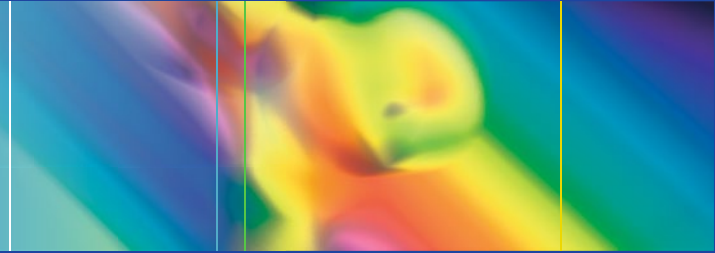


Sandra Steingard  
*Editor*



# Critical Psychiatry

Controversies and  
Clinical Implications

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*To Phyllis and Sol Steingard  
Exemplars of integrity and  
perseverance*

# Acknowledgments

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# Contents

- 1 What Is Critical Psychiatry? . . . . . 1**  
Joanna Moncrieff and Sandra Steingard
- 2 Toward Conceptual Competence in Psychiatric  
Diagnosis: An Ecological Model for Critiques  
of the DSM . . . . . 17**  
Justin M. Karter and Sarah R. Kamens
- 3 The Influence of Pharmaceutical Companies  
and Restoring Integrity to Psychiatric Research  
and Practice . . . . . 71**  
Lisa Cosgrove and Akansha Vaswani
- 4 An Alternative Approach to Drug Treatment  
in Psychiatry . . . . . 97**  
Joanna Moncrieff
- 5 Clinical Implications of the Drug-Centered  
Approach . . . . . 113**  
Sandra Steingard
- 6 Deprescribing and Its Application to Psychiatry . . . . 137**  
Swapnil Gupta and Rebecca Miller
- 7 Coercion and the Critical Psychiatrist . . . . . 155**  
Nicolas Badre, Shawn S. Barnes, David Lehman,  
and Sandra Steingard



**8 Listening to Those with Lived Experience . . . . .179**  
Emily Sheera Cutler

**9 A Path to the Future for Psychiatry . . . . .207**  
Sandra Steingard

**Index . . . . .221**

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# Chapter 1

## What Is Critical Psychiatry?



**Joanna Moncrieff and Sandra Steingard**

### Introduction

In some respects, the critique of the mental health professions is as old as the professions themselves. Over many years, new theories or treatments – often critical of their predecessors – supplant the accepted practices of an earlier era. The Victorian asylums were envisaged as a new and radical form of treatment for madness that would restore people to sanity through immersion in a quiet and orderly environment [22]. Moral treatment, which was practiced in some of these institutions, was a reaction against previous ideas that madness represented unchangeable animalistic and irrational tendencies [21]. When the asylums became increasingly custodial and authoritarian, enlightened psychiatrists, including Philippe Pinel in France and John Connolly in England, advocated a more liberal approach by unlocking the doors and unchaining the inmates. Although Freud worked within the mainstream of

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Viennese medical circles, his ideas were revolutionary and shocking to many, yet psychoanalysis soon became incorporated into conventional practice. Social psychiatry was also influential in the twentieth century, despite the rising dominance of biological theories and treatments. The leading US psychiatrist of the first half of the twentieth century, Adolph Myer, argued that mental disorders arose out of a reaction to an individual's life experiences and stresses and urged psychiatrists and others to incorporate occupational activities into therapeutic practice [9]. In the United Kingdom, psychiatrist Aubrey Lewis initiated a long-standing tradition of social psychiatry; many psychiatrists were involved in the therapeutic community movement that recognized the social and relational antecedents of mental disorder and aimed to help people through participation in supportive communities. In this regard, the "mainstream" can be hard to define, given the shifting notions of accepted doctrine in the field.

While some might argue there is still no singular notion of "psychiatry" toward which one can be critical, there are predominant views. These are the opinions and policies promoted by professional organizations such as the American Psychiatric Association and research funding agencies such as the National Institute of Mental Health. The paradigm promoted by these organizations includes the following premises: There is a role for physicians to address the needs of individuals afflicted with conditions characterized as mental illness; these conditions can validly be thought of as illnesses or disorders; there is enough consistency in these disorders among individuals that they can be studied independent of social context and individual experience; the brain is an important substrate for the study of these conditions; and understanding the genome and brain anatomy, chemistry, and physiology is critical to achieving a fundamental understanding of these conditions. These beliefs have an enormous effect on the kinds of inquiry that are supported by dominant funding agencies with billions of dollars dedicated to research into the biological origins of mental disorders and more limited funds made available for the investigation of some cir-

cumscribed social approaches. We live in the era of evidenced-based practice. If an approach is not funded, then it will never acquire the kind of data that would allow it to be considered evidence-based. This creates a closed loop: only research that is hypothesized to be of value is funded; understudied approaches that might be of value are ignored because they are not considered evidenced-based.

This dominant paradigm is often traced to the work of Emil Kraepelin. He attempted to apply the principles emerging in modern medicine in the late nineteenth century to determine the putative pathological basis of the problems he observed in his patients in a German psychiatric hospital. He was a pathologist and thought that by carefully categorizing the symptoms, signs, and course of the conditions afflicting his patients, he would discover the underlying brain pathology responsible for their conditions. He used the expression “dementia praecox” to characterize those who experienced psychosis associated with inexorable decline in function. This syndrome was contrasted with manic-depressive insanity which described patients who experienced relapsing and remitting symptoms that often included profound alterations of mood [18]. It was this work that inspired the so-called neo-Kraepelinians who came to dominate American – and worldwide – psychiatry in the later part of the twentieth century. They achieved their predominant position with the publication of the third edition of the *Diagnostic and Statistical Manual* (DSM-III) which reflects the idea that mental distress can be divided into categories that reflect specific underlying pathological states [1]. Although this is a publication of the American Psychiatric Association, it has influenced psychiatric practice and research all over the world and served as a model for future versions of the International Classification of Diseases.

The editors of the DSM-III describe the manual as agnostic with respect to etiology or treatment. They argued that it was important to have consistent ways of characterizing conditions in order not only to advance in both the clinical and research domains, but also to protect psychiatry from the

accusation that it was pathologizing ordinary human misery [20]. But it presupposes that generalizable psychopathological entities exist that can be demarcated and that individuals who are categorized in a particular way share much in common with others who are assigned the same diagnosis. It assumes that mental disorders can be characterized independently from other characteristics of the individual who is affected. This was and is a hypothesis. However, in the years since its publication, the diagnostic categories of the DSM-III and its successor editions have been reified in the minds of many clinicians and members of the public. Much of the discourse in both professional and lay circles refers to categories of mental disorder in an essentialist manner. One might hear, “He has schizophrenia” or “He is a schizophrenic” more often than one hears, “He has the symptoms and course consistent with the current definition of schizophrenia.” This may appear to be a subtle distinction, but it has important implications for how individuals and others think about their experiences.

Paralleling the ascendance of the DSM-III diagnostic system was the growing dominance of drug treatments as the primary therapeutic modality in psychiatry. For reasons that will also be explored further in this book, the DSM helped to promote the interests of groups – primarily the pharmaceutical companies – who stood to gain enormously from this situation. The increasing prevalence of drug treatment also enhanced the perceived legitimacy of psychiatry as a branch of medicine since it created the impression that the field had clearly delineated pathological conditions that could effectively be targeted using sophisticated, disease-specific treatments as in many other areas of medicine.

Critical psychiatry is a broad tent, with many different perspectives and influences. Broadly, it can be characterized as a field that takes exception to some or all of the current dominant premises and paradigms and endeavors to explore the implications of various critiques of mainstream psychiatry for actual clinical practice and for the nature and shape of mental health services.

## Critiques of Psychiatry

### *Antipsychiatry*

Recent academic and theoretical criticism of psychiatry started with the antipsychiatry movement of the 1960s and 1970s. Antipsychiatry is usually taken to refer to ideas expressed by some philosophers, sociologists, and psychiatrists that started to be put forward during that time. While there had been criticism of psychiatry before this, the ideas of antipsychiatry were new in the sense that they presented a fundamental critique of psychiatry from a philosophical and political perspective [5]. They became popular and influential and converged with many of the wider changes in social attitudes and behavior that occurred during the 1960s.

Although he personally rejected the label of “antipsychiatry,” a leading figure in this movement was the psychiatrist, Thomas Szasz. In his numerous publications, Szasz argued that the concept of mental illness is a myth or a “metaphor.” He maintained that illness and disease were concepts that were rooted in the body and that a mind can therefore only be “sick” in a metaphorical sense. With physical diseases there are characteristic pathological findings or objective signs. In contrast, mental illnesses are ascribed on the basis of behaviors that deviate from social norms. Diagnosis of mental disorder is therefore an inherently subjective process, involving normative judgements that will vary depending upon the particular social and cultural context. Szasz’ first book was a case study of the diagnosis of hysteria [23], but he applied his ideas across the broad array of psychiatric conditions that were at one time referred to as “functional” [25]. Regardless of findings of some group-level biological features (such as larger brain ventricles and smaller brain volumes in the case of people diagnosed with schizophrenia<sup>1</sup>), major mental disorders like schizophrenia are still diagnosed on the basis of behavioral criterion and hence are still defined

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<sup>1</sup> Recent research suggests these differences are caused largely, if not wholly, by antipsychotic treatment [8, 12].



by deviation from social and ethical norms. If specific and consistent neuropathology is uncovered, Szasz argued that the condition would cease to be a “mental illness” and would become a neurological condition instead.

Szasz was a long-time, passionate advocate of the complete abolition of involuntary psychiatric hospitalization and treatment. For Szasz, what we refer to as mental disorders are situations that arise from conflict between the individual at the center of concern and the demands of society or the person’s social network. Psychiatry is thus a “moral and social enterprise” dealing with “problems of human conduct” [24, p. 47]. Medicalizing these situations denies people their rights to freedom from incarceration and interference and hence psychiatry functions as a form of social control.

The Scottish psychiatrist, R.D. Laing, is another key figure in the antipsychiatry movement. Laing’s main concern was to render the symptoms and behaviors associated with mental illness as meaningful experiences, not merely as the products of pathological processes. His first book, *The Divided Self*, is a detailed examination of how the “symptoms” of long-term, institutionalized patients could be understood with reference to their personal histories and circumstances [13]. His later work is a celebration of the experience of psychosis and its possibilities for expanding consciousness and transcending the alienation of everyday life [14]. Laing’s ideas were popular in the countercultural movement of the 1960s and 1970s, and antipsychiatry’s antiestablishment and anti-authority inclinations were consistent with the aims of civil rights movements of the same period.

The antipsychiatrists have been criticized from many different perspectives, and their popularity and influence have declined since their heyday of the 1960s and 1970s. Philosophers and psychiatrists have defended the notion of mental illness, sometimes by pointing to the difficulties of defining physical illness. Others have accused the antipsychiatrists of giving fuel to right wing political imperatives to cut spending on mental health care. However, the ideas of antipsychiatry were influential far beyond psychiatry and were taken up by the media, the arts, and the political and social

sciences [5]. Within psychiatry, their influence and popularity elsewhere presented a challenge to the psychiatric establishment. It has been suggested that the shift toward a more biologically based psychiatry that has occurred since the 1980s represents a tactical response to this challenge [26].

### *Alternative Services*

In addition to their intellectual critiques, antipsychiatry figures as well as others established projects offering alternative forms of management of the mentally disordered. In 1965, Laing and colleagues set up the Philadelphia Association, a charitable trust that ran a number of therapeutic communities, the first being Kingsley Hall in London. The principle of these communities was that people with psychosis should be encouraged to live through their psychotic episode with the hope that this would lead to an enlightened recovery. There was also an emphasis on breaking down distinctions between staff and patients.

In Italy, psychiatrist, Franco Basaglia, established an organization called *Psichiatria Democratica*. This group successfully campaigned for the passage of a law that shuttered all psychiatric hospitals in Italy. Loren Mosher, an American psychiatrist, set up the Soteria project in the 1970s which was designed to treat people with severe psychotic illnesses in a small therapeutic environment with no or minimal psychotropic drugs. He conducted a randomized controlled trial of the project comparing it to routine care in a hospital ward [17]. While the original project is no longer operative, other similar projects have been developed in the United States and elsewhere.

### *Postmodernism*

Postmodernism and the work of Michel Foucault, in particular, also provided a critique of psychiatry and its relationship with madness. Foucault traced how attitudes to madness were transformed over the seventeenth and eighteenth centuries

in response to the Enlightenment, the emergence of Protestantism, and the beginnings of capitalism. As industrial society started to emerge, rationality was valued above other attributes; hard work and discipline became economically imperative. Whereas in earlier times madness was respected as having social or spiritual significance, with the rise of reason, madness was stripped of its meaning and the mad started to be confined and corrected. During the nineteenth century, this system was overlaid with science, disguising its fundamentally moral or political nature [10].

Foucault's work on madness and psychiatry was part of his wider endeavor to uncover the development of methods of control and authority in modern societies. Over the last two centuries, the belief has emerged that social problems and conflicts can be effectively dealt with by experts implementing technical solutions. Handing over these problems to professionals allowed modern governments to shed some of their thorniest problems and to present themselves as more liberal than they might otherwise appear. It was the government, for example, not psychiatrists, which took the leading role in medicalizing the legal processes surrounding psychiatric confinement in England in the twentieth century [16].

Psychiatrists Pat Bracken and Phil Thomas from the United Kingdom have applied Foucault's insights to modern-day psychiatry to highlight the dehumanizing aspects of its technological orientation. They argue for greater involvement of people who have been labeled as "mentally ill" in determining both the nature of mental health problems and the sort of responses that would be helpful [2].

### *Marxist Theory*

Marxist theory has also inspired critiques of psychiatry. Some antipsychiatry figures, such as South African psychiatrist, David Cooper, who coined the term "antipsychiatry," identify themselves as Marxists. Marxist scholarship highlights how institutions like psychiatry support the status quo by providing a disguised form of social control by medicalizing and

thereby individualizing social and economic injustices [4]. These writers have also highlighted the role of psychiatry in its alliance with the pharmaceutical industry in supporting recent trends toward market liberalization and social inequality referred to as “neoliberalism.” The expansion of psychiatric diagnoses and increasing use of psychiatric treatments such as antidepressants encourages a consumerist attitude to discontent that diverts attention from profound social and political changes that are likely drivers of distress [4, 6].

### *The Service User Movement*

At this same time, as the civil rights movement gained momentum, former mental patients fought for their rights and many of them became vocal critics of the profession which had forced both hospitalization and drugs on them. In Britain, groups such as the Federation of Mental Patients Union campaigned against compulsory treatment and the over use of psychiatric drugs. In the United States, groups such as Mind Freedom followed a similar agenda.

Other groups such as MIND in the United Kingdom, National Association on Mental Illness, and National Mental Health Association in the United States, while less critical of the medical model, campaigned for improved services for people with mental health problems. In recent years, groups of service users have focused on the nature of treatment and services offered while challenging some core premises of modern psychiatry. The recovery movement arose as a direct challenge to the psychiatric conceptualization of schizophrenia as an inherently chronic and debilitating condition. This concept was bolstered by research from Courtenay Harding and others which revealed that the long-term outcomes for individuals deemed to be most ill and impaired were far better than the Kraepelinian model suggests [11]. Taking control over one’s mental health problems is a central part of the recovery philosophy. Writers who have experienced mental health problems themselves have been leaders of this movement and have emphasized the importance of making

shared decisions and respecting the values of the individual who is receiving treatment even if those values do not fully align with those of the clinician [7].

Increasingly, those with lived experience have emphasized the important contributions they can make to guiding others toward their own recovery. Recently, the concept of “recovery” which was initially meant to challenge the notion that many individuals would be indefinitely afflicted, is itself under scrutiny since it can imply an implicit acceptance of the medicalization of human distress. Approaches have been designed both in conjunction with and independent of the traditional system. The Hearing Voices Movement is an international organization that evolved through partnership between a psychiatrist and one of his patients. Hearing Voices groups seek to provide a space where service users can meet, find out about others’ experiences, and use these as the basis for mutual understanding [19]. Intentional Peer Support is another approach that was designed by and for peers [15]. It emphasizes working from a stance of mutuality and respect and places emphases on the value of being open about one’s own experiences as a way to meet people in a more democratic way.

### *The Critical Psychiatry Movement*

In the last few decades, working psychiatrists with a variety of critical perspectives have increasingly come together to forge new academic critiques and to consider issues relating to clinical practice. In the United Kingdom, the Critical Psychiatry Network was formed in 1998. The Network now hosts a large and robust list serve, holds conferences, and participates in national political initiatives at government and grassroots level. Many members write texts for both academic and lay audiences.

Critical psychiatry is distinct from antipsychiatry in that its practitioners generally accept the need for services of some description to support people with mental health problems and have been involved in a wider dialogue about how psychiatric practice needs to change to reflect challenges from the intellectual critiques and the service user movement.

## Conclusion

How does a practicing psychiatrist make sense of the current situation in which the dominant paradigm of modern psychiatry and the critical reflections on it seem so much at odds? Medical students who chose to specialize in psychiatry enter the profession with varying levels of exposure to these critiques. Some begin with a sophisticated grasp of critical ideas; in fact this familiarity might have drawn them to the profession. Others may enter with a curiosity based upon their experiences in medical school and may be relatively naïve to the controversies. Some come to this field because of their own or family members' encounters with psychiatry, and those experiences influence how they think about the field in both positive and negative ways. Some align with those who want change and others want to emulate the care provided to them or loved ones. However, while it is unusual among other medical specialties to have protestors at professional meetings, this is not uncommon for psychiatry. At some point, a psychiatrist will be exposed to the profession's critics and will develop some personal perspective about them.

Among the antipsychiatry, Marxist, and service user movements, the most extreme critics of the field are abolitionists – they want to end what they consider the scourge of psychiatry. They often blame psychiatry for the problems it purports to address, and some deny that there is a need for any service aimed at what we currently designate as “mental disorder” [3]. Other critics believe that psychiatry addresses real social problems but that the current system that considers these as medical disorders is wrought with contradictions and dangers. The primary target of this book is the growing group of psychiatrists who believe that while there is a need for a professional service for people who are referred to as “mentally ill” that would include elements of medical practice, the current system is deeply flawed. Thus, they seek ways to practice with an appreciation of critical perspectives.

