What is stigma? One may initially define stigma, simply, as negative attributes an individual assigns to himself or herself. Or stigma may evoke labels placed by society on individuals with membership in a particular category or group. For many, stigma remains an enigma, perhaps due to the complexity of the inherent individual and public processes involved and their interactions.

The act of defining stigma often creates discord among stakeholders; however, repeated documentation of the negative outcomes of stigma (e.g., discrimination in employment, social systems, education; Livingston & Boyd, 2010) has garnered agreement among all. Individuals who perceive self-stigma and are stigmatized by others experience various levels of social injustice. Yet, these are precisely the individuals, those who have particular vulnerabilities and/or challenges, whom we, as a society, should be working our hardest to support.

**What Is Stigma, and How Do We Study It?**

Patrick Corrigan has edited a comprehensive volume on stigma intended to reach a wide audience, including researchers, students, advocates, and the lay public. The opening chapter of *The Stigma of Disease and Disability: Understanding Causes and Overcoming Injustices* provides a comprehensive yet efficient overview of the history, conceptualization, and study of the concept of stigma within the context of social (i.e., public policy) and empirically driven (i.e., academic research) systems. Nev Jones and Corrigan highlight three theoretical frameworks for understanding stigma (cognitive, affective, motivational) and four types of stigma (public stigma, self-stigma, label avoidance, and structural stigma), and they weigh the pros and cons of examining stigma with specific research designs (participatory, population based, experimental).
Studies that use participatory, or “patient-centered” as referred to in the medical community, research designs indeed provide stronger ecological validity. Given the personal nature of perceived stigma and the condition-specific factors that contribute to an individual’s experience, it will be necessary to involve the very individuals who experience stigma in the development of evidence-based tools to measure interventions to decrease felt stigma. Such patient-centered research is the entire focus of the Patient Centered Outcomes Research Institute (PCORI; www.pcori.org), authorized by Congress to fund projects that involve patients as primary stakeholders.

**Stigma in Specific Populations**

Following the opening chapter, the book proceeds with individual chapters on stigma in nine diseases/disabilities, including serious mental illnesses, substance-related disorders, intellectual disabilities, physical and sensory disabilities, infectious diseases (with separate chapters on HIV and leprosy), cancer, obesity, and Alzheimer’s, and a general chapter on childhood conditions and stigma. These chapters are formatted in a way similar to the introductory chapter, covering public policy and legal implications, discussion of theoretical underpinnings of stigma, advocacy, and efforts to reduce stigma within the context of the particular condition and the condition-related factors unique to that population.

For example, genetic and behavioral components of alcohol dependence (Georg Schomerus), obesity (Rebecca Puhl and Jamie Lee Peterson), mental health (Corrigan and Kristin Kosyluk), and specific types of cancer (e.g., lung; Nicole Else-Quest and Tracy Jackson) are discussed, with implications for society’s response in the form of stereotypes and discrimination toward these populations. Further, Schomerus discusses the necessary distinction between developing public campaigns aimed at stigmatizing behavior versus presenting behaviors as a public health concern (e.g., smoking, alcohol use).

Although the information is comprehensive and pertinent for the nine conditions represented, two relevant populations are not adequately represented: (a) children and adolescents with physical, behavioral health, and/or educational conditions, and (b) individuals with epilepsy. In the chapter on children and adolescents, Caroline Heary, Ellis Hennessy, and Lorraine Swords include only several paragraphs on stigma in youths with pediatric conditions but instead focus on the development of stigma in otherwise healthy children. Although a developmental perspective is important to the scope of this book, the experience of stigma in youths with chronic conditions is equally relevant. Indeed, there is a growing body of literature on how children and adolescents with pediatric chronic illnesses experience stigma and factors related to the nature of the disease or disability (Roberts & Steele, 2009). As Heary and colleagues discuss, cognitive and social development affect the experience of stigma, so it would seem pertinent to include information on the experience of stigma in youths with pediatric conditions.

Persons with epilepsy constitute 1 to 2 percent of the population, and evidence supports considerable self-stigma and public stigma in both children and adults (Jacoby, 2008). Fifty percent of persons with epilepsy also have mental health and/or cognitive comorbidities, both of which have been associated with considerable stigma (Jensen, 2011). Persons with epilepsy and one of these comorbidities may deal with a double impact of stigma. A current International League Against Epilepsy (ILAE) Task Force identified over 800 articles with reference to stigma in epilepsy; therefore, inclusion of epilepsy, both for the nature of the
Further, noteworthy pieces of the stigma framework—religious/spiritual and cultural factors—are minimized throughout the individual condition chapters. In the introductory chapter, Jones and Corrigan present stigma as a socially constructed phenomenon. In the chapter on leprosy, Wim Van Brakel and Beatriz Galarza do include a section on religious and spiritual practices and beliefs, and Hanoch Livneh, Fong Chan, and Cahit Kaya allude to attributions for physical or sensory disabilities as punishment for sin. However, there is no mention of the religious- or spiritual-based etiological beliefs related to the cause of mental health disorders (e.g., punishment, lack of faith, demons) and how those affect mental health stigma. Similarly, cultural traditions and practices, often influenced heavily by religious and spiritual beliefs and practices, are minimized throughout most chapters despite research on cultural difference in stigma in conditions across various countries and cultures (e.g., Jacoby, 2008).

