of stigma interact with each other and the illness in a series of vicious cycles that push people with BD towards social and vocational marginalization (Brohan et al., 2011; Michalak et al., 2006, 2011; Vazquez et al., 2011). Reversing the impact of stigma on functioning in BD will likely require simultaneous interventions on multiple fronts. First, advocacy is needed to reform laws and regulations that restrict the rights and opportunities of people with BD. Second, funding is required for supported employment and social programs that empower them. Third, a major effort at reducing public stigma and discrimination against BD, both in the family and society at large, is required for developing the necessary social support and employment opportunities for psychosocial adjustment. Finally, counseling in BD needs to include methods for addressing stigma-related shame, self-criticism, social anxiety and avoidance, which carry detrimental clinical and psychosocial effects.

From a broad-based perspective, the presence of powerful societal barriers to functioning limits current efforts to improve functional outcomes in BD, which mostly focus on interventions that address internal factors. An inhospitable social climate hampers psychosocial development in ways that are unaffected by psychopharmacology or psychotherapy. For this reason, significant improvement to functioning in BD requires balancing investment into interventions aimed at removing societal barriers to functional adjustment and alleviating the ill effects of these barriers on the individual, with more traditional forms of treatment.

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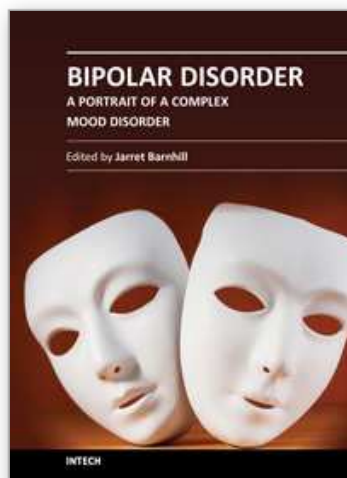


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## **Bipolar Disorder - A Portrait of a Complex Mood Disorder**

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Bipolar Disorder: Portrait of a Complex Mood Disorder is a step towards integrating many diverse perspectives on BD. As we shall see, such diversity makes it difficult to clearly define the boundaries of BD. It is helpful to view BD from this perspective, as a final common pathway arises from multiple frames of reference. The integration of epigenetics, molecular pharmacology, and neurophysiology is essential. One solution involves using this diverse data to search for endophenotypes to aid researchers, even though most clinicians prefer broader groupings of symptoms and clinical variables. Our challenge is to consolidate this new information with existing clinical practice in a usable fashion. This need for convergent thinkers who can integrate the findings in this book remains a critical need. This book is a small step in that direction and hopefully guides researchers and clinicians towards a new synthesis of basic neurosciences and clinical psychiatry

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