If one accepts some elements of existing critiques of psychiatry, it raises a serious quandary for a conscientious doctor. Psychiatrists make decisions that have enormous effects on

people's lives. Psychiatrists determine who can be forced into hospitals, deprived of their liberty, and have their bodies altered by drugs and other procedures (like electroconvulsive therapy) against their will. In an increasing number of jurisdictions, outpatient commitment or community treatment orders give psychiatrists the authority to force someone to take medication against their will, even when the individual has the capacity to live independently. Psychiatrists are considered experts in the legal arena where decisions regarding competence to stand trial and responsibility for criminal actions are determined. When fundamental aspects of psychiatric practice are questioned, critical psychiatrists need to ask if and when it remains ethical to use psychiatric authority to determine who can be forced into treatment and who can be held responsible for a crime. Even in less fraught situations where people voluntarily seek consultation, critical psychiatrists may also question how to approach discussions about the nature of their problems and possible solutions, including the use of drugs and other medical interventions. In the chapters that follow, the authors address these dilemmas.

## Book Chapters

Chapter 2 addresses the limitations of the current diagnostic system, but, more importantly, the authors call for the need for conceptual competence and suggest what they call an “ecological approach” to the various critiques of our diagnostic systems. This is a helpful clarification of what can seem like a cacophony of criticism. They make a compelling argument that this framework will help to “facilitate discussion about solutions for reform.”

Chapter 3 provides an overview of the influence of pharmaceutical companies on the knowledge base of psychiatry. The authors, who have done extensive research in this area, discuss the many conflicts of interest in the field and how they have led to distortions in our understandings of the effects of therapeutic agents. They discuss this within the framework of “institutional corruption” and elucidate ways that the profession can work to better inoculate itself from these influences.

Chapters 4, 5, 6, and 7 offer suggestions for how, when one accepts the critiques, one might continue to practice with integrity. In Chap. 4, Dr. Moncrieff elaborates on the concept of a drug-centered vs. disease-centered approach to pharmacotherapy. She explains what these terms mean as well as the implications of adopting one approach rather than the other. She argues that a drug-centered approach has many advantages for the profession and, most importantly, for people who take these compounds.

In Chap. 5, Dr. Steingard expands upon Dr. Moncrieff's formulations to propose a more modest approach to the use of psychoactive drugs.

In Chap. 6, the discussion of optimal prescribing practices is extended to a review of the concept of "deprescribing." Initiated in geriatric medicine, deprescribing acknowledges that polypharmacy carries risks and that many people end up taking multiple drugs over time without adequate attention to whether the accumulated risks outweigh benefits. Drs. Gupta and Miller offer guidelines for deprescribing in psychiatric practice.

Chapter 7 addresses the major concerns of coercion in psychiatry and asks the question whether, given all that we know about the potential harms of some forms of psychiatric treatment, it is ever ethical to force people into treatment. This is written from the perspective of clinical psychiatrists who work in settings where they confront daily the risks of the behaviors with which psychiatric problems can be associated. The authors discuss how to balance those concerns with the risks and damage – often minimized by our colleagues and in standard practice guidelines – associated not only with some recommended treatments but also by the act of coercion itself.

Chapter 8 offers the perspective of those who have experienced psychiatric treatments and are now working to reform the system. The author uses the Mad Pride movement and neurodiversity as examples of alternative perspectives that do not insist on the acceptance of a pathologizing framework for understanding human distress. Acknowledging and reckoning with the perspective of those who have been the recipients of psychiatric labeling and treatment is one of the most important aspects of embracing a critical stance in psychiatry.



The book concludes with suggestions of how to integrate these ideas. Open Dialogue and related practices that are less hierarchical than the more traditional expert-driven medical-model approach, respect the importance of the social context, and value the voice of the person at the center of concern are introduced. We argue that these are practices that allow psychiatrists to embody principles of recovery-oriented care as well as the humility our profession demands.

If the field of psychiatry is to change, critical psychiatrists can help to shape its future. This book is intended as a guide for those psychiatrists who understand that radical and fundamental reform is imperative and are struggling with how to incorporate transformational strategies into their clinical work.

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# Chapter 2

## Toward Conceptual Competence in Psychiatric Diagnosis: An Ecological Model for Critiques of the DSM



**Justin M. Karter and Sarah R. Kamens**

*... without measuring reality against the wholly invented world of the unconditioned and self-identical, without a constant falsification of the world through numbers, people could not live.*

Friedrich Nietzsche, *Beyond good and evil*, p. 7

*The order that our mind imagines is like a net, or like a ladder, built to attain something. But afterward you must throw the ladder away, because you discover that, even if it was useful, it was meaningless.*

Umberto Eco, *The name of the rose*, p. 492

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## Introduction

Dissatisfaction with the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), once an exception within mainstream clinical literature, has become a new kind of norm in recent decades. Critiques of the DSM, now in its fifth edition [4], have been put forward by psychiatrists, psychologists, and other scholars from across the sciences and humanities, as well as by service users, families, and diverse stakeholder groups. Researchers and scholars of diverse theoretical orientations have questioned the taxonomy on various grounds, including its potential and actual effects on social systems and individuals, flawed scientific and methodological assumptions, and implications for clinical practice and research agendas. Others have raised philosophical and empirical questions concerning the classification of “mental disorders,” and the role of labeling in social processes. Here, in order to understand the multiple levels on which the DSM-5 has been critiqued, we apply an ecological systems model and attempt to synthesize a range of perspectives. Finally, we consider the ways in which critiques of DSM-5 have been used to promote new diagnostic taxonomies (e.g., the Research Domain Criteria [RDoC] project of the National Institute of Mental Health) as well as the ways in which an ecological model might be applied to future diagnostic paradigms.

## Brief History of the Response to the DSM-5

This chapter owes a great deal to the influx of writing on these issues that accompanied the development, release, and implementation of DSM-5. Indeed, both authors were profoundly influenced by debates about the manual at critical points in the course of doctoral training and professional development. As a result, it is important to attempt briefly to situate this chapter within the context of those DSM-5 controversies [91].

There are several strands to the movement to critique and reform DSM-5. Three groups that played a large role in the

effort were dissenting psychiatrists, led by Allen Frances and Robert Spitzer; the British Psychological Society, and humanistically oriented psychologists, social workers, and mental health professionals in the Society for Humanistic Psychology (SHP; American Psychological Association Division 32). The disputes over the DSM-5 cannot be reduced simply to a conflict between psychologists and psychiatrists, although some have tried to frame them this way [131]. To this point, over 29 psychiatrists co-authored an article expressing their concerns about the manual in the *British Journal of Psychiatry* in December of 2012 [14]. Further, two of the most vocal critics of the DSM-5, Allen Frances and Robert Spitzer, are well-known and prominent psychiatrists who led the creation of the DSM-4 and DSM-3, respectively.

In 2011, the British Psychological Society (BPS) issued a statement in response to the APA draft diagnostic criteria for the DSM-5. Inspired by the BPS statement, David Elkins, who was SHP President at the time, established an “Open Letter” Committee (later the International DSM-5 Response Committee). The Committee, which included Brent Dean Robbins, then the SHP Secretary, drafted the *Open Letter to DSM-5* [93], which publically critiqued the proposals for the manual and asked other professionals to express their concern by signing. The letter was posted on an online petition, and over 15,000 people, many of them mental health professionals, signed the letter; it was also endorsed by over 50 mental health organizations, including 16 divisions of the American Psychological Association. The letter focused on the lowering of diagnostic thresholds, risks to vulnerable populations, socio-cultural variation, and a departure from theoretical “agnosticism” through an explicit emphasis on neo-Kraepelinian theory. The letter concluded by voicing agreement with several statements in the BPS letter, including the concern that

... clients and the general public are negatively affected by the continued and continuous medicalization of their natural and normal responses to their experiences; responses which undoubtedly have distressing consequences which demand helping responses, but which do not reflect illnesses so much as normal individual variation. [93]

The eminent psychiatrist and chair of the DSM-4 task force, Allen Frances, supported the petition and credited it with summarizing “the grave dangers of DSM-5 that for some time have seemed patently apparent to everyone except those who are actually working on DSM-5” [56, para. 2].

The DSM-5 Open Letter led to a conversation between the SHP and the American Psychiatric Association (APA) that resulted in two additional SHP letters to the DSM-5 task force, reiterating concerns and calling for an independent review of the proposed manual. That conversation is currently archived at <http://dsm5-reform.com/the-conversation/> and summarized in Robbins, Kamens, and Elkins [93]. Corresponding to the publication and release of the DSM-5 in 2013, influential medical journals, including *The Lancet* and the *British Medical Journal*, ran editorials that covered the controversies surrounding the manual. Following the publication of the DSM-5, the BPS Division of Clinical Psychology issued a position statement calling for a “paradigm shift” away from the disease model of mental disorders inherent in the DSM-5 [16]. Also in 2013, SHP established the Global Summit on Diagnostic Alternatives (GSDA), which began as an Internet-based forum for discussing the DSM-5 and offering alternatives, and progressed to a meeting coinciding with the 2014 American Psychological Association meeting in Washington, DC. Under the SHP Presidency of Brent Dean Robbins, GSDA and the International DSM-5 Response Committee (which eventually became the SHP Task Force on Humanistic Alternatives to Psychological Diagnosis) expanded its focus to include alternatives to the DSM/ICD model. The online version of GSDA concluded in 2015 and is archived at [dxsummit.org](http://dxsummit.org).

## Structural and Conceptual Competence

In light of these debates, more attention has been given to the training necessary for mental health professionals to engage with the DSM-5, and psychiatric diagnosis more broadly, in a

responsible, thoughtful, and ethical manner. New training models calling for *structural competency* in psychiatry present one such attempt to create goals and standards. Structural competency involves the development of an in-depth and probing awareness of the ways in which social, institutional, and political disparities shape clinical interactions (including diagnosis), access to healthcare, and health-promoting resources [78]. For example, institutional racism and a history of societal oppression are two structural factors posited to underlie higher rates of the “schizophrenia” diagnosis in African American men [124]. Recent large-scale epidemiological work using data from 50 countries [87] has suggested that there is a strong relationship between psychosis and economic inequality, even when controlling for per capita income, regime type, and years of democracy. Metzl and Hansen [123] identify four benchmark skills for structural competency that can also be applied as standards in preparing clinicians and researchers for responsible use of the DSM. These include “recognizing the structures that shape clinical interactions,” “rearticulating ‘cultural’ formulations in structural terms,” “observing and enacting structural interventions,” and “developing structural humility.”

In order for researchers, mental health workers, psychologists, and psychiatrists to ethically engage with any psychiatric taxonomy, “critical consciousness” is necessary [105]. Structural competency goes a long way toward the development of “critical consciousness,” but we argue that *conceptual competency* is also necessary. As Marecek and Gavey [120] write:

When we teach about psychodiagnosis, we can also teach about the historicity of categories of psychological disorder and of psychological knowledge more generally. We can also discuss with clinical trainees how the workaday language practices of mental health professionals ... tacitly reaffirm the subordination of patients and uphold institutional power. (p. 7)

To responsibly utilize (or choose not to utilize) the DSM-5, a researcher or clinician should be equipped to consider potential effects of the diagnosis on a client or patient, technical

issues in testing of the diagnostic construct, major institutional players that have stakes in the definition of the disorder and its codification in the manual, broader social and political concerns about the use of particular diagnoses to disadvantage certain groups, and contemporary debates concerning the relationship between the brain and an individual's experiences, thoughts, and behaviors. The ecological approach to critiques of the DSM-5 presented here offers a framework for teaching and developing such "conceptual competence" in psychiatric diagnosis.

## Ecological Approach to Critiques

Our ecological approach (see Fig. 2.1) proceeds from macro-level critiques (epistemological problems such as the empirical and conceptual status of diagnosis) through exo-level critiques (broad structural and sociocultural concerns such as the role of the DSM-5 in neocolonialism and neoliberalism), meso-level critiques (concrete institutional and societal controversies such as the influence of pharmaceutical companies on diagnosis and treatment), microlevel critiques (specific historico-scientific events such as technical flaws in the manual's revision process), and finally ends with individual-level critiques (potentially iatrogenic effects on individual persons such as the nocebo effect). This ecological meta-classification is intended to illuminate the ways in which potential diagnostic reforms leveled at specific issues in the construction and/or application of the DSM-5 may be strengthened by consideration of critiques at other levels.

While this chapter deals with overarching critiques of the DSM as a diagnostic system, and not critiques of the individual diagnoses that it contains, it is important to recognize that any one argument may not apply equally to diagnoses as diverse as autism spectrum disorder, insomnia, pica, and post-traumatic stress disorder (PTSD) [9]. Critiques of individual diagnostic categories, although beyond the scope of this manuscript, are abundant in the scholarly literature [112, 159, 178].



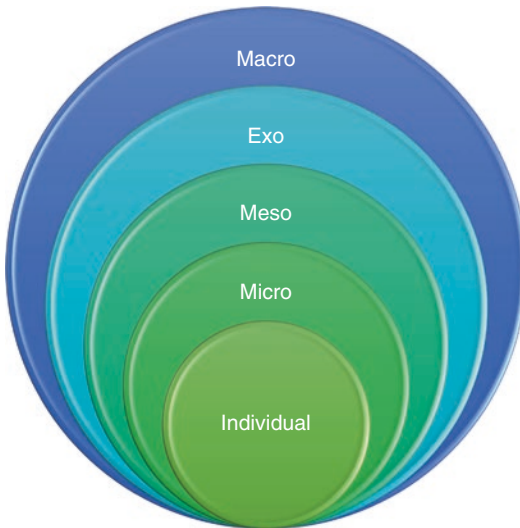


FIGURE. 2.1 An ecological model

## Macro-level Critiques

Macro-level critiques of psychiatric diagnosis in general, and the DSM in particular, question both the ontological and epistemological foundations of the psy-taxonomic project. *Ontology* refers to the nature of being or existence and here pertains to the issue of whether and in what ways the diagnostic entities or spectra that comprise psychiatric taxonomies *exist* as biological, social, cultural, and/or otherwise theoretical entities. Epistemology refers to theories of knowledge and here includes arguments concerning how researchers, practitioners, and others *know* anything about mental disorders if they do exist. Therefore, macro-level critiques ask ontological questions about the relationship between the brain and mind, the validity of categories attempting to reflect human experiences [43, 137], and whether mental disorders can be understood to exist within an individual person. Macro-level critiques also ask epistemological

questions concerning the role of historical, cultural, and social processes in our understanding of these categories as well as how to draw conceptual or nomenclatural lines between normality and pathology.

### *Ontology: Biological Reductionism and the Explanatory Gap*

Perhaps the most common macro-critique of the DSM involves the biological reductionism inherent in the manual. Although DSMs III and IV (1980 and 1994, respectively) took a putatively “atheoretical” approach to etiology, the neo-Kraepelinian ideology on which their criteria were based was characterized by the presumption that descriptive taxonomy would eventually lead to the discovery of biomarkers, or clear boundaries between disease entities [25, 147]. Biological reductionism refers to the view that the subjective experiences associated with a psychiatric diagnostic category have a one-to-one relationship with underlying biological and neurological mechanisms and, going further, that uncovering these mechanisms is imperative to the treatment of mental disorders [98, 163]. The privileging of biological explanations risks ignoring problems that are best understood at a psychological and sociological level. When the larger mental health discourse involves frequent descriptions of diagnoses such as major depressive disorder (MDD) as “brain disorders” [134, 152, 191], we risk ignoring or discounting the considerable evidence suggesting that these disorders are strongly correlated with psychological and sociological factors [3, 24].

With advancements in neuroscience and molecular biology in mind, leaders in the field of psychiatry have called for research linking DSM diagnoses with what are assumed to be underlying neurobiological markers. For example, the preface to the DSM-5 explains that the manual was revised through the “integration of scientific findings from the latest research in genetics and neuroimaging,” in order to “improve clinicians’ ability to identify diagnoses in a disorder spectrum based on common neurocircuitry, genetic vulnerability, and

environmental exposure” [4, p. xlii]. However, the claim that subjective experiences of distress can be pathognomonically linked to measurable and observable neurobiological phenomena has been a subject of considerable debate and criticism. While scholars in the philosophy of psychiatry, philosophy of psychology, and philosophy of mind continue to engage these questions from a variety of perspectives [68, 168, 169], we aim here to illuminate only a minimum number of points to highlight the unsettled ontological foundation of reductionist biopsychiatric approaches to nosology; put simply, that mental illnesses represent underlying brain malfunctions.

Attempts to link the mental disorders captured in the DSM-5 to neurobiology inevitably run up against what philosophers refer to as “the hard problem of consciousness” and the “explanatory gap” [22, 115]. The “gap” is between physical processes (matter, the brain, etc.) and consciousness or subjective experience (also referred to as *qualia*). DSM diagnoses are largely based on self-report and behavioral observations that describe categories of mental, “first-person, subjective experience, such as mood, perception, and cognition,” [135] and are often termed *phenomenal* [97]. Therefore, any attempt to explicitly ground such diagnoses in neurobiology must wrestle with philosophical questions concerning the connection between the physical process and the phenomenal, conscious, subjective experience – between the brain and the mind.

The view that the brain/body and mind are distinct entities, commonly referred to Cartesian dualism, is itself a matter of significant debate with a diverse set of responses that are beyond the scope of this chapter. However, for our purposes it may suffice to point out that if one takes the position that Cartesian dualism is false and that there is a one-to-one or type-type relationship between neurobiological processes and conscious experience (as the DSM has historically functioned to support), then “the declaration that a particular psychiatric disorder is biological is a tautology and is as informative as saying, ‘This circle is round’” [97, p. 434]. Presumably, this would indicate that all positive or healthy experiences

were also the product of particular neurobiological processes. That is to say, the claim that all mental processes are inextricably linked to brain processes does not necessarily suggest that deviations in behavior and mental experience within a specific environment are best explained at the level of biology. Indeed, there is substantial evidence for the effect of both environments and subjective experiences (e.g., trauma) on brain processes (for philosophical discussion of the causal role of mental events, see [11]).

As evinced here, the connection between descriptions of subjective states and the brain is a matter of substantial philosophical debate. Psychiatric diagnoses, however, are complicated further by the fact that they attempt to operationalize descriptions of subjective experiences and group them together into disorders based on common symptoms. It is perhaps even more dubious to suspect that categories based on checklists of such decontextualized symptoms, themselves fashioned by committees, would map onto distinct brain processes. Put another way, it is not obvious that nature will correspond with classifications constructed by people, reflecting sociocultural-historically situated values concerning normality and mental health (more on these epistemological issues below). Indeed, this problem is at the heart of the National Institute of Mental Health (NIMH) decision, under the leadership of former director Tom Insel, to move away from the use of DSM categories in research. Insel explained that the DSM manual is limited by its “lack of validity” as “DSM diagnoses are based on a consensus about clusters of clinical symptoms, not any objective laboratory measure” and added that the exploration of the biology of psychiatry cannot succeed if it is “constrained by the current DSM categories” [86]. However, Insel’s Research Domain Criteria (RDoC) initiative [10], offered as an alternative paradigm for psychiatric research, doubles down on biological reductionism and has also faced criticism for failing to address the explanatory gap (see, e.g., [101, 136]).