Clarity of Stigma Definitions and Terms: Toward a Concise Framework

Each chapter stands independently rooted in stigma theory, with an adequate overview of the extant literature. However, after finishing the book (or any individual condition chapter), I recognized little synergy between the introductory chapter and the individual condition chapters. To illustrate, many of the individual chapters frame stigma using different terminology than does the introductory chapter. The reader must attempt to link the new terms introduced in each chapter to the original typologies.

For example, Jones and Corrigan introduce public versus self-stigma, and Gregory Herek later discusses enacted versus felt/perceived stigma. Second, the chapter on physical and sensory disabilities (Livneh et al.) begins with a long description of the models of disabilities and stigma, which would be unnecessary if these ideas were presented in the initial chapter. One of the final chapters (David Roe, Paul Lysaker, Philip Yanos) does refer to stigma types using terminology introduced in the introductory chapter; however, the reader muddles through 10 chapters of confusion to get to this chapter.

Similarly, the authors of the individual condition chapters introduce a host of terms for ways to decrease stigma, including interventions, programs, strategies, and media campaigns. It is unclear whether all authors are using these terms uniformly. In psychology, these terms can have very different meanings and are not interchangeable (e.g., interventions may suggest therapeutic elements). Readers outside of psychology could easily get lost in the terms. Also, in their brief review of efforts aimed at decreasing stigma, some authors (e.g., Herek) do not distinguish whether the studies cited are aimed at reducing perceived or felt stigma in an individual versus those aimed at society and of what these interventions consist (i.e., therapeutic components). In contrast, Perla Werner does an excellent job of displaying in table form the empirical studies on stigma in Alzheimer’s. Therefore, there is great variability in the conciseness and clarity of stigma concepts among the condition chapters.

Although it may be understandable for academic psychologists to retain multiple terms for the same concept based on theoretical differences, use of various terms for the same
concept does not assist in demystifying stigma but instead contributes to the enigma of it. If the purpose of this book, as stated in the introduction, is to provide clarity and understanding of stigma within legal and public policy guidelines for a wide audience, initial clarification of these terms and concepts and their meanings in the introductory chapter would greatly resolve potential confusion. Perhaps models of stigma and of disease and disability in the form of figures could provide a visual framework for these complex concepts that readers could refer to as they encounter these terms in each chapter. Notably, complete agreement on use of terms is difficult with numerous authors of varying expertise; however, there must be some resolution if readers are to extract a clear take-home message.

The collective impact of the book may also be enhanced simply by the reordering of certain chapters. As mentioned above, cultural factors are not woven throughout the book. The Heary, Hennessy, and Swords chapter on developmental considerations for stigma in children and adolescents, which is much more heavily weighted toward the cognitive and social development of stigma in otherwise-healthy children, would provide a salient framework for digesting the information contained in the rest of the book. Tally Moses’s chapter on family does not appear to relate to the second section of the book titled Stigma and Action. Because family dynamics and stigma experience (e.g., courtesy stigma, internalized family stigma) cross all diseases and disabilities, this chapter could also set the stage for the individual condition chapters. If these chapters preceded the individual condition chapters, readers would view stigma within the context of these various complicated systems and processes as they progress through the individual conditions.

In summary, Corrigan’s book provides a concise yet fairly comprehensive presentation of the literature on stigma. Strengths of the book lie in the chosen context of legal issues and public policy and in the individual condition chapters. The book frames stigma within the context of societal, legal, and public policy ramifications, which is definitely an addition to the literature in this area. Each of the condition chapters stands well as an individual unit. Weaknesses of the book include organization of the chapters, neglect of salient populations (people with epilepsy), minimal attention to culture and religion until one of the final chapters in the book, and disparity among stigma definitions. Thus, the book leaves something to be desired in terms of its impact as a collective unit.

Moving forward, it will be necessary to clearly and concisely define *stigma* and, for investigators, policy makers, and advocates, to use the same terminology when referring to types of stigma. Investigators are encouraged to consider patient-centered or participatory research designs to use the input of the individuals experiencing stigma in the development of tools to assess and interventions to decrease stigma. Specific populations, such as individuals with intellectual disabilities, who have been underrepresented in research thus far should be a priority for researchers. Indeed, there are current recommendations to encourage, not discourage, the practice of research with individuals with intellectual disabilities (Feudtner & Brosco, 2011). It will be important to assess the different types of stigma as perceived by family members of individuals with specific conditions.

Such efforts will provide a substantial contribution to the development of evidence-based interventions and public policies to protect and provide supportive resources to these individuals. In essence, these efforts will help to reduce the enigma of stigma in our society and to promote acceptance of individuals.
References