Here we arrive at one intersection of ontological and epistemological critiques of psychiatric diagnosis. That is, even among supporters of the ontological position that psychiatric

disorders exist in reality as brain diseases, there is disagreement over whether the taxonomic approach of the DSM-5 is capable of adequately capturing or pointing to those underlying diseases. This problem is evident in the question that often arose during DSM-5 debates of whether the manual is capable of “carving nature at its joints” [129, p. 68].

### *Epistemology: Measuring Madness*

Issues of ontology and epistemology in psychiatric diagnosis are distinct but necessarily intertwined. For example, if one begins from the ontological assumption that psychiatric disorders do not exist as entities in the world apart from our observation and interpretation, then it would be difficult to accept an epistemological approach that claimed that such disorders could be fully identified, isolated, and empirically measured by medico-biological tests. Conversely, even if one begins from the ontological assumption that psychiatric disorders exist in reality as diseases of neurobiology, others still question whether measurements and observations of neurobiological processes alone can escape the epistemological problems presented by the role of consciousness and subjectivity in the formation of knowledge. For example, in “Simplification in Scientific Work: An Example from Neuroscience Research,” Star [162] demonstrates how the complexity of the brain is filtered first through the perceptual apparatuses of the scientists (such as the maps and names used to describe brain regions and processes) and then through a variety of pragmatic and technical constraints. In this way, scientific knowledge about a complex system undergoes a simplification process, reflecting the social context in which it was produced [162]. In short, what you think a mental disorder is reflexively affects how you think it can come to be known, understood, or measured [128].

Allen Frances, the chairman of the DSM-4 task force and a frequent critic of the DSM-5, has offered a useful tool for illustrating the various ontological and epistemological positions that critics have taken in regard to psychiatric diagnosis.

In the midst of the DSM-5 debate, Frances offered the metaphor of the “Five Umpires of Epistemology” as an attempt to structure debate and advocacy efforts among critics of the new manual. Addressing the question of whether DSM diagnoses should be treated as social constructs or medical diseases, Frances asked respondents where they fell in reference to five different positions: “Umpire 1) There are balls and there are strikes and I call them as they are; Umpire 2) There are balls and there are strikes and I call them as I see them; Umpire 3) There are no balls and there are no strikes until I call them; Umpire 4) There are balls and there are strikes and I call them as I use them; Umpire 5) Don’t call them at all because the game is not fair” [140].

Each umpire corresponds to a particular understanding of the nature and measurement of mental disorders. Fig. 2.2

5 Umpires Analogy		Philosophical position
Ontology (existence/being)	Epistemology (knowledge)	What you think a mental disorder is will affect how you think it can be known
<i>What is mental disorder?</i>	<i>How can we know anything about them if they do?</i>	
1) There are balls and strikes (realist)	1) I call them as they are (realist)	<b>Strong realist:</b> Mental disorders exist as abstract entities and we can detect them accurately
2) There are balls and strikes (Kantian realist)	2) I call them as I see them (weak constructionist)	<b>Nominalist:</b> Mental disorders are out there but not sure if diagnoses correctly sort them out (“carve nature at its joints”)
3) There are no balls and strikes (antirealist; normitivist)	3) Until I call them (strong constructivist)	<b>Constructivist:</b> Mental disorders are constructs and have “uncertain ontic status apart from persons who instantiate them” (p. 7) and attempts at description create ways of seeing
4) There are balls and there are strikes (realist)	4) I call them as I use them (pragmatist)	<b>Pragmatist:</b> Mental disorders exist in nature and we create and use diagnoses that do the most good and least harm
5) The game is not fair and I will not play (Szazian)		<b>Szazian:</b> Mental disorders are a means of social control and to talk about them legitimizes their authority

FIGURE. 2.2 Developed based on the 5 umpires analogy presented by Allen Frances

breaks apart the ontological and epistemological positions of each umpire. The first umpire (“There are balls and there are strikes and I call them as they are”) expresses the view often attributed to biological psychiatry that mental disorders are real, exist independent of our subjective experience of them, and can be accurately discovered through empirical study. Despite the advances of neurosciences, Frances admits that this view is “now widely recognized to be a misleading and reductionistic simplification” [63, p. 112].

Frances himself endorses the second umpire (“There are balls and strikes and I call them as I see them”; [62]). Umpire 2 similarly believes that mental disorders are the result of neurobiological processes that exist “out there” but doubts the epistemology of umpire 1. In contrast, umpire 2 doubts the ability of diagnostic constructs to “carve nature at its joints” and sees diagnoses as useful heuristics that through time come to more accurately approximate the boundaries of the “actual” psychopathology as it exists in nature. While this view, which Frances refers to as the “nominalist” position, may be the “consensus of most serious students of mental illness” [63, p. 113], it relies on a “view from nowhere” [130], effectively leaving the “mind” out of mental disorders. Indeed, in a paper on “The nature of psychiatric disorders” [96], Kendler explains that the position that mental disorders exist apart from our naming and observing them depends on a “mind-independent space” [96, p. 5]. The nominalist position involves “explanatory dualism” by assuming a first-person perspective for the psychiatrist but a third-person perspective for mental disorders [95].

The third umpire (“There are no balls and strikes until I call them”) agrees with the second that psychiatric diagnoses are social constructs but, going further, denies that it is possible to say that mental disorders exist “apart from persons who instantiate them” [140, p. 7]. Critical social scientists, including many feminist psychologists [105, 122, 170, 171, 174, 175], have similarly challenged the neo-Kraepelinian ontological assumption, baked into the DSM, that psychiatric diagnoses are predominantly neurobiological phenomena that exist apart from history and culture. To the contrary,

these social theorists have demonstrated that the approach to understanding mental disorders implicit in the DSM-5 necessarily implicates the social, cultural, historical, and political contexts in which they arise and are applied in clinical practice. The third umpire, taking a constructivist epistemological stance, also understands the act of creating diagnostic categories to affect what is seen or made salient in social interactions, thus generating the “disease” it is meant to define. For example, the philosopher Ian Hacking argues that the creation of psychiatric diagnostic categories and the power that they take on in the public discourse, as well as the reflexive or “looping” role they play in the self-narratives of those diagnosed, serves to attenuate the experiences and expression of suffering and distress [74–76]. Thus, the reification of mental disorders in common language alters how people experience one another and make sense of their own experiences, effectively bringing mental disorders into existence.

The fourth umpire (“There are balls and there are strikes and I call them as I use them”) takes a realist approach to the ontology of mental disorders like umpires 1 and 2 but adds a pragmatic epistemological view. In this position, mental disorders exist “out there” but are imperfect constructs that should be constructed to maximize their utility. Like the second umpire, the pragmatist is not confident that diagnostic constructs effectively “carve nature at its joints” but, instead of attempting to map these constructs onto the ever-elusive underlying psychopathology, this umpire argues that they should be defined and applied toward the goal of being useful. This approach proves difficult to implement, however, as there may be different opinions on what is in the best interest of an individual patient, let alone what is best for all psychiatric patients or society more generally. Indeed, DSM categories do have profound implications for “who gets diagnosed, how they are treated, who pays for it, whether disability is appropriate, and whether someone can be involuntarily committed, released from legal responsibility, or sue for damages,” [63], but the fourth umpire may defer these questions to a utilitarian risk-benefit analysis that allocates this power



to those in positions of authority, rather than the service users themselves. In the past; such an approach may have justified the inclusion of homosexuality in the diagnostic manual, and it is not clear how this perspective would prevent such mistakes, based on prevailing cultural prejudices, from reoccurring in the present or the future. Of course, more nuanced and subtle forms of this position are possible. For example, the psychologist Peter Zachar sets out a radical empiricist and instrumental nominalist perspective of scientifically inspired pragmatism in his book *A Metaphysics of Psychopathology* [194]. This position posits that we only know what we observe (radical empiricism), that there are concepts that might not be perfectly delineated but nevertheless helpful (instrumental nominalist), and we use them to do the work we need to do (scientifically inspired pragmatism).

Finally, the fifth umpire (“The game is not fair and I will not play”) rejects the game, as it is rigged from the start, and, as the saying goes, takes the ball and goes home. The fifth umpire was created to accommodate the Szaszian position that mental disorders do not exist and that they are created to reinforce social conventions and standards of normality, often entailing the loss of legal rights and personal autonomy of those so labeled [167]. This view sees the medical model as an inappropriate tool for understanding human struggles and problems of living. Umpire five might also be said to represent alternative and grassroots perspectives to mental distress that have emerged outside of the mainstream mental health model, including the psychiatric survivor, ex-patient, neurodiversity, and Mad Pride movements [1, 51, 153].

The five umpires present a useful heuristic for presenting an introduction to the various philosophical viewpoints undergirding the macro-level critiques of the DSM-5. Although there are certainly ontological and epistemological approaches that do not fit Frances’ metaphor, we will not review them in detail here, instead taking a somewhat pragmatic approach to this chapter. The macro-level critiques of psychiatric diagnosis outlined above inform all of the critiques presented at subsequent levels in the ecological model.

As we have seen, disagreements about individual diagnoses and appropriate treatments often begin from fundamentally different philosophical assumptions about the ontology and epistemology of mental disorders. It is our hope that by situating these debates within an ecological model, service users, students, and professionals engaging in these debates can more readily locate the level at which their disagreement originates, thereby helping to facilitate discussion and clarify points of real disagreement.

## Exo-level Critiques

Once the realist epistemological position of the first umpire is rejected, as Frances claims has been done by the vast majority of professionals, the division between the scientific and the political breaks down. Indeed, if diagnostic categories are not simply ever-closer approximations of underlying biological reality, then they are vulnerable to being socially constructed in such a way that they reproduce or even create systemic biases. Kendler articulates the historical nature of DSM diagnoses clearly, writing:

Much of our current nosology arose from a series of historical figures and events which could have gone differently. If we re-run the tape of history over and over again, the DSM and ICD would not likely have the same categories on every iteration. Therefore, we should argue more confidently for the reality of broader constructs of psychiatric illness rather than our current diagnostic categories, which remain tentative. [96, p. 5]

What does it mean to say that the mental disorders enumerated in the DSM-5 are historically contingent and vulnerable to social and political influences? For Kendler and other psychiatrists committed to a realist ontology of mental disorders, this means that in the quest to “carve nature at its joints,” social factors enter the debate and disrupt what would otherwise be a “purely” scientific process [96]. Thus, the majority of exo-level critiques begin from the assumption that it is *not* possible to accurately capture the reality of mental disorders through diagnostic constructs and subse-

quently consider the social, historical, cultural, and political implications of this. However, critiques at this level vary considerably in their assumptions about the ontological status of mental disorders while taking disparate, albeit predominantly non-realist, approaches to epistemology. For example, the sociologist Allan Horwitz, in his influential book, *Creating Mental Illness* [82], discusses the problematic construction of normal reactions to adverse circumstances as pathology in the DSM, yet maintains that some mental disorders are valid disorders and stem from an underlying dysfunction. In this way, Horwitz's critique can be understood as pairing a light-realist ontology of mental disorders with a social constructionist epistemology.

Exo-level critiques of the DSM-5 are differentiated from macro-level critiques in that they are less concerned with specifically targeting the "existence" of mental disorders or whether these disorders can be adequately measured or described but instead focus on the ways the DSM-5 categories operate within broader cultural, social, and political processes. Meanwhile, they are differentiated from the next level, meso-level critiques, by their explicit targeting of the ways in which psychiatric diagnoses operate at a sociohistorical and cultural level. The latter targets the function of diagnoses within institutions without necessarily addressing the historical and ideological contexts in which these institutions exist. Critiques at the exo-level can roughly be broken down into two categories: (1) those exploring the impact of social, cultural, and historical factors on how psychiatric disorders are conceptually delimited, defined, and applied, and (2) those investigating how these factors affect the experience and expression of mental distress.

### *The Social Production of Disorders*

The first type of exo-level critiques of the DSM begin from questions about how predominant social, historical, cultural, and political processes affect the development and implementation of the disorders described within the manual. These critiques

problematize what is considered “abnormal” and in need of psychological and/or psychiatric intervention and/or address how the DSM diagnoses are applied within domestic and international populations.

Scholars from various fields in the social sciences and humanities have theorized and researched the process through which certain thoughts and behaviors come to be deemed socially deviant or abnormal within a given cultural and historical context [82]. While this topic is rich and varied, one takeaway for the purposes of this chapter is that thoughts and behaviors are not objectively “disordered,” per se, but first come to be understood and labeled as such through processes of social interaction. It is not inevitable, however, that those who come to be labeled as socially deviant would be understood as possessing a mental disorder, as social systems often have several alternative systems for interpreting and responding to perceived deviance, such as criminalization or ostracization.

The process through which certain thoughts and behaviors come under the purview of psychiatric diagnostic systems is often referred to as *medicalization* [84, 85]. Medicalization involves two assertions: that deviant behaviors are more often conceptualized as medical issues in modern industrial societies [26] and that the boundaries of what is considered an abnormal behavior and in need of intervention, as opposed to a common kind of human suffering, are expanding [83]. Going further, conceptualizing thoughts and behaviors deemed socially undesirable to be medical issues may serve to insulate a cultural or social system from change, as it locates the cause of deviance in nature rather than as a product or failing of the social system itself [146].

This last point raises the question of what larger social patterns might be driving medicalization. A prevailing view among social theorists is that the process of medicalization is one form of social control, as is criminalization, and that it acts to enforce standards of normality among populations [53, 54]. From this vantage point, scholars explore the connections between the medicalization evident in the development and use of the DSM and other/concurrent social and political

issues. For example, Joanna Moncrieff argues that medicalization is consistent with neoliberalism, an ideology that attempts to bring both economic policy and social life under the evaluation of the market [127]. Neoliberalism shifts policies away from social investments and toward privatization and encourages individuals to see themselves as commodities subordinated to market rationality [33, 38]. The medicalizing discourse of the DSM encourages individuals to see themselves as “neurochemical selves,” thinking of “their moods and their ills in terms of the functioning of their brain chemicals” [150, p. 28], and thus prevents these individuals from thinking collectively about the effect of neoliberal policies on their communities and their quality of life. Seen through the lens of medicalization and neoliberalism, the DSM-5 can be understood to contain value judgements about what is healthy or functional that are based on assumptions about what it takes to be successful or productive within the marketplace [45].

Evidence for the effect of social and political processes in psychiatric diagnoses can also be found in the way that DSM categories are applied. Many exo-level critiques of psychiatric diagnosis argue that the disorder categories are often used in such a way as to increase the marginalization, oppression, and disadvantage of individuals and communities based on race, ethnicity, gender, sexual orientation, disability status, and socioeconomic status [16, 19, 28, 183, 185]. For example, many critics point to the diagnoses “homosexuality” and “ego-dystonic homosexuality,” which were included in the DSM until 1978, but effectively lived on as sexual identity disturbance until 1987 [40]. Similarly, LGBTQ+ activist groups have challenged the gender-related diagnoses included in the DSM-4 (gender identity disorder) and DSM-5 (gender dysphoria) which are currently necessary for access to hormone therapy and surgical treatments. Activists have argued that these diagnoses pathologize normal variations of human experience and that related distress results from the social discrimination to which diagnostic labeling contributes [40, 94, 154]. Critics have also challenged the social and political bias in diagnosis evident in DSM-5’s inclusion of premenstrual dysphoric disorder (PMDD), which many argued was a

codification of sexism and gender bias [29, 79, 111], and the addition of minor neurocognitive disorder, which may pathologize normal aging and lacks sufficient data to suggest the diagnosis has value beyond identifying memory-impairment in those who are not demented [138, 180].

In the book *The Protest Psychosis: How Schizophrenia Became a Black Disease* (2009) [124], medical sociologist Jonathan Metzl describes how psychiatric diagnoses can reinforce systems of societal oppression at certain historical moments. Specifically, he explores the connection between race and psychiatry in the USA and documents how racist ideas, like the psychiatric classification of drapetomania [21], which referred to a form of madness attributed to escaped slaves, came to be reproduced in diagnostic definitions of schizophrenia following the civil rights movement in the 1960s. Metzl explains that prior to the civil rights movement white women were disproportionately diagnosed with schizophrenia. By the 1970s, however, the diagnosis was altered and began to be disproportionately applied to African American men – just as medical advertisements and cultural tropes about the diagnosis portrayed civil rights activism as “belligerence” and “aggression” to be quelled with antipsychotic medications. Reflecting on these injustices, some may attempt to dismiss them as unfortunate moments in history and put faith in the objectivity of modern scientific practice, but doing so flies in the face of the documented issues of racism and sexism within diagnostic practices that remain prevalent in our own time. Further, the move to relegate these criticisms to the past may prevent current practitioners from looking closely at our historical moment:

Nowadays, *drapetomania* does not ring a bell for most people. It did in the nineteenth century, at least in the United States. Official Western medicine then recognized drapetomania, the tendency of slaves to run away from their owners, as a disease that commonly afflicted black persons. Being civilized you may feel that this kind of oddity has no foothold any more in our culture, since modern medicine and psychiatry, based as they are on objective science, have outgrown old shortcomings and superstitions ... With hindsight, drapetomania is easily dismissed as a harmful fabrication of ficti-

tious disease, in a culture violating human rights. Less easy is it to recognize harmful fabrications of our own era for what they are. [176, p. 29]

Indeed, Metzl points out that the overdiagnosis of schizophrenia in Black males continues at an alarming rate. Comprehensive reviews of the existing research on race and diagnosis report that African American and Black patients are three to four times more likely than comparable White patients to be diagnosed with a psychotic disorder [15]. Similarly, Latino and Hispanic patients are three times more likely to receive a diagnosis for a psychotic disorder [155]. Researchers have also found an increased risk for a wide range of different migrant groups [13], especially when they move to a country where they are part of an ethnic minority group. In the UK, researchers have found high rates of psychosis diagnoses among Afro-Caribbean immigrants and their offspring, [100] while clinical and epidemiological studies of their countries of origin do not reveal notably high rates [172]. This discrepancy, combined with the diversity of the groups implicated, argues against any single biological or genetic cause [177]. A number of potential explanations for the disproportionate diagnostic rates have been offered, such as clinician racial bias, structural racism, post-migration socio-economic disparities, and adaptive cultural distress, e.g., “paranoia” or fear of police [182, 184] in minority patients in response to perceived threat [49, 156]. The longstanding and international nature of the trend represents convincing evidence that modern psychiatric diagnosis *has not* “outgrown old shortcomings and superstitions” [176, p. 29].

### *Do DSM Diagnoses Travel?*

The second form of exo-level critiques of the DSM in our model targets the ways in which the very experience and expression of mental distress itself is culturally mediated or, as others have argued, culturally produced. Indeed, since the writings of radical psychiatrist Frantz Fanon, those who challenge

Western psychiatry have critiqued the lack of cultural consideration in clinical diagnosis, stressing the ways in which experiences of mental distress are culturally bound [6, 46]. Historically, scholars have disagreed as to whether underlying, universal pathologies are expressed differently due to cultural factors, or whether cultural and historical factors themselves influence or even produce the types of mental distress experienced. Some researchers have suggested that Western diagnostic discourse – and psychiatric theory more broadly – is itself a cultural phenomenon that influences the experience and expression of putative symptoms [166]. Evidence for this hypothesis comes from phenomenological studies suggesting vast cultural variation in the types of experiences presumed to be universal (including psychotic experiences; e.g., [118]), ethnographic, and journalistic documentation of epidemiological shifts upon the dissemination of Western diagnostic discourse in new places (e.g., [181]; see below) and the historical appearance and disappearance of specific syndromes and symptoms (e.g., [75]).

In the development of the DSM-5, the manual was amended to respond to such criticisms over cultural disparities [116]. The manual now states that the clinical significance of a symptom may vary based on cultural norms and adds, “awareness of the significance of culture may correct mistaken interpretations of psychopathology...” [4, p. 14]. The previously used concept of “culture-bound syndromes” was rejected and replaced with the categories of “cultural syndromes,” “cultural idioms of distress,” and “cultural explanation/perceived distress.” This new formulation admits culture as factor that both mediates the expression of distress and also shapes the experience of distress. This has not satisfied its critics [41, 139]. The DSM has faced criticism for failing to equally consider epidemics of strange beliefs in the West, such as UFO sightings or religious activities, and for reifying behaviors deemed “abnormal” in foreign or non-Western communities as illnesses without convincing scientific evidence [7]. Further, the question might be asked whether many of the most common DSM diagnoses represent cultural syndromes in



themselves. On this view, these diagnoses are inextricably linked to the culture and material conditions of Western societies in this current historical period.

Previous models of cultural psychiatry saw culture as somewhat self-contained, closed patterns of behavior that were largely shared among individuals of similar position within a social system. From this perspective, a clinician might be able to consider the social location and cultural group of a patient and attempt to account for any divergences from their “standard” patient that might be expected to affect a diagnosis. One alternative treatment of culture in psychiatry emphasizes the ways in which individuals’ cognitions and lived experiences are shaped in complex relationship with discourses within their social context [17]. From this discursive perspective, critics of the DSM see psychological distress as inevitably caught up in a knot of competing culturally contingent narratives and consider the implications of the particular constructions of mental disorders that are represented in the manual and their interaction with individuals’ self-understandings [102]. Understood this way, mental distress not only arises from but also is in itself a social and cultural experience; the DSM’s diagnostic categories are thus descriptions of sociocultural phenomena.

DSM diagnostic constructs are particularly problematic in the context of globalization, as they have been developed historically in Western populations and remain Eurocentric. Despite this, the World Health Organization and other international groups have attempted to standardize approaches to psychiatric diagnosis and prescribe best practices for treatments and prevention initiatives; these decidedly Western constructs are being exported into cultures that may have fundamentally different assumptions about the nature of the mind and the meaning of distress. Scholars of indigenous psychology and media culture have pointed out that the unprecedented globalization of mental health discourse in high-income countries is rapidly eclipsing local healing traditions, as well as indigenous ways of expressing and experiencing emotional distress [73]. The journalist Ethan Watters

[181] brought this critique into the mainstream with his book, *Crazy Like Us: The Globalization of the American Psyche*. In it, he details four case studies where DSM disorders were introduced to previously DSM-naïve populations documenting the media coverage of anorexia nervosa in Hong Kong, the introduction of PTSD in Sri Lanka following the tsunami, the experience of schizophrenia in Zanzibar, and the pharma-fueled marketing of depression in Japan. Through each of these examples, Watters illustrates how DSM categories bring with them culturally specific ideas about human nature, selfhood, time, memory, and the relationship between the body and the mind that may, at best, be inapplicable in non-Western settings and, at worst, harmful. For example, Kirmayer [104] has explored how the psychiatric construct of somatization, the tendency to express psychological conflicts in physiological terms, is incompatible with Japanese cultural understandings of the interconnectedness of body and mind.

Indeed, the cultural psychiatrist Derek Summerfield describes the DSM and its European counterpart, the International Classification of Diseases (ICD), as “Western cultural documents par excellence,” shaped by “contemporary notions about what constitutes a real disorder, what counts as scientific evidence, and how research should be conducted” [165, p. 992]. Decisions to apply psychological diagnoses and their attendant measures, developed in Western populations, to non-Western populations ignore several decades of ethnographic work in anthropology describing many variations in understanding distress, emotions, and illness across the globe [103, 106]. In this impulse to “educate” different cultures about mental health and impose Western conceptions and treatments, Summerfield sees an urge toward “medical imperialism, similar to the marginalisation of indigenous knowledge systems in the colonial era ...” [165, p. 993]. Similarly, China Mills [125] has pointed out that efforts to increase access to mental healthcare in the global South have also served to reify and universalize theories of mental distress from the global North. In Mills’ words:

Psychiatry's journey out from the global North is made possible at ground level by diagnostic and classificatory tools (such as the Diagnostic and Statistical Manual – DSM, and the International Classification of Diseases – ICD), which are translated in order to travel across geographical borders. This 'diagnostic creep' works as a form of psychiatrization that frames increasing numbers of experiences, globally, in psychiatric terms. (p. 9)

Moreover, the standards for what constitutes acceptable forms of evidence, namely, randomized controlled trials, effectively prevent cultural groups with alternative ways of knowing and/or lacking the means to conduct these studies from contributing to the Western psychiatric evidence base that informs the creation of psychiatric disease categories [164]. On this point, Summerfield [165] points out that psychiatric "disease classifications are essentially conceptual devices emerging from committee decisions" (p. 992). The pressures on these committees, how they are formed, and the multiple interests they serve become a focal point for meso-level critiques.

## Meso-level Critiques

Meso-level critiques target the role of specific political and economic pressures in the creation of the DSM-5 itself. They do not explicitly address questions about the existence or appropriate measurement of mental disorders or the role of DSM-5 categories in larger societal, cultural, and historical movements. However, in examining the role of guild and corporate interests in the development of the DSM, these critiques may begin from a rejection of a realist epistemology of mental disorders (see macro-level) and commit to some form of social construction or social constructivism. Ontological assumptions about the reality of mental disorders as primarily neurobiological conditions may differ widely among authors at this level. While those authoring critiques at the meso-level may express concerns about exo-level issues, such as medicalization, neocolonialism, neoliberalism, etc., we have placed them at this level of the model if the primary target of their

critique is a more immediate system that either directly influences the development of the DSM or directly affects the way in which DSM categories are put into practice.

A number of leading researchers have expressed concern over the influence of the pharmaceutical industry and special interest groups on medical research and practice [5, 72, 108]. However, the field of psychiatry is facing “an intellectual and clinical crisis” beyond those of other specialties due to the contested nature of diagnosis in the field [48, p. 220]. In their 2015 book, *Psychiatry Under the Influence*, Lisa Cosgrove and Robert Whitaker apply an “institutional corruption” model to the field of psychiatry. Institutional corruption, a concept initially developed by law professor Larry Lessig, provides a framework for understanding how “systems of incentives, or economies of influence, might advance or deter a collective objective” [114, p. 2]. This model does not place responsibility on quid pro quo corruption or individual “bad apples.” Instead, it looks at systematic practices that come to undermine an institution or “bad barrel” corruption [34]. Using the institutional corruption framework to investigate the development of the DSM, Cosgrove and Whitaker find that the financial interests of the pharmaceutical industry and the guild interests of the psychiatric profession unduly influenced the expansion of psychiatric diagnosis in the DSM-5 [186, pp. 112–5]. As was the case with the DSM-4, the majority of those assigned to the DSM-5 task force had some financial tie to the pharmaceutical industry, and, looking closer, disorders that are more likely to be treated with medication had the highest percentages of conflicted task force members involved in their definitions and criteria ([30]; for further details, see Chap. 3 in this volume).

In order for a drug to receive approval by the US Food and Drug Administration (FDA), the company must submit an indication for the drug in question, meaning that a disorder or illness “exists” that it is capable of treating. As such, the construction of a new mental disorder, or the expansion of an existing category in the DSM can create opportunities for the pharmaceutical industry to receive new patents for

such indications. For this reason, the principal architect of the DSM-3, Robert Spitzer, remarked in 2011 that the creation of a manual of psychiatric diagnosis initiated a “gold rush” for pharmaceutical companies [149, p. 45]. Following the publication of the DSM-5, *The Wall Street Journal's MarketWatch* reported that 15 new categories in the manual had created opportunities for pharmaceutical companies to develop and sell new drugs [189]. In this vein, Whitaker and Cosgrove [186] document three instances where someone working as a principal researcher for a clinical trial of a drug for a new condition was also on the DSM-5 work group with “decision-making authority” over developing the diagnosis for that very same indication (see also [32]). Interestingly, the widening of diagnostic boundaries in the DSM, which opens up markets for pharmaceutical companies by increasing the percentage of the population who may qualify for a disorder and thus, treatment, has also been cited as a culprit for the failure of many clinical trials in psychiatry. If, for example, the population of people who meet criteria for MDD and are included in the sample for a clinical trial for antidepressants is too large and heterogeneous, then reactions to the drug may vary widely and, in the end, decrease the average effectiveness found [65].

Beyond the influence of the pharmaceutical industry, the field of psychiatry as an institution, or guild, also has a lot at stake in the development of a new diagnostic manual, in that it brings credibility to a medical specialty that has faced sustained critique over the last century [190]. Additionally, the American Psychiatric Association (APA) depends as an organization on profits related to the publishing of new diagnostic manuals; a budget crunch may have contributed to the decision to abandon the difficult-to-operationalize spectrum approach to diagnosis [188] in a rush to publish the DSM-5 [57].

Premenstrual dysphoric disorder (PMDD) is one example that illustrates the ways in which these economies of influence can affect the construction of a disorder in the DSM. In the DSM-4, PMDD was limited to the appendix as a “depressive disorder not otherwise specified,” but in the DSM-5 it

was conceptualized as a mood disorder and added to the main text of the manual [195]. The mood disorders working group, in which three out of every four members had a financial conflict of interest, made the decision to include PMDD in the DSM-5. This decision was justified by the APA committee by referencing the fact that “several medications have received an indication for treatment of PMDD” and that the inclusion may “further facilitate development of treatments...” (as quoted in [31]). The medications referenced here include Sarafem, a remarketed version of Prozac, which Eli Lilly put forward to the FDA in an attempt to gain a new indication before the patent on the blockbuster drug expired [18, 31]. In this way, we can see how the needs of a large pharmaceutical company come to influence what is considered a disorder in the DSM.

It is not only industry, however, that has a stake in the mental disorders that are inserted into and defined in the DSM. The history of how PTSD came to be included in the DSM-3 illustrates how social movements, advocacy groups, and political interests can also affect what is considered a disorder and how that disorder is defined [47, 193]. In the 1970s, there was substantive debate over whether many of the symptoms observed in Vietnam veterans were better conceptualized as reactions to war experiences by individuals with underlying pathologies or as a new disorder, “war neurosis” or “post-Vietnam syndrome,” until then undiscovered and now in need of inclusion in the new diagnostic manual. The sociologist Wilbur J. Scott documents the political alliances and social movements that led “war neurosis” to be included in the DSM-3 as PTSD, against the wishes of psychiatrists who remained opposed to the addition [157, 158].

When diagnostic categories in the DSM are unduly influenced by industry or special interest groups, it can create a “false positive problem.” Those beginning from a realist ontology, such as Allen Frances (as discussed earlier), define false positives as cases where diagnoses are too broad to separate “the inevitability of human unhappiness and the difficulties caused by deviant behaviors” from true “mental

illness” [8]. While failing to consider how social and political conditions might themselves contribute to the experience of symptoms associated with a particular mental disorder (see macro- and exo-levels), Frances and others making this critique are concerned with how the false positive problem exacerbates inequalities. The widened diagnostic boundaries are then linked to “unnecessary side effects, stigmas, cost, and a misallocation of mental health services” [8, p. 7]. For example, changes in the DSM-5 criteria for mood disorders have been linked to the overuse of antipsychotic medication in children and adolescents, and industry-conflicted guidelines now recommend second-generation antipsychotics for depression with “mixed features” [34, 35, 63]. Diagnostic overreach can expose large swaths of the population to dangerous and potentially life-altering medications [187]. One of the factors that has been linked to the popularity of the biomedical model of mental illnesses is that it allows healthcare and insurance companies to more easily demarcate a line between what can be covered and what will not be [141].

The inclusion of (and criteria for) mental disorders in the DSM, beyond influencing the use of medical resources and the effects of diagnosis on individuals, also have striking political and legal consequences [77]. For example, the conceptualization and definition of paraphilic disorders in the DSM-5 has implications for the civil commitment of sexual offenders, even after criminal sentences are served, if behavior is deemed to be the result of a mental disorder [179]. Conversely, removal of a particular disorder from the manual, like “homosexuality,” for instance, can help to establish civil rights protections, ensuring nondiscrimination policies in contexts such as housing and employment [160].

Even granting the systemic influences on the way that psychiatric disorders come to be defined in the DSM and applied in clinical, legal, and political contexts, problems remain concerning the scientific procedures used in the development of the classification system. These critiques, presented next at the microlevel, may consider the reasons why particular decisions were made concerning diagnostic constructs but are

primarily concerned with the process surrounding research design and statistical issues in the DSM field trials.

## Microlevel Critiques

Micro-critiques are differentiated from meso-critiques in that they target specific technical and methodological issues in both the science underlying the testing of the DSM-5 and the process by which the manual was constructed, without necessarily addressing the larger systems in which these decisions are made.

During the development of the DSM-5, a central issue was whether mental disorders are better conceptualized by a categorical or dimensional approach. This debate is closely tied to ontological and epistemological disagreements discussed at the macro-level, but many of the arguments for and against either position focused on psychometric results and practical issues concerning application. When the APA first announced it was undertaking the development of DSM-5, it framed the project as a “paradigm shift,” as it was in part meant to move away from a categorical approach to mental disorders toward a dimensional approach. It was thought that this shift to assessing patients along a spectrum from normality to pathology would improve the reliability of the diagnostic constructs and “shore up the bona fides of psychiatry” [188, p. 38]. This hope was founded on new research suggesting that dimensional models may yield better measurements. For example, Borsboom and colleagues [12] reviewed psychometric and statistical models to compare continuous and categorical constructs of mental disorder. Their research reveals that “both the models and the data used in current research on the structure of psychopathology are limited and often suboptimal” (p. 10). Additionally, factor mixture models may suggest that disorders can appear to be both categorical and continuous in different populations [66]. Findings suggest that certain disorder categories are better captured by dimensional models than categorical models and dimensional measures consistently



show greater reliability than categorical measures [80, 121]. However, Whooley [188] documents, through in-depth interviews with those working on the DSM-5 revision, how the effort to dimensionalize diagnosis ultimately failed as researchers were confronted by clinicians arguing that dimensionality lacked “clinical utility” and was a poor fit for practice. Thus, the DSM-5 was caught between the goal of “reducing complexity” in order to maximize the ease of clinical use and the goal of striving for validity and reliability through dimensionalizing diagnosis [143].

As anticipated, continuing with a categorical approach to mental disorders led to reliability issues in the DSM-5, and a number of critiques target both the reliability and validity of psychiatric diagnoses. Validity refers to the degree to which a construct captures “reality” or “nature” and is often differentiated by content validity and criterion-related validity [23, 81]. Content validity tests whether the way a construct is operationalized (i.e., the symptoms included in the checklist for a particular disorder) is an adequate reflection of the construct as a whole. For example, we might ask whether the symptoms listed in the DSM-5 for major depressive disorder (MDD) cover the comprehensive domain of the subject or all of the potential symptoms of depression. Along these lines, a network analysis of 28 different symptoms associated with depression on common measurement tools and rating scales, such as the Beck Depression Inventory (BDI), attempted to identify whether the symptoms listed in the DSM-5 were more “central” to depression than other common symptoms. The network analysis identified several “nodes,” symptoms that seem to be central to the experience of depression, but the DSM criteria were no more central than non-DSM symptoms [67]. So, even if the 28 symptoms derived from standard depression measures were assumed to constitute the universe of depression symptoms, the DSM-5 criteria for major depressive disorder would fail the standard of content validity. As Fried and his colleagues write, “the reasons why particular symptoms are featured in the DSM seem to be based more

on history than evidence” (p. 318). Alternatively, criterion-related validity tests whether the way a construct has been operationalized behaves in association with other variables in a manner consistent with the theory of that construct. To use the same example, criterion-related validity for the diagnosis of MDD in the DSM-5 is tested by considering whether the operationalized construct predicts the outcomes that it would be expected to predict in theory. Of course, there are a wide variety of theories of the etiology and course of depression, as there are for many of the disorders in the manual, which complicates tests of validity.

Reliability refers to the amount of agreement between independent clinicians concerning the diagnosis of an individual patient. Rather than testing whether a DSM category, as it is defined, adequately approaches the theoretical understanding of depression or depression “in nature,” reliability tests the extent to which clinicians and researchers reach agreement for any given diagnosis. Reliability is measured and indexed according to a kappa coefficient, ranging from zero (representing agreement no better than chance) to one (signaling complete agreement). Since the development of the DSM-3, benchmarks have been utilized to separate good (0.6 and above) from moderate (0.4–0.6), fair (0.2–0.4), and poor (<0.2) kappa scores [173]. By these standards, the DSM-5 field trials did not fare well. The results showed dramatic declines in kappa scores from DSM-3 for diagnoses such as schizophrenia and MDD. Only 5 of 23 diagnoses tested met the criteria for good kappa scores; 9 were moderate, and 9 more were poor. The kappa scores for MDD (0.25) and major anxiety disorders (0.2) were so low that they suggest that independent clinicians came to agreement by little more than chance [58, 144]. However, the DSM-5 field trials did not report the kappa scores in this way. Instead, in what Allen Frances referred to as “a classic example of Orwellian ‘newspeak,’” the DSM-5 leadership redefined what kappa scores were deemed acceptable, and the *American Journal of Psychiatry* published these renamed results uncritically [59].

Another controversy during DSM-5 development surrounded “attenuated psychosis syndrome” (APS), meant to capture people with subclinical psychotic experiences, in Section III of the manual (for conditions needing further research before consideration as official diagnostic categories). Critics pointed out that the majority of those diagnosed with APS will not transition to a full psychotic disorder [69] and that the label could expose young people to unnecessary social stigma and antipsychotic drugs [55, 60]. In May of 2012, the DSM-5 task force officially dropped the proposal [20, 61]. Yet, once the manual was published, attenuated psychosis syndrome was included under the codable “Other Specified Schizophrenia Spectrum Disorder/Other Psychotic Disorder.” While “Other Specified” DSM-5 categories are intended to include vague and nonspecific categories of “other specified” and “unspecified” bipolar disorder, depressive disorder, anxiety disorder, etc., under “Other Specified Schizophrenia,” the authors specifically refer to APS [4, p. 122, 90].

These criticisms of specific technical and scientific issues in the construction of the DSM are important when considering the meaning of psychiatric diagnosis without reference to the controversies discussed at the preceding levels. Individual-level critiques target the application of DSM-5 diagnoses in practice and consider the impact of this action on practitioners and patients alike.

## Individual-level Critiques

At the individual-level we come to the clinical encounter and decisions concerning how to utilize a psychiatric diagnosis with a patient or client. Critiques at this level are concerned with how diagnostic categories affect an individual and their relations with others, including the medical professional or psychotherapist. In his book *The Gift of Therapy*, the famous existential psychotherapist and psychiatrist, Irvin Yalom [192], warns that if mental health professionals or carers “take the DSM diagnostic system too seriously, if we really

believe we are truly carving at the joints of nature, then we may threaten the human, the spontaneous, the creative and uncertain nature of the therapeutic venture” (p. 5).

Research supports the contention that diagnoses has an impact on how professionals conceptualize their patients or clients despite the purported atheoretical stance of the DSM-5. For example, Kim and Ahn found, through a series of five experiments, that clinical psychologists use etiological theories when applying DSM diagnoses [99]. Furthermore, clinicians’ beliefs about the causes of mental disorders affect the type of treatment recommended. A study that included psychiatrists, psychologists, and social workers revealed that all three groups of mental health workers often think of particular diagnoses as either mostly biological or mostly psychological and that one’s belief about the causes of a disorder affects how helpful a treatment is considered to be. Thus, clinicians who assign a primarily biological cause to a disorder are more likely to believe that medication is a helpful intervention for treating that disorder [2]. These beliefs also affect how likely a clinician is to judge a person as responsible for their behaviors. Miresco and Kirmayer [126] found that professionals who attribute a disorder to biological causes were less likely to judge a person responsible than if they attributed it to psychological causes (see also [113]). The term “epistemic injustice” has been used to describe the ways in which people given psychiatric diagnoses are subsequently perceived as less informed and reasonable than others [36, 64]. The phenomenon can lead clinicians and practitioners to discount the knowledge and preferences of those given psychiatric diagnoses, and this dismissal can be internalized by those diagnosed [36].

Taking a qualitative discursive approach, Goicoechea analyzed conversations between staff and patients in an involuntary psychiatric unit in the USA, finding that diagnostic terms are often used to claim authority over patients in order to justify treatment decisions and serve to “avoid the task of formulating connections between the individual and the social, including [clinician’s] own culpability in relation to a

patient's struggles" ([71, p. 116]; see also [70]). On a relational level, the biggest problem with the DSM may be that the categories get in the way of actually listening to the lived experiences of those they are intended to describe. For example, if clinicians become attuned to simply checking for the presence of "auditory hallucinations," do they then neglect to consider that people who hear voices may well find the content of what the voices are saying to be instrumental to living and coping [39, 133, 148]?

Moreover, what of the experiences of those on the "sharper" end of psychiatric diagnosis? If patients assigned a disorder assumed to be biological in origin are judged less responsible for their behaviors as demonstrated, does this in fact reduce stigma? To the contrary, research evidence supports just the opposite; Increasing belief in the biomedical model of mental illness actually increases the likelihood that someone will want to maintain a social distance from those diagnosed [119]. Alternatively, evidence indicates that psychosocial explanations of mental disorders reduce stigma and increase empathic responses from others [117]. Further, patients who actively resist the stigma associated with such a diagnosis have better overall outcomes, self-efficacy, quality of life, and improved chances of recovery [50].

Labeling theory and modified labeling theory [110] connect the social rejection of those deemed different to individuals' understandings of themselves as disordered and different [142]. Research on the nocebo effect, where patients taking placebo appear to have nonspecific side effects, suggests that self-stigma and identification with an illness following a diagnosis may have negative effects on individual patients [145, 161]. The more discrimination a diagnosed patient perceives in their environment, the more vulnerable they are to low self-esteem and low empowerment [151]. A psychiatric diagnosis can gravely alter an individual's self-perception; it also casts them in a particular social role that can lead to multiple forms of oppression and marginalization [37]. Although conventional psychiatric theory suggests that persons who reject their diagnosis "lack insight," Forgione

[52] has called this refusal “diagnostic dissent” and suggested that rejection of a diagnostic label can constitute an active reassertion of agency in the face of perceived invalidation.

While many patients may experience a diagnosis positively, critiques at the individual level make clear that mental health professionals should not assume this is the case. Practitioners should consider the various multileveled critiques of psychiatric diagnosis and discuss these issues with their patients or clients as part of a robust informed consent process.

## Conclusion

One purpose of this ecological model, toward the goal of conceptual competence, is that it will facilitate discussion about solutions for reform and alternative classification systems. For example, in order to mitigate the impact of the pharmaceutical industry on the DSM-5 revision process and on clinical trials, many have called for increased transparency. However, requiring individual committee members and researchers to disclose industry funding was insufficient to prevent bias in the development of the DSM-5 or its clinical trials [32]. Using our ecological model, one could place transparency in industry funding at the meso-level and then consider how this attempt at reform may be co-opted by macro-level processes like neoliberalism and medicalization and what it may mean in the context of macro-level debates about the existence and measurement of mental disorders. In this vein, bioethicist Carl Elliot has called for “a focus of eliminating practices that allow for corruption rather than a focus on requiring individuals to disclose industry ties,” [44, p. 153]. Lisa Cosgrove and colleagues have entreated that APA actively recruit critics of current diagnostic practices onto DSM work groups [30]. Taken together, these suggestions point toward increasing conceptual competence and critical consciousness concerning psychiatric diagnosis in the development and application of diagnostic categories.

As this chapter illustrates, diverse researchers and scholars have critiqued the DSM not only for its weak scientific foundation but also for the methodological problems it creates for clinical science and its problematic application to clinical practice. Additionally, the DSM reinscribes mind-body dualism and reifies social and political structures that take power from patients while strengthening problematic institutions. In response to these problems, researchers have begun to propose alternative classification systems. In 2017, a group of researchers attempted to follow through on the initial hopes of the DSM-5 by dimensionalizing psychiatric diagnosis, placing disorders on a continuum rather than in categories. The result, an alternative classification system known as the Hierarchical Taxonomy of Psychopathology (HiTOP), attempts to address a number of the technical and microlevel issues associated with the DSM-5 [107].

In a contribution to the *Journal of Humanistic Psychology's* Special Issue series on Diagnostic Alternatives, Peter Kinderman and Anne Cooke [27] call for approaches that include the voices of service users and survivors. They stress the need to move the conversation beyond “brain or blame” explanations that either subtly suggest that individuals are to blame for their distress or that their problems are simply the result of faulty neurobiology. In 2018, the British Psychological Society, in partnership with service users and survivors, published the “Power Threat Meaning Framework” as an alternative to diagnosis [88]. The framework is designed with the intention of supporting “the construction of non-diagnostic, non-blaming, de-mystifying stories about strength and survival, which re-integrate many behaviors and reactions currently diagnosed as symptoms of mental disorder back into the range of universal human experience” [89, p. 17]. The framework understands distress as resulting from the meanings people assign to perceived threats and power in their particular contexts.

Following an idea born during the in-person SHP- and BPS-sponsored Global Summit on Diagnostic Alternatives in 2014, the *Standards and Guidelines for the Development of*

*Diagnostic Nomenclatures and Alternatives in Mental Health Research and Practice* were recently published in the *Journal of Humanistic Psychology* [92]. The *Standards and Guidelines* are intended as a guide for the development of diagnostic systems and descriptive alternatives in mental health research and practices. More specifically, these aspirational guidelines focus on the creation of scientifically sound, ethical diagnostic systems and alternatives that prioritize sociopolitical context, lived experience, and the democratization of input from diverse stakeholders and multidisciplinary professionals.

It is also important to acknowledge that psychiatric diagnosis in the USA takes place within a complicated healthcare system and that diagnoses are currently entrenched as a collective gatekeeper, opening the door for the insurance reimbursements that make psychiatrists and psychologists alike financially viable. For this reason, any alternative to the current diagnostic system must also address the changes to healthcare policy that would be necessary for their implementation.

## Authors' Reflexivity Statement

As many of the critiques discussed in this chapter have made apparent, the social position and intentions of the authors are necessarily implicated in any analysis. For this reason, it is important that we, as authors of this chapter applying a structural analysis, examine our own commitments and interests. We are both professionally invested in the field of mental health and our perspectives on the social and political power wielded by clinical psychology and psychiatry are inevitably influenced by this investment. This synthesis of critiques of the DSM is consistent with the aims of a growing movement challenging the hegemony of rigidly biological understandings of human experience and calling for a greater diversity of models for understanding and supporting human beings in their social, psychological, cultural, spiritual, and biological complexity. We believe that dominant diagnostic paradigms, the DSM included, are themselves a symptom of broader scientific, conceptual,



and social problems, including the problem of scapegoating marginalized members of society (see [146]). And we believe that the DSM, as in Kriss's [109] parodic review of the manual as if it was a dystopian novel, has a "looping effect" [76] on the very social ills that it creates. Or as Kriss puts it:

The setting of the novel isn't a physical landscape but a conceptual one. [...] The scene [...] is one of a profoundly bleak view of human beings; one in which we hobble across an empty field, crippled by blind and mechanical forces whose workings are entirely beyond any understanding. [...] As you read, you slowly grow aware that the book's real object of fascination isn't the various sicknesses described in its pages, but the sickness inherent in their arrangement. [...] For much of the novel, what the narrator of this story is describing is its own solitude, its own inability to appreciate other people, and its own overpowering desire for death – but the real horror lies in the world that could produce such a voice.

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# Chapter 3

## The Influence of Pharmaceutical Companies and Restoring Integrity to Psychiatric Research and Practice

**Lisa Cosgrove and Akansha Vaswani**

### Introduction

We [psychiatrists] will never have a biomedical science that is similar to hepatology or respiratory medicine, not because we are bad doctors, but because the issues we deal with are of a different nature. [10]

Primum non nocere is perhaps the best-known ethical principle in medicine. Today however, critics charge that the medical profession's culture and its public health mission are being undermined by commercial interests. The problem is so pernicious that in May 2017 the Journal of the American Medical Association (*JAMA*) published an entire special issue

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devoted to addressing conflicts of interest in medicine [22]. Indeed, concerns about overdiagnosis and overtreatment are increasingly prominent across areas of healthcare [52, 60, 71]. However, these concepts have gained little traction in psychiatry, where there is no accepted definition of overdiagnosis or overtreatment and where opinion leaders focus on undertreatment. Why is psychiatry both more vulnerable to and yet defensive about undue industry influence? One important reason is that, compared to other branches of medicine, diagnostic criteria for mental disorders are more subjective, variable, and open to question; there is no blood test or scanning technique to determine when a patient has a psychiatric disorder. As a result, diagnosis becomes a matter of deciding when human emotions, thoughts, and behaviors are to be considered pathological and in need of treatment. The absence of definitive diagnostic tests for psychiatric conditions makes psychiatry more vulnerable to commercial interests than other medical specialties, and industry has been able to co-opt the lack of biological markers to its own advantage. This fact was noted explicitly by a former president of the American Psychiatric Association (APA) in response to concerns about the integrity of the revision process for the *Diagnostic and Statistical Manual of Mental Disorder, Fifth Edition* (DSM-5):

The flexible boundaries of many psychiatric diagnostic categories, in the absence of definitive diagnostic tests, may encourage expansive definitions of affected populations and create opportunities for industry to promote treatments for people who would not previously have been seen as having a disorder. [4, p. 256]

In this chapter, we review the subtle but powerful ways that commercial interests have influenced psychiatric taxonomy and treatment guidelines. Although we discuss conflicts of interest, we focus on the more robust framework of institutional corruption to understand the economies of influence and problematic incentive structures that have had a distorting effect on psychiatric research and practice. Focusing mainly on the distortions in current understandings of the effects of therapeutic agents, we

show how academic-industry relationships and guild interests have led to the corruption of the evidence base upon which accurate diagnosis and sound treatment depend. We argue that transparency alone is not a sufficient solution (and may have unintended iatrogenic effects) and offer suggestions for how the profession can work to better inoculate itself from these influences.

## Institutional Corruption in Psychiatric Research and Practice

When the term corruption is invoked, the typical image that comes to mind is of a clandestine and illegal interaction: a person in a position of power accepting money in exchange for something. In a democratic society, there are certain elements common to this interaction: (1) something specific is given or taken in exchange for something else (*quid pro quo*), (2) the parties involved know it to be morally wrong, and (3) it is illegal, and there will be negative consequences if the behavior is made public. As Harvard law professor Lawrence Lessig [39] and philosopher Dennis Thompson [65, 66] make clear, such *quid pro quo* corruption is very different from institutional corruption. In the latter, the trouble is not with a few corrupt individuals hurting an organization whose integrity is basically intact. Unlike individual corruption, which occurs when “bent or bad souls” [39, p. 227] engage in clearly unethical and illegal behavior, institutional corruption results when an organization is no longer sufficiently independent to pursue its stated goals or mission effectively. Within organized psychiatry, there have been many “economies of influence” or systemic and accepted practices (e.g., serving as experts on clinical practice guidelines and receiving consulting monies from the drug companies whose products are recommended in the guideline) that have taken psychiatry “off course,” undermined its public health mission, and weakened the public’s trust [18].

Using this framework helps us identify the conditions under which *institutions* fail, even though the individuals within the organization believe they are acting in ways congruent with the organizational mission. Whereas individual corruption is conscious and explicit – a “bad apple” problem – institutional corruption is about the “bad barrel” [39]. This is a critically important distinction, not only because it points to very different etiologies for the corruption problem but also because it leads to quite different solutions. In *quid pro quo* corruption, the cause is greed and weak character; the solution is blame-oriented and aimed at the individuals involved. For example, the researcher who willfully engages in fraud is analogous to the CEO who pays handsomely for an undeserved corporate privilege. In contrast, institutional corruption focuses on implicit bias, problematic incentive structures, and restoring professional/organizational integrity. Additionally, as bioethicist Carl Elliot [21] has noted, a focus on conflicts of interest deflects attention away from the systemic nature of the problem: “This way of framing the issue makes it sound as if these financial ties are a purely individual problem—that an individual has a problem and we need to manage it.”

Thus, although outright manipulation of data (research fraud) certainly occurs, a great deal of research bias occurs unconsciously. As we shall show in the next section, bias in psychiatric drug trials or in clinical guidelines is not a “bad apple” problem. The dissemination of imbalanced and sometimes inaccurate information about psychotropic medication is not the fault of a few unethical researchers or profit-minded pharmaceutical companies. The problem is more insidious and pernicious and, to a large degree, due to implicit or unconscious bias. In fact, decades of research in social psychology have shown that self-deception and cognitive biases are common and difficult to overcome. Thus, there is a *generic* risk that guild and commercial interests may result in implicit, unintentional bias [66]. The conceptual and normative framework of institutional corruption can help us map out how these risks developed in organized psychiatry and how they can be avoided in the future.

## Distortions in the Psychiatric Evidence Base

The following are examples of why clinicians and patients need to critically assess claims made about the efficacy and safety of many psychotropic drugs. These examples also illuminate Lessig and Thompson's position that commercial ties are not an a priori indictment of wrongdoing but instead point to a generic risk and the need to "minimize conditions that would cause reasonable persons (patients, colleagues, and citizens) to believe that professional judgment has been improperly influenced, whether or not it has [66, p. 574].

### *Did the DSM-5 Inadvertently Function as a Vehicle for High-Profit Patent Extensions?*

The controversy that ensued when the DSM-5 was published in 2013 has been well-documented. In addition to criticisms about poor inter-rater reliability, there were also strong concerns raised about "diagnostic creep" [50, 51] and pathologizing everyday problems. Indeed, as Appelbaum and Gold [4] cautioned, the expansion of diagnostic boundaries runs the risk of exposing people to unnecessary treatments. It is noteworthy that many commonly used psychiatric drugs were blockbusters (defined as those that generate over US\$1 billion in revenue in 1 year). For example, the antipsychotic drug Abilify was the top prescription drug in terms of sales in 2013, generating US\$6.5 billion [42], and the second bestselling drug in 2014, generating US\$7.8 billion [43]. Certainly, pharmaceutical companies have a fiduciary responsibility to serve their shareholders' interests by working to increase their shareholder value. However, if the heavy emphasis on the use of psychotropic medications to treat new DSM-5 disorders is linked to the financial interests of the APA panel members and researchers who test the safety and efficacy of drugs, then it is reasonable to be concerned about the interplay among industry, DSM panel members, and principal investigators running psychotropic drug trials for new DSM disorders.

Our team examined the financial conflicts of interest (FCOI) of DSM panel members responsible for decisions about the inclusion of five new DSM disorders and one major revision (elimination of the bereavement exclusion for major depressive disorder) and the pharmaceutical companies conducting clinical trials for drugs to treat these new disorders [17]. The disorders investigated were bereavement-related depression, binge eating disorder, disruptive mood dysregulation disorder, autism spectrum disorder, mild neurocognitive disorder, and premenstrual dysphoric disorder. These disorders were selected because of documented problems with reliability [11, 63], questions raised regarding their validity [11–13, 24], and concerns that these diagnoses lack specificity and would result in diagnostic inflation [7]. The elimination of the bereavement exclusion from the diagnostic criteria for a major depressive episode was one of the most controversial revisions in the DSM-5. With this change, individuals who are actively grieving a loss may be diagnosed with major depressive disorder if they present with symptoms of depression 2 weeks after the loss. Many clinicians argued that people who are going through the normal process of grieving would now be diagnosed with depression. It is noteworthy that the DSM-5 included an explicit recommendation for antidepressant medication (ADM) for grief for depression following the loss of a loved one (see Fig. 3.1).

As we previously reported, there were financial ties between DSM panel members and pharmaceutical companies in 12/13 of the drug trials for these six disorders that met inclusion criteria for our study. Also, most of the trials were for medications that were off-patent or had patents that were about to expire within the next 2 years.<sup>1</sup> Of note is the fact

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<sup>1</sup> It should be emphasized that many trials were running *before the DSM-5 was published*. In other words, clinical trials were being run to test drugs for disorders that did not yet officially exist (e.g., binge eating disorder, mild neurocognitive disorder, disruptive mood dysregulation disorder, bereavement-related depression). Certainly, pharmaceutical companies would be delighted by the official inclusion of new DSM disorders; obtaining 3 more years of exclusivity for drugs capable of generating over US\$1 billion in sales is a boon to industry.

<p>DSM IV TR - Criterion E:</p> <p>“The symptoms are not better accounted for by Bereavement i.e., after the loss of a loved one, the symptoms persist for longer than 2 months...” (p.356)</p> <p>No statements about carefully considering whether grief may actually be MDD</p>	<p>DSM 5:</p> <p>“ A diagnosis [of Major Depressive Disorder] based on a single episode is possible...Careful consideration is given to the delineation of normal sadness and grief from a major depressive episode... and <i>recovery</i> [from bereavement] <i>may be facilitated by antidepressant treatment.</i>” (p. 155, emphasis added)</p>
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FIGURE. 3.1 Comparison of DSM IV and DSM-5

that 70% of the patented drugs included in the trials were defined as “blockbuster” drugs or drugs that have earned at least US\$1 billion in revenue over 1 fiscal year. Drug companies are incentivized to widen diagnostic boundaries and to find new indications (i.e., conditions/diseases) for previously approved drugs. If a new indication is found, regulatory bodies have the authority to grant the company “exclusivity” for an additional 3 years for that drug. Pharmaceutical companies have used “exclusivity” as an informal mechanism to effectively extend patent protection for that time period [26].

There were three clinical trials for “binge eating disorder,” testing an antidepressant, a mood stabilizer, and a psychostimulant as potential treatments for this new indication. The three trial drugs, Cymbalta, Lamictal, and Nuvigil, made US\$5 billion, US\$937 million, and US\$347 million in revenue in 2012, respectively. Cymbalta, whose patent was set to expire in 2013, was also being tested for “bereavement-related depression” and was one of Lilly’s recent blockbuster drugs: In just the fourth quarter of 2012, Lilly reported revenue of US\$1.42 billion from Cymbalta alone (24% of total revenue for that quarter; [8]). As can be seen in this brief summary, new diagnoses in the DSM-5 may have provided an

opportunity for pharmaceutical companies to effectively extend their patents on blockbuster drugs. Moreover, these findings suggest that FCOI might function subtly, but powerfully, to shift the direction of research, focusing on interventions that are the most commercially attractive but that do not necessarily represent the best science [17].

### *Should SSRIs Be Used Routinely in Children and Adolescents? A Disconnect Between Scientific Evidence and Common Clinical Practice*

For over two decades, the safety and efficacy of the class of drugs known as selective serotonin reuptake inhibitors (SSRIs) in pediatric populations have been the subject of heated debates; the New York Times compared this controversy to a “religious war” (Carey, [14] as cited in *New York Times*). However, a well-publicized and heavily marketed 2001 study, funded by SmithKline Beecham (subsequently, GlaxoSmithKline (GSK)), was instrumental in convincing many psychiatrists and pediatricians that SSRIs were indeed safe and effective. This study was influential because it was the first double-blind placebo controlled trial with adolescents, (“Efficacy of Paroxetine in the Treatment of Adolescent Major Depression: A Randomized, Controlled Trial”), and it was published in the prestigious *Journal of the American Academy of Child and Adolescent Psychiatry* (JAACAP) [33]. Investigators reported that withdrawal rates for adverse effects were 9.7% and 6.9% for paroxetine and placebo, respectively, and they concluded that “Paroxetine is generally *well tolerated and effective* (emphasis added) for major depression in adolescents” (p. 762). Although in 2004 the US Food and Drug Administration (FDA) issued a strong warning about the increased risk of suicide associated with SSRI use in children [38], the continued dissemination of the JAACAP study (referred to as “study 329”) proved to be a strong counter to that warning. In fact, the rates of antidepressant prescription, especially SSRIs, increased worldwide most

notably for 10–19-year-olds from 2005/2006 to 2012, despite no concomitant increase in children’s mental health conditions [5]. Moreover, this was observed across all age cohorts and prescription of all classes of antidepressants in the countries studied: the United States (+26.1%), the United Kingdom (+54.4%), Denmark (+60.5%), the Netherlands (+17.6%), and Germany (+49.2%). In the United States, there was an initial reduction in prescriptions of antidepressants (in 2005–2006) following the FDA’s boxed warning (i.e., the strongest warning that the FDA issues that signals that a drug has been shown to be associated with serious risks/adverse events); however this trend did not persist after that time interval [47].

It is noteworthy that at least one of the co-authors of that study was an employee of GSK, and many others, including the lead author, had significant financial ties to the company. The lead author, who was deemed a “Key Opinion Leader” by GSK, initiated study 329 (see, e.g., Ref. [46]). Pharmaceutical companies refer to psychiatrists who serve on their speaker bureaus or advisory boards as “Key Opinion Leaders” or “KOLs” because they are known to be instrumental to the marketing of the disease as well as the therapeutic agent [15, 61]. In order to present the results in a way that minimized “potential negative commercial impact,” GSK contracted a medical communications company, Scientific Therapeutic Information (STI), to prepare the manuscript. As McHenry and Jureidini [46] report, there was substantial evidence that most of the manuscript as well as responses to peer reviewers were ghostwritten by an employee from STI; although all authors could provide their comments and edits, GSK had the final rights about what was published.

In 2015, after years of trying to get the individual patient-level data from GSK, an independent group of researchers, concerned about the underreporting of negative results in the medical literature, published the results of their analysis in the *British Medical Journal* in accordance with the initiative “restoring invisible and abandoned trials” (RIAT) [37]. They concluded that paroxetine had no clinical or statistical efficacy advantage over placebo and there was a “disturbing pattern



of harms.” Specifically, once they had access to the complete data set and patient-level data, Le Noury et al. found that severe adverse events were 2.65 times more frequent in the paroxetine group compared to those reported in the Keller et al. paper. There were 11 incidents of suicide in the paroxetine group versus 1 in the placebo arm. Adverse events, including suicidality, were underreported, the effects of drug withdrawal were omitted, and a misleading conclusion that paroxetine was superior to placebo was reported:

Contrary to the original report by Keller and colleagues, our reanalysis of study 329 showed no advantage of paroxetine or imipramine over placebo in adolescents with symptoms of depression on any prespecified variables. *The extent of the clinically significant increases in adverse events in the paroxetine and imipramine arms, including serious, severe, and suicide related adverse events, became apparent only when the data were made available for the analysis. Researchers and clinicians should recognize the potential biases in published research, including the potential barriers to accurate reporting of harms that we have identified.* ([37] p. 13, emphasis added)

### *Do the Randomized Controlled Trial Data Get Codified Accurately in Psychiatric Practice Guidelines?*

There has been increasing evidence that the proposed efficacy (i.e., benefit demonstrated under the ideal conditions of a short-term clinical trial) as well as effectiveness of antidepressant medication has been overstated. For example, in the large-scale sequenced treatment alternatives to relieve depression (STAR\*D) study, where patients were treated in naturalistic or real-world settings, it was found that less than one-third experienced a remission of symptoms [64]. Additionally, prescription of multiple drugs (either two antidepressants or an antidepressant and another drug such as a mood stabilizer) or switching antidepressants led to lower rates of remission and an increase in the dropout rate [55, 59]. The STAR\*D authors reported a “theoretical cumulative

remission rate” (p. 1910) of 67%, but a reanalysis of the data by Pigott et al. [55] shows that only 45.9% of the patients experienced remission and of these, “36.7% dropped out within 1 month of their remission and only 108 (5.8%) survived continuing care and took the final assessment without relapsing and/or dropping out.” Thus, an important conclusion from this study is that even under conditions of high-quality care, the effectiveness of antidepressants is far more limited than was previously believed.

Especially insofar as this was a study designed to replicate real-world circumstances and thus inform clinical treatment in a large-scale way, these findings are not promising. However, they are consistent with many meta-analyses. In a high-profile study published in *PLoS Medicine*, Kirsch et al. [36] found that the degree of response to the medication depended on the initial severity of measured depression. They report, “A substantial response to placebo was seen in moderately depressed groups and in groups with very severe levels of depression. (The placebo effect) decreased somewhat, but was still substantial, in groups with the most-severe levels of depression... [and] increased benefit for extremely depressed patients seems attributable to a decrease in responsiveness to placebo, rather than an increase in responsiveness to medication” (p. 0266).

Similarly, in their patient-level meta-analysis of antidepressant RCTs, published in *JAMA*, Fournier et al. [23] conclude:

*The magnitude of benefit of antidepressant medication compared with placebo increases with severity of depression symptoms and may be minimal or non-existent, on average, in patients with mild or moderate symptoms. For patients with very severe depression, the benefit of medications over placebo is substantial (p. 47, emphasis added)... Prescribers, policy makers, and consumers may not be aware that the efficacy of medications largely has been established on the basis of studies that have included only those individuals with more severe forms of depression. This important feature of the evidence base is not reflected in the implicit messages present in the marketing of these medications to clinicians and the public. (p. 52)*

These findings clearly show that treatment with antidepressants should be more judicious with a thorough consideration of the risk/benefit profile and assessment of depression severity. It would be expected that such a recommendation be included in clinical practice guidelines (CPGs); however, in the American Psychiatric Association's treatment guideline for major depressive disorder, antidepressants are recommended as a first-line intervention for all levels of depression ([1], reaffirmed [2]), including mild depression. Further, and in contrast to the Fournier et al. meta-analyses, and Kirsch's assessments, the APA guideline makes the following statement: "Response rates [for ADM] in clinical trials typically range from 50 to 75% of patients, with some evidence suggesting greater efficacy relative to placebo in individuals with severe depressive symptoms as compared with those with mild to moderate symptoms" (p. 31). This statement and the recommendation for ADM for mild depression stands in stark contrast to recommendations developed by independent and multidisciplinary groups such as the National Institute for Health and Care Excellence (NICE [53]). NICE thoroughly addresses the risk/benefit profile of antidepressants and explicitly states that they should *not* be used as a first-line intervention for individuals with mild depression: "Do not use antidepressants routinely to treat persistent subthreshold depressive symptoms or mild depression because the risk-benefit ratio is poor" ([53], 1.4.4.1). Similarly, recent Dutch guidelines recommend antidepressants only for severe depression [70]. There are also guidelines developed in the United States, such as those produced by the Institute for Clinical Systems Improvement [49], which do not recommend pharmacotherapy and take a more cautious and stepwise approach. Of note is the fact that these guidelines were produced by panels that had no or few FCOI and were interdisciplinary in composition.

A recent study [30] assessing statistical versus clinical significance of ADM corroborates findings from Kirsch's and Fournier's meta-analyses and supports a stepwise approach to depression treatment. The authors found that even though

SSRIs compared to placebos led to statistically significant responses, this did not translate to clinical significance (which they considered a 3-point drug-placebo difference on the 17-item Hamilton Depression Rating Scale). They conclude, “Even based on our predefined minimal thresholds for clinical significance, the effects of SSRIs did not have a clinically meaningful effect on depressive symptoms” (p. 21). Moreover, all of the 131 trials they included for analysis were coded as being affected by a high risk of bias for several reasons including incomplete or selective reporting of outcomes. In addition, the risk of adverse events was found to be much higher in patients taking an SSRI than among those given placebo. Additionally, there were very few data on long-term outcomes, quality of life, or suicidal behaviors.

*Can We Trust the Literature When We Read About “Novel” Psychotropic Medications? Another Case Study of the Disconnect Between the Data and What Is Disseminated in the Published Literature*

Meta-analyses that are funded by drug companies have higher rates of discordance between the published result and the conclusions thereby giving an exaggerated sense of efficacy [74]. Such insidious forms of bias escape standard risk-of-bias assessment tools (e.g., the tool developed by the Cochrane Collaboration: [29]). This problem is compounded by the well-documented “spin” – specific strategies, whether intentional or not, that highlight the benefit of a new drug or treatment despite a statistical lack of efficacy – that occurs in print and social media and in press releases (see, e.g., Refs. [9, 16, 75, 76]).

Over a decade ago, Turner et al. [67] provided clear evidence that there is publication bias in psychotropic drug trials (i.e., negative trials are not published), and negative trial results are written in a way that convey a positive result (e.g., reporting on secondary rather than primary outcome mea-

tures). Clearly, the relationships among academe, publishing, and industry can facilitate commercial bias in how drug efficacy and safety data are obtained, interpreted, and presented to regulatory bodies and prescribers. Recently our team [19] examined the drug approval process for the serotonergic antidepressant, vortioxetine, which was approved by the FDA and European Medicines Agency (EMA) in 2013. The choice to focus on a serotonergic agent was purposeful. There are over a dozen SSRIs already on the market, and weak regulatory policies allow for design choices and reporting strategies that can make marginal products look novel, more effective, and safer than they are. Additionally, the selective and imbalanced reporting of clinical trial data in medical journals can result in the marketing of expensive “me-too” drugs with questionable risk/benefit profiles.

Through an examination of published and unpublished trials submitted to the FDA and EMA for approval of vortioxetine, we found evidence of the “ghost management” of the information delivery process. For example, in 11 of 13 published articles, the majority of the authors were employees of the drug’s manufacturer, and 9 of 13 the disclosure statements state that the manufacturer was also involved in designing the study as well as collecting, analyzing, and interpreting data. The 13 studies were published in 7 journals, and the editors of 5 of these journals had commercial ties to vortioxetine’s manufacturer [19].

All of the published reports overstated benefit and did not fully explain the limitations of the trial data, including small effect sizes and limited trial duration. Also, most of the trials used a passive adverse event ascertainment protocol: spontaneous reports to one open-ended question, “How do you feel?” The few trials that used an active adverse event design for sexual side effects (a well-known but not thoroughly studied side effect of SSRIs) were not adequately powered to detect sexual side effects. However, in the published trial, the following statement is made: “In both men and women ASEX [Arizona Sexual Experiences Scale] total scores were similar in the placebo and vortioxetine groups at study end” [44, p. 590]. This statement gives the misleading impression that vortioxetine

had a favorable sexual side effect profile compared to placebo. Most busy clinicians would most likely miss the more accurate statement that was buried in the discussion section: “The sample number is too small to draw any conclusions” [44, p. 590].

Most clinicians also would not be aware of the fact that regulatory agencies do not require head-to-head comparisons for a drug to be approved. This regulatory practice of showing superiority only over placebo has spawned a class of “me-too” drugs that are similar in their actions and efficacy but are marketed as novel drugs that are more expensive than older, off-patent compounds. Our examination of the seven trials that used an active comparator (duloxetine or venlafaxine) with vortioxetine revealed that the comparator was significantly more effective at three of the four dose levels tested. The FDA and EMA, following current regulatory standards, based its approval on a subset of six positive trials. This regulatory practice is in contrast to meta-analyses and review standards that call for examining the full picture of results. In fact, systematic reviews conducted by non-industry-funded researchers who examined the same data as the FDA and EMA concluded that vortioxetine was *not* as effective as other similar drugs on the market [48] and the statistically significant effects observed in the placebo controlled trials may not translate into a meaningful clinical difference [54]. Unfortunately, however, the public remains ill-informed and the drug continues to be marketed as a novel effective ADM that is well-tolerated. Although the generic comparators demonstrated greater efficacy than vortioxetine, it is novel-in its cost: whereas duloxetine and venlafaxine cost US\$11.43–45.54 for a month’s supply, the lowest price for a month of vortioxetine is US\$351.45 (goodrx.com, January 2018).

## Conclusion

There’s this assumption that a tie with the company is evidence for bias. But these people [APA guideline authors] can be objective. ([58] in *USA Today*)

Not everything that is faced can be changed but nothing can be changed if it is not faced. [6]

As the examples in this chapter and other research findings (see, e.g., Refs. [37, 46, 67]) demonstrate, clinical trials in psychiatry are often designed in commercially friendly rather than scientifically robust ways and are almost exclusively conducted and interpreted by industry-funded researchers. These researchers firmly believe that they are objectively reporting balanced and accurate information about DSM disorders and therapeutic agents. Although physicians often believe they are not affected by industry ties, research suggests otherwise: a ProPublica analysis [31] revealed that doctors who received payments from drug companies were more likely to prescribe more expensive brand name drugs than were physicians who received no payments. The assumption that one could will oneself to be immune to implicit bias is what Lessig has called the “ethically tough-guy assumption ... like avoiding a cupcake, or a drink before driving, the issue is simply one of will and determination” [40, p. 102]. This assumption is clearly evidenced in Regier’s response to DSM panel members and guideline developers having commercial ties. However, as Lessig succinctly puts it, “Here’s what we know about the tough guy assumption: it’s completely false. The influences that operate to bend our judgment don’t operate at the conscious level. They don’t announce themselves ... the psychological influences that institutional corruption must reckon with are the very essence of our species” [40, p. 103].

The end result is that the evidence base in psychiatry is distorted and has become a driver of nonrational prescription practices and low-value care. The tainted evidence base, along with other factors such as marketing, frequently results in clinical practice guidelines that are not trustworthy. As we have shown in this chapter, psychiatrists creating clinical practice guidelines who continue to broaden the definitions of psychiatric illness often have extensive links to the very companies that stand to benefit from expanded markets. Combined, these practices lead to the medicalization of normal human experience, overdiagnosis, and overtreatment.

Thus, the combined commercial and guild self-interests result in undue influence over what diagnostic and treatment

recommendations are included in the official psychiatric evidence base (e.g., in the DSM, in treatment guidelines). However, it is not realistic to expect the members of any guild – including medical specialty groups – to be fully cognizant of the ways in which their behavior may reflect implicit bias and self-interest [57]. Increased transparency with regard to both intellectual and financial conflicts of interest and clinical trial data has helped, but it is clear that more comprehensive strategies are needed. Below we outline the way forward for psychiatry to inoculate itself from the economies of influence that have taken the profession off course.

## Solutions for Reform

A leading researcher in medical decision-making, Harold Sox, succinctly identified the problem in the special issue of *JAMA* devoted to COI: “[When COI’s exist], these individuals, their co-panelists, and the public cannot be certain that their judgments are free from the influence of their competing interests” [62, p. 1739]. The paradigm shift to a classical medical model of disease opened the door for industry to exert an undue influence on psychiatric taxonomy and treatment. The time has come for organized psychiatry (as well as individual psychiatrists) to acknowledge this influence and respond accordingly.

First, it should be recognized that semantic decision-making biases often combine with marketing strategies in ways that impede critical thinking. For example, psychiatrists as well as their patients are more likely to remember industry-promoted indications and benefits of a therapeutic agent over the adverse events and side effects listed in the product labeling material. Moreover, physicians are not immune to automated thinking [27], the “irrational persistence in belief” [28, p. 640], and a newer-is-better bias. As Gopal et al. [25] note, many clinicians have internalized the belief that second- or third-generation antidepressants are always the treatment of choice. Once prescribing habits are established, they



become difficult to change. Additionally, pharmaceutical detailing and marketing encourages questions such as “Which among this new class of drugs is better than the others?” rather than “How are these new drugs any better than older drugs or alternative treatments?” In an industry-dominated climate, rational prescribing requires extra effort: one must be mindful of these subtle but powerful influences, be aware of the ubiquitous nature of cognitive biases, and actively search for independent information about therapeutic agents (e.g., from the Cochrane databases and libraries; RIAT reanalyses; clinical trials published in medical journals with robust conflict of interest policies such as *PLoS Medicine* and the *British Medical Journal*).

Second, embracing the grounding principle in medicine – *primum non nocere* – is needed. Of course this is a tall order: the pull to do something, to screen and intervene, is especially strong in the United States today. As is well known, the US Preventive Services Task Force has recommended routine depression screening for everyone over 13, including, for the first time, routine screening during pregnancy and the postpartum period [69]. What is less well-known is the fact that the evidence does not support routine depression screening and the United Kingdom’s National Screening Committee [68] and the Canadian Task Force on Preventive Health Care [34], *looking at the same evidence*, did not recommend screening. The importance of a stepwise approach and watchful waiting in mental health treatment almost seems like malpractice when in fact it is often evidence-based and patient-centered care. As Mangin, Heath, and Jamouille [45] note, good care “would place equal value on the art of ‘not doing’ – making complex decisions not to give treatments, not to order tests, and to stop current treatments when in the best interests of the patient.” For example, although rarely taught in medical school or in psychiatric residency programs, there are documented high rates of spontaneous remission of depression symptoms – one review estimates that 23% cases remit within 3 months, 32% within 6 months, and 54% within

12 months [72]. Moreover, it has been shown that depression symptoms remit either with care as usual [20] or placebo treatment [35]. A reason placebo treatment is hypothesized to work is that patients with mild to moderate depression symptoms are particularly amenable to non-specific therapeutic effects [35]. One such effect in placebo studies is hypothesized to be a warm and supportive patient-clinician relationship [32].

To further inoculate against industry-influenced prescribing, perhaps psychiatry can take the lead from guidelines published by other medical specialties. For example, a recent guideline published by the American Academy of Pediatrics [41] for managing acute otitis media calls for more stringent criteria before prescribing antibiotics. The guideline development group advises against prophylactic antibiotics even for children with recurrent infection. A leader in the field of psychiatry famously quipped that psychotropic medication for mental illness can be compared to insulin for diabetes [3]. Rather than lifelong insulin, perhaps the new model for psychopharmacology should be analogous to the judicious use of amoxicillin for ear infections.

Finally, and admittedly, the most difficult to achieve is the need for a climate change, a paradigm shift in the field. Psychiatrist Dainius Pūras, appointed as the United Nations' Special Rapporteur on Health [56], has been on the forefront of such efforts. He has called the mental health field, and psychiatry in particular, to task for decontextualizing and over-medicalizing emotional distress. In a recent report to the UN, he suggested that a focus on the "global burden of obstacles" should replace the rhetoric and policy initiatives directed at the global burden of mental illness. That is, rather than focusing exclusively on intraindividual factors to explain the etiology of emotional distress, the social determinants of mental health should take center stage. As historian of science Mitchell Wilson argued a quarter century ago, there must be a reconceptualization of psychiatric problems as "not truly medical but social, *political* [emphasis added] and legal" [73, p. 402].

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# Chapter 4

## An Alternative Approach to Drug Treatment in Psychiatry



**Joanna Moncrieff**

### Introduction: Models of Drug Action

Psychiatric drugs are currently understood to exert their beneficial effects by helping to normalise an underlying brain abnormality that is thought to be responsible for producing the symptoms of a particular mental disorder. Thus antipsychotics are believed to reverse the pathology that produces psychotic symptoms or schizophrenia, antidepressants are believed to act on the biological processes that produce symptoms of depression, mood stabilisers are thought to help normalise the processes that produce abnormal mood swings, and so on. The underlying pathology is sometimes proposed to consist of an imbalance in neurotransmitters or neurocircuitry [15], but often it is not specified. This view of drug action is promoted by the pharmaceutical industry, whose websites frequently refer to the idea that psychiatric drugs work by “balancing the chemicals naturally found in the brain” [12]. Literature produced by professional organisations like the United Kingdom’s Royal College of Psychiatrists

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TABLE 4.1 Alternative models of drug action

<b>Disease-centred model</b>	<b>Drug-centred model</b>
Drugs help correct an abnormal brain state	Drugs create an altered brain state
Drugs as disease treatments	Psychiatric drugs as <i>psychoactive drugs</i>
Therapeutic effects of drugs derived from their effects on an underlying disease process	Therapeutic effects derive from the interaction of drug-induced alterations on behavioural and emotional problems

conveys the same message. The College leaflet on antidepressants, for example, describes how “we think that antidepressants work by increasing the activity of certain chemicals that work in our brains called neurotransmitters ... the chemicals most involved in depression are thought to be serotonin and noradrenalin” [33]. The American Psychiatric Association suggests that “antidepressants may be prescribed to correct the levels of chemicals in the brain” [3].

Assumptions about drug action are rarely articulated, but this view can be set out in what I have called the “disease-centred” model or theory of drug action (Table 4.1). The disease-centred model has been imported from general medicine, where most modern drugs are correctly understood in this way. Although most medical treatments do not reverse the original disease process, they act on the physiological processes that produce symptoms. Thus, beta agonists help reverse airways obstruction in asthma and chemotherapeutic agents counteract the abnormal cell division that occurs in cancer. Analgesics such as paracetamol and non-steroidal anti-inflammatory drugs also work in a disease-centred manner by acting on the physiological processes that produce pain.

The disease-centred model assumes that drugs exert their relevant effects only in people with a specific bodily abnormality or disease. The effects of drugs can therefore be meaningfully divided into the therapeutic effects, which are the effects on the disease process, and other effects, which are

referred to as “side effects.” The therapeutic effects will only be apparent in people who have the underlying pathology.

An alternative explanation for the effects of drugs in psychiatric disorders can be called the “drug-centred” model of drug action. This model highlights that psychiatric drugs can be considered to be “psychoactive” drugs in the sense that they are substances which cross the blood-brain barrier and affect brain functioning, thereby producing characteristic mental and behavioural alterations in anyone who ingests them [22]. There is no essential distinction, according to this view, between drugs used for psychiatric treatment and recreational psychoactive drugs, like alcohol and cocaine. All psychoactive drugs produce altered physical and mental states which can influence the way people think, feel, and act, with different sorts of substances having different sorts of effects. The effects of recreational drugs are experienced as desirable by at least some people, but some drugs produce mental and physical changes that are generally disliked (e.g. antipsychotics and lithium). The drug-centred model suggests that it is these psychoactive properties that explain the changes seen when drugs are given to people with psychiatric problems. Drugs like benzodiazepines and alcohol, for example, reduce arousal and induce a usually pleasant state of calmness and relaxation. This state may be experienced as a relief for someone who is intensely anxious or agitated. But taking a drug like this does not return the individual to “normal” or to their pre-symptom state. It is simply that the drug-induced state may be preferable to anxiety.

There are few examples of drugs working in a drug-centred way in modern medicine, but historically the psychoactive effects of alcohol were an important part of its analgesic properties. Opiates also work partly through a drug-centred mechanism. Although they reduce pain directly by inhibiting the conduction of pain stimuli (a disease-centred action), they are psychoactive drugs which induce an artificial state of emotional indifference and detachment. People who have taken opiates for pain often say that they still have some pain, but they do not care about it anymore. This is a drug-centred effect.

According to a drug-centred model, therefore, psychiatric drugs produce an altered global state characterised by a range of psychological and behavioural as well as physiological changes. These changes may interact with the symptoms of mental disorders, and sometimes the modifications these interactions produce are perceived as beneficial, either by the sufferer themselves or by others.

## History of Models of Drug Action

When modern psychiatric drugs were introduced in the 1950s, they were understood according to a drug-centred model. Antipsychotics, for example, which were then known as “major tranquilisers”, were regarded as a special sort of sedative. They were thought to have properties that made them uniquely useful in situations like an acute psychotic episode, because they could slow up thought and dampen emotion without simply inducing sleep, but they were not regarded as a disease-targeting treatment. By the 1970s, however, this view was eclipsed, and the disease-centred model of drug action became dominant. Psychiatric drugs were regarded as specific treatments that worked by targeting and reversing, or partially reversing, an underlying disease or abnormality. The change is demonstrated most clearly in the way drugs have come to be named and classified. Prior to the 1950s, drugs were classified according to the nature of the psychoactive effects they produce. After the 1950s, drugs come to be named and classified according to the disease or disorder they are thought to treat. Modern drug classifications therefore classify drugs as “antipsychotics”, “antidepressants”, “anxiolytics”, “mood stabilisers”, etc.

The ascendance of the disease-centred model of drug action did not occur because of overwhelming evidence of the superiority and truth of the disease-centred model. There was not then, and is not now, any convincing evidence that any class of psychiatric drugs has a disease-centred or disease-targeting action [22, 25]. There was not even any real debate

about alternative theories of drug action. The disease-centred model just took over the drug-centred view, which then simply faded away. People forgot there had ever been another way of understanding how psychiatric drugs might work.

## Evidence on Drug Action

Currently, the use of drugs for the treatment of mental health problems rests on the results of placebo-controlled trials. These trials do not distinguish whether drugs have a disease-centred or drug-centred action, however. They only indicate that drugs have different effects from an inert substance, the placebo.

Evidence that might indicate that drugs have a disease-centred action could come from:

### *Research on the Neurochemical Origins of Mental Disorders*

Hypotheses abound that suggest that certain neurotransmitters are involved in the aetiology of particular psychiatric disorders. If evidence confirmed that a particular disorder was related to a specific neurochemical abnormality that was reversed by a drug, then this might constitute evidence for the disease-centred theory of drug action. Antipsychotic drugs, for example, affect dopamine, among other neurotransmitters, but evidence for perturbations in the dopamine system that are specific to schizophrenia or psychosis, and independent of prior drug treatment, remains weak [19, 23]. Studies of the dopamine content of post-mortem brains and dopamine metabolites are negative, for example. The increased concentration of dopamine D<sub>2</sub> receptors, which was identified in brains of people with schizophrenia, transpired to be due to the effects of drug treatment. Recent studies report that indirect measures of dopamine activity are sometimes abnormal in people with acute psychosis. However, we know that

dopamine is implicated in a range of functions including arousal, movement, and stress that will confound its relations with any specific psychiatric disorder [23]. Moreover, the total number of drug naïve participants in these studies is small.

Evidence on whether depression is caused by abnormalities of brain chemicals that might be reversed by drugs is even more contradictory. Studies of serotonin receptors, for example, show increased levels in depression in some studies, decreased levels in other studies, and no difference in some [26]. There are claims that tryptophan depletion produces depression, but the research has involved people who had been previously treated with SSRIs, and studies with volunteers show no effects [29]. In 2001, the leading American textbook of psychiatry concluded that “studies of serotonin function in depression suggest both hypofunction and hyperfunction” [11]. In 2013, psychopharmacologist Stephen Stahl concluded: “direct evidence for the monoamine hypothesis [of depression and mood disorders] is still largely lacking” [35, p. 262].

### *Comparisons with Non-Specific Drugs*

Although drugs may exert useful effects through a drug-centred mechanism, a drug that is believed to have disease-specific effects should, by definition, be more effective than a drug that produces only non-specific, drug-induced effects. Therefore a drug considered to be an “antidepressant” should be superior to drugs that are not thought to act on the biological basis of depression, and drugs that exert effects on the presumed basis of psychotic symptoms should be superior to drugs that do not act on these processes. The comparative studies that exist, however, do not strongly support the idea of specificity. Numerous drugs that are not normally considered to be antidepressants, for example, have been found to be superior to placebo in randomised trials or equivalent to standard antidepressants. The list includes substances with such diverse actions as antipsychotics [32], benzodiazepines, and stimulants [21]. Moreover, antidepressants themselves

come from a wide variety of chemical classes and cause a huge array of physiological effects, such that it is difficult to believe that there could be any common underlying pathway for their action.

There is also little evidence that so-called antipsychotic drugs are superior to other sorts of sedatives. Two early studies of patients with schizophrenia did find greater benefits for people taking chlorpromazine compared with those taking barbiturates, the most common drug treatment prior to the introduction of the antipsychotics [8, 9]. However, comparisons between antipsychotics and benzodiazepines have given mixed results, with many finding the benzodiazepine to be equal or superior [37].

Antipsychotics might be superior to other sedatives, however, on the basis of the drug-centred model, as was first postulated by researchers in the early days of their use. In other words, antipsychotics might be particularly effective because of the specific neurological state they induce, rather than because they reverse an underlying disease process. Only comparisons with drugs that produce a similar state by mechanisms that are not thought to be involved in the biological basis of psychosis could confirm that they had a disease-specific action. It is difficult to find such comparisons. An old trial of opium is interesting in this respect, since opiate drugs induce a characteristic state of emotional indifference, albeit with a different quality from that produced by antipsychotics, and accompanied by a different profile of physiological and neurological effects [1]. The trial found no difference between opium and chlorpromazine for the treatment of people with acute schizophrenia. So overall, evidence that antipsychotics are more effective than other sedatives is inconclusive, and their superiority to sedatives with similar emotion-dampening effects has not been demonstrated.

Lithium is often said to be the best example of a specific psychiatric drug. However, its psychoactive effects of sedation and cognitive slowing, which are well documented in volunteers, could easily provide an alternative explanation for its effects [17, 18]. Several comparative studies found that lithium was not superior to other sedative drugs such as antipsychotics



and benzodiazepines for the treatment of acute mania or affective psychosis [6, 10, 16, 31]. One of these studies claimed to show that although there was no difference in overall efficacy between lithium and pimozide for people with mania compared to other forms of psychosis, lithium was more effective for manic symptoms in people with a range of diagnoses. However a complex analysis was required to make this point, and there is no direct comparison of the two drugs [16]. In contrast, another study found no difference between lithium and chlorpromazine for typical manic symptoms [31].

### *Animal Studies*

Animal models of mental disorders have been developed in order to screen for specific drugs. Numerous criticisms can be levelled against the validity of animal models, but if they select specific drugs, this may add some support to a disease-centred model of drug action. However, as well as giving varying results in different laboratories, animal models of depression yield positive results with many substances not thought to be antidepressants, including amphetamines, in particular, but also opiates and antipsychotics. Moreover, recognised antidepressants such as SSRIs often do not give positive results [5].

Animal models of psychosis include amphetamine-induced stereotypy (repetitive stereotyped movements), which is considered a model of psychosis because prolonged stimulant use is also known to cause psychosis. Dopamine is known to be involved in the induction of stimulant-induced movement disorders, although other neurotransmitters may also be involved [4]. It is not surprising, therefore, that dopamine blocking drugs reduce stereotypies. However, the test can be viewed more as a test of dopamine blockade, than antipsychotic action; atypical antipsychotics, such as clozapine, which have weaker dopamine blocking effects, are not very effective at suppressing stereotypies [36].

## Using Drugs According to a Drug-Centred Model

If the disease-centred model cannot be definitively supported, the drug-centred model of drug action has to be accepted as a possibility. No one disputes that psychiatric drugs alter normal mental functions, even if these “psychoactive” effects have attracted little attention. It would be implausible to think these effects have no impact on the thoughts and behaviours that constitute the criteria for mental disorders.

A drug-centred approach to the use of psychiatric drugs fundamentally challenges much current psychiatric knowledge and practice. Instead of prescribing treatments for particular conditions, psychiatrists should see themselves as offering drugs which produce drug-induced states which people may or may not find helpful. In order to do this conscientiously, prescribers need to have comprehensive information about the sort of state that different psychiatric drugs induce as well as the full consequences of taking them over short and longer periods. Only then can they help patients to decide whether taking the drug will offer more benefit than harm.

Unfortunately, research on psychiatric drugs has been limited by its focus on the disease-centred model, so that we have limited information about their full range of effects. We know little about what it feels like to take them; physiological and biochemical research has focussed on their effects on presumed disease mechanisms, such as dopamine or serotonin receptor levels, and ignored the many other effects that drugs have. There is a particular paucity of research on the long-term consequences of taking these drugs, including the rate at which the body develops tolerance to various effects and the nature and duration of withdrawal symptoms.

We can glean some idea of the sorts of states that different drugs induce from sporadic accounts by patients and volunteers who have taken them and rare studies that have

TABLE 4.2 Psychoactive effects of psychiatric drugs

<b>Type of drug</b>	<b>Psychoactive effects<sup>a</sup></b>
Antipsychotics	Sedation, subjective and objective cognitive slowing or impairment, emotional blunting/indifference, reduced libido, demotivation, dysphoria
Tricyclic antidepressants	Sedation, cognitive impairment, dysphoria
SSRIs and related antidepressants	Drowsiness, lethargy, emotional blunting, loss of libido, “activation” (agitation, irritability)
Lithium	Sedation, cognitive impairment, lethargy, emotional blunting, dysphoria
Benzodiazepines	Sedation, cognitive impairment, physical and mental relaxation, euphoria
Stimulants	Increased arousal, vigilance and attention, euphoria

<sup>a</sup>The effects of different drugs within each class vary, particularly drugs classified as antipsychotics. The data provided is necessarily a summary which glosses over distinctions between individual agents

explored their effects in volunteers in a detailed and informative way (Table 4.2), although much still needs to be explored and clarified.

## A Drug-Centred Approach to the Treatment of Psychosis

Different sorts of drugs may be helpful in people who are experiencing an acute psychotic or manic episode. Sedative drugs of all sorts may also be helpful to reduce arousal, and some studies suggest that sedatives such as benzodiazepines may also reduce psychotic symptoms [37]. Antipsychotics produce a specific state of neurological inhibition, characterised by cognitive slowing, reduced initiative and motivation, and emotional restriction that is not simply attributable to their (mostly) sedative effects

[7, 27]. These effects are likely to reduce the intensity of emotional distress and psychotic thoughts, and some research shows that, although antipsychotic treatment does not generally remove abnormal thoughts altogether, it does make people less concerned by them [20]. The sedative effects and physical restriction produced by antipsychotics are also likely to play a significant part in the effects they exert in people with acute psychosis and mania, and these effects also make antipsychotics effective interventions for aggressive behaviour as part of “rapid tranquilisation” regimes [2].

It is clear, however, that the alterations induced by antipsychotics may also impair global functioning. This is particularly significant when they are prescribed for long periods of time, especially to people who have made a full recovery. In this situation it is possible that the considerable harms associated with antipsychotics, including weight gain, diabetes, cardiovascular disease, tardive dyskinesia, and brain volume reduction, may outweigh any reduced risk of relapse that long-term treatment may confer [24, 30].

## A Drug-Centred Approach to the Treatment of Depression

Tricyclic antidepressants are strongly sedating which suggests they might be useful for symptoms of anxiety and insomnia across different disorders, although there are many other types of sedatives available for this purpose. SSRI antidepressants have more subtle psychoactive effects and are not profoundly sedating. They may produce a state of emotional restriction which may reduce the intensity or salience of emotions. There may be times when people are so distressed that they desire this effect. However, most people take antidepressants because they believe the drugs are helping to reverse an underlying biochemical imbalance that is producing their symptoms and thereby helping to return them to a normal state.

Placebo-controlled trials suggest that antidepressants are barely distinguishable from placebo and their effects are far

from being clinically significant [28]. Although antidepressants do not cause the sort of common and serious adverse effects associated with antipsychotics, they do produce common disabling effects such as sexual dysfunction and rare but potentially life-changing effects such as prolonged withdrawal reactions and persistent sexual dysfunction [13, 14]. In younger people, especially, they can cause a state of agitation which may be linked with suicidal behaviour and aggression [34]. Therefore, current evidence would suggest that any marginal benefit obtained from the mind-altering effects of the newer antidepressants is unlikely to outweigh the risk of adverse effects.

## Conclusion

The conventional view of how psychiatric drugs work, namely, the idea that they counteract underlying disease processes, is not supported by evidence. The fact that psychiatric drugs are psychoactive substances that induce altered physical and mental states provides an alternative explanation for how they affect people with mental disorders. The emotional, physical, and cognitive suppression induced by antipsychotic drugs, for example, may help suppress the symptoms of an acute psychotic episode. Viewing psychiatric drugs as substances that can produce abnormal bodily states, however, alters presumptions about risks and benefits that form the basis of decisions about whether to use drug treatments. The benefits of being in an altered state need to be balanced against the damage that may occur with long-term treatment and against our uncertainty about the nature and extent of both benefits and harms.

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# Chapter 5

## Clinical Implications of the Drug-Centered Approach



**Sandra Steingard**

### Introduction

Although many of the problems that fall under the umbrella of psychiatric disorder can be addressed adequately in non-medical ways, medically trained clinicians have a valuable role to play in evaluating people who experience depression or hear voices or suffer from debilitating anxiety. There are identifiable medical conditions such as endocrine disturbances, inflammations, vitamin deficiencies, and tumors that can cause these types of problems. Physicians, among the ever-growing field of professionals who are trained to help those in emotional distress, are best qualified to do the assessments these conditions warrant.

When the assessment is complete, then what? If a demonstrable underlying etiology is identified, it is usually addressed by other physicians. When no clear etiology is identified, the problem is considered psychiatric. Although a variety of

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treatment strategies might be helpful, the predominant role of the psychiatrist focuses on pharmacotherapy. This is not to say that is all psychiatrists do and practice patterns vary. But in many settings, there are other professionals who are trained to offer non-pharmacologic treatments, usually at a lower cost, and the work of psychiatrists consists primarily of rendering diagnoses and prescribing psychiatric drugs.

Some psychiatrists critical of the focus on pharmacotherapy may argue for psychiatrists to return to the era when their primary function was as psychotherapists. That is not the position taken here. Psychiatrists are the professionals within the mental health field who have had the most rigorous medical training. People have sought out drugs for millennia to alter their mental states and moods, and this inclination is not likely to subside. It is important to have a field of medicine that specializes in understanding how best to use psychoactive drugs. But in ways outlined in this book thus far, the current model of psychiatry is flawed. What is proposed here is that psychiatry remains the medical subspecialty whose members possess expertise in prescribing psychoactive substances but that we do so from the perspective of the drug-centered model that Dr. Moncrieff has articulated in the previous chapter.

In the past 50 years, psychiatry has transformed its approach from a drug-centered to a disease-centered approach due to the impact of legal requirements combined with guild and pharmaceutical company interests. This has resulted in the dominance of one particular way to best understand, describe, study, and treat mental distress. A return to a drug-centered approach would lead to more cautious and collaborative use of the drugs than is the norm in many current practices. It would open up the discussion of drug discontinuation to consider withdrawal phenomena as prominently as relapse risk as well as affect the way psychiatrists talk to their patients about drugs and the way patients think about the drugs they chose to take.

Many psychoactive drugs were introduced into clinical practice in the 1950s and 1960s, and at that time they were thought about and studied in a drug-centered way; drugs were classified broadly as tranquilizers and stimulants. Drugs

were marketed for a wide variety of indications. Combination drugs were popular. In that era, stimulants, for example, were marketed to treat depression as well as overeating. A popular drug called Dexamyl contained both a barbiturate and a stimulant. It was marketed to treat depression, anxiety, overeating, and fatigue among housewives and was diverted onto the recreational drug scene, where it was known by various nicknames such as the “purple heart.”

In 1962 in the USA, the Kefauver-Harris Amendments to the Food, Drug, and Cosmetics Act were passed in response to the discovery that the drug thalidomide caused severe birth defects. Going forward, drug makers were required to demonstrate that a drug approved for the market was not only safe but also effective for a specific condition or indication. During that same era, recreational drug use became more common in the USA, and, as concerns about this grew, restrictions were placed on the prescription of some drugs, such as LSD and psychostimulants. Psychiatrists felt a need to distinguish what they conceived as drugs used as medicines from drugs used for recreation.

There were other struggles within psychiatry. In the USA, psychoanalysts led many major academic psychiatry departments from the 1950s through the 1970s, but a growing group of psychiatrists wished to reestablish what they considered a more scientific and medical foundation. They included those from the Washington University School of Medicine, who were the leaders in restoring fidelity to psychiatric diagnosis. Known as the neo-Kraepelinians, they were among the driving forces behind the emergence of the modern diagnostic manual, the third edition of the *Diagnostic and Statistical Manual* (DSM-III), published in 1980.

The neo-Kraepelinians sought an approach to diagnosis that would allow researchers to use modern scientific methods to determine the underlying etiologies and pathophysiologies of psychiatric disorders. This required consistent and systematic classification so that people who were given the label of schizophrenia, for example, were more likely to bear relevant similarities to one another, despite where and by whom their diagnoses were assigned.

The 1962 Food and Drug Act made this system critical for the ongoing drug development that proliferated over the next few decades, as diagnostic categories – disease targets – were required by the law. The publication of the DSM-III addressed the aspirations of these powerful forces – the neo-Kraepelinians and the drug companies – and was the final stage in the transformation of psychiatry’s approach to understanding psychoactive drugs from drug- to disease-centered.

But to this day, despite the promise heralded by the Washington University group and their many adherents, the etiologies of these disorders remain murky at best; no clear pathophysiology has been identified for the vast majority of the disorders in the DSM. In a blog written when he was director of the National Institute of Mental Health, Thomas Insel [1] wrote, “Terms like ‘depression’ or ‘schizophrenia’ or ‘autism’ have achieved a reality that far outstrips their scientific value. Each refers to a cluster of symptoms, similar to ‘fever’ or ‘headache’. But beyond symptoms that cluster together, there should be no presumption that these are singular disorders, each with a single cause and a common treatment.”

In some quarters, there is growing concern about the damage caused by the disease-centered approach to psychopharmacotherapy [2, 3]. Approval by the US Food and Drug Administration (FDA) only requires testing over a short duration; relatively little attention is paid to the impacts of long-term use. The shift to long-term treatment is based on studies of drug withdrawal. A disease-centered approach facilitates the assumption that problems that emerge when drugs are stopped signal the reemergence of the disease that was the target of drug treatment. In contrast, rather than concluding that reemergence of problems after a drug is stopped indicates that the person should remain on the drug indefinitely, a drug-centered approach acknowledges that withdrawal effects are likely to emerge upon drug discontinuation. It is helpful to understand the consequences of a disease-centered versus drug-centered approach by more closely examining specific classes of commonly prescribed drugs.

## The Psychostimulants

Psychostimulants are old drugs. Amphetamines were first synthesized in the 1880s and methylphenidate appeared in the 1940s. For many years, it was accepted that they had broad effects that might be helpful to people who were struggling in a variety of ways. They were given to overweight people to promote weight loss and to depressed people to improve mood, and, as noted above, they were prescribed to housewives – sometimes in the form of Dexamyl, in which a stimulant was combined with a barbiturate – to give a general boost to help them deal with the drudgery of daily life. As early as the 1930s, they were reported to help calm children. But it was also recognized that they could trigger a host of cognitive changes including paranoia, agitation, and obsessional and tic-like behaviors. They were used in research as a model for psychosis [4]. The essence of the drug-centered perspective is a recognition of the broad effects of drugs – good and bad – and an acknowledgement that anyone who takes a drug might experience a range of responses. For some they would be pleasant, for some not, and for some they might help to reduce troubling or impairing experiences. Although it has been argued that the calming effects of psychostimulants are “paradoxical” and specific to those with attention-deficit/hyperactivity disorder (ADHD), in fact low doses of stimulants reduce activity and increase focused attention in animals as well as humans with and without ADHD [5]. The effects are not specific to individuals who have a disorder; they affect anyone who ingests them in these broad ways.

Due to their euphoriant effects, these drugs were widely abused, and, with the beginning of the “drug wars” in the 1970s, the use of these drugs in the USA was restricted primarily to children diagnosed with ADHD. This was the shift from a drug-centered to a disease-centered perspective; stimulants were considered to target ADHD specifically. In 2007, a new drug gained FDA approval: lisdexamfetamine, marketed as Vyvanse. This drug is a modification of older drugs; it has a longer elimination half-life and it is harder to

crush, snort, and inject than prototypic psychostimulants already on the market, but it is essentially a psychostimulant.

Coincident with the approval of lisdexamfetamine, there has once again been an expansion of the indications for psychostimulant use, and consequently the number of people considered good candidates to take them. First of all, there has been a broadening of the definition of ADHD. Whereas the DSM-IV [39] required “clinically significant impairment” before age 7, the DSM-5 [40] only requires that “the symptoms interfere with, or reduce the quality of, social, academic, or occupational functioning” and that symptoms be present before age 12. In addition, adults only need to have five rather than the six symptoms required of children to meet the diagnostic criteria. These changes coincided with increased use of these drugs in the adult population. ADHD was no longer considered a developmental problem that generally abated with age; it was now considered a life-long affliction. More people are now diagnosed for the first time as adults.

Secondly, there has been an expansion of indications for lisdexamfetamine. The DSM-5 added binge eating disorder (BED) as a new diagnostic category, and in 2015 the FDA approved lisdexamfetamine for BED. In 2015, the drug was studied as an aid to improve cognition in postmenopausal women [6].

How does a drug-centered approach help us to understand this contraction and then re-expansion of indications? In a disease-centered approach, these drugs are treatments for specific disorders such as ADHD and BED. These drugs are thought to relieve the suffering of people impaired by these disorders. But this implication of specificity is illusory; after all, people who get some relief from these drugs are probably doing so via the same mechanism of action regardless of the disorder being targeted. It is not likely that they act in one way in people who are inattentive and another in those who overeat. It is just that some of the effects are considered to be of particular benefit to some people. Put another way, an overeater will experience an alteration of attention and an

inattentive person might eat less while on these drugs, but those are not the reasons why such people choose to take them. Two college roommates – one diagnosed with ADHD and the other using the drug to improve his ability to cram for a test – are experiencing the same impact of the drug. One is following doctor's orders and the other may be breaking the law. With a drug-centered approach it would be acknowledged that stimulants affect cognitive function in everyone and that they suppress appetite in everyone. It is the requirement of the disease-centered approach – the illusion of specificity – that results in this circuitous route we have traversed over the past 60 years from broad to narrow and, more recently, to ever-broadening indications.

There are other serious implications of the disease-centered narrative. In a disease-centered approach, psychosis that emerges during the course of pharmacotherapy with a psychostimulant for ADHD is often conceptualized as the emergence of a psychotic condition such as bipolar disorder, resulting in the use of other drugs to target this newly diagnosed condition. Likewise, in a disease-centered paradigm, one might diagnose ADHD in a person being treated with sedating drugs who was experiencing poor concentration rather than identify the problems as effects of the sedating drugs. In a drug-centered approach, one is more likely first to stop the stimulant when psychosis emerges and to reduce the sedating drugs when inattention is observed. These problems would be recognized primarily as drug effects rather than the uncovering of yet another disorder.

## Neuroleptic Drugs

The neuroleptic drugs - or antipsychotic drugs - are among the oldest class of psychiatric drugs still in common use. They are considered essential to the treatment of psychosis. For a variety of reasons, this may be the class of compounds that many psychiatrists have the hardest time conceptualizing in a drug-centered manner. Most psychiatrists begin their careers

on inpatient units where they frequently encounter people who come in to the hospital extremely psychotic and who, after taking neuroleptics for a few days, are much less bothered by voices and delusional beliefs. Thus, the drugs appear to have specific antipsychotic effects. How can these observations be reconciled with a drug-centered approach that posits that these drugs are not specifically targeting psychosis?

Laborit, the French physician who first suggested that chlorpromazine might be of benefit to the people housed in France's mental hospitals, noted that neuroleptic drugs induced indifference [7]. In the 2009 edition of the *American Psychiatric Publishing Textbook of Psychopharmacology*, the authors note that these drugs can induce "a state of relative indifference to the environment leading to behavioral inhibition and diminished emotional responsiveness" ([8], p. 538). This cognitive indifference made it easier to "manage" people on psychiatric wards.

When these drugs were introduced to mental hospitals in the 1950s and 1960s, they rapidly transformed care. By the 1970s, they were used ubiquitously. Studies compared rate of relapse between patients who continued on the drugs and those who had them withdrawn; they found a higher relapse rate when the drugs were discontinued [9]. This led to the recommendation that they should be continued indefinitely. In the early 1990s, a hypothesis that delaying their use would negatively affect outcomes gained wide acceptance [10]. Consequently, initiating the drugs as soon as possible became standard practice. All of this resulted in a system of care in which short-term hospitalization was deemed not only cost-effective but adequate to providing good care. A psychotic individual who is admitted to a hospital is started on a drug almost immediately. Rapid discharge is encouraged and attempts to slow the process down are often met with opposition. Once discharged, long-term maintenance of the drug – sometimes even over the individual's objection – is urged. If a person wants to try an alternative approach, there is little support from any quarter – professionals, insurers, and even ethicists, who argue that by slowing the process down, we are depriving people of necessary and effective treatment.



However, there is a paradox embedded in our current system of care. Although antipsychotic drugs are widely considered to be extremely effective drugs, there is growing concern about the need for more inpatient care and even calls to return to the use of asylums [11]. A drug-centered approach offers another way to understand not only how these drugs work but also why we continue to struggle to address the needs of psychotic individuals.

As noted, the rationale for long-term use of the drugs is predicated on what are referred to as relapse studies. In these studies, individuals are stabilized on antipsychotic drugs and then randomly assigned to either drug continuation or placebo substitution. The two groups are then followed over time, usually for 1–2 years. In a meta-analysis of relapse studies [9], 64% of those who were switched to placebo relapsed, as compared to 27% of those maintained on active drug. Notably, a substantial minority of individuals (36%) do fine when drugs are stopped. Combined with those 27% who still relapsed despite continuing to take the active drug, it appears that only about 40% of patients derive benefit from taking the drug during the study period. The challenge in clinical practice is that there is no way of knowing into which group any given individual will fall.

While a recurrence of psychosis can be a serious and debilitating problem for many individuals and those who care for them, the recurrence that occurs when the drug is stopped cannot necessarily be attributed straightforwardly to the reemergence of the chronic, persisting condition labeled as schizophrenia. As early as the 1980s, some psychiatrists wondered whether the brain alterations caused by antipsychotic drugs might render people more vulnerable to psychosis when the drugs are stopped [12]. This phenomenon, labeled supersensitivity psychosis, was thought to be a product of the alterations in the brain brought on by exposure to antipsychotic drugs. There is good evidence that when postsynaptic dopamine receptors are blocked, the brain adjusts by producing more receptors [13]. When the drug is no longer present, the dopamine system becomes hyperactive (as it is now

unopposed by dopamine-blocking agents), which may increase an individual's vulnerability to psychosis [14]. Supersensitivity psychosis remains an underappreciated phenomenon. Almost no research has been done on ways to mitigate its impact on recurrence of symptoms.

The relapse studies have a further limitation. They only study people for up to 2 years, with the majority of studies following subjects for less than a year. Many individuals are on these drugs for decades. In recent years, several studies have suggested a paradox: while over the short-term there might be benefit from drug treatment, over a longer period of time this benefit wanes; for many the risks of the drug might come to outweigh the benefits. Martin Harrow and colleagues studied 139 individuals who experienced an initial episode of psychosis. They followed them over the course of 20 years, conducting assessments at 2–5-year intervals. The study was conducted to identify determinants of outcomes such as temperament, cognition, and premorbid functioning. It began in the era when long-term use of medications was accepted as best practice and the initial aims did not include the evaluation of the impact of medications on outcomes. However, medication adherence was tracked. The researchers found that, as predicted, those who scored poorly on assessments of premorbid developmental achievements had worse outcomes than those with higher scores. However, they also found that medication adherence was associated with inferior outcomes and this effect remained after controlling for premorbid function [41].

Harrow's study has the limitation of being naturalistic. Individuals were not randomly assigned to receive any particular treatment. Those who stopped medications may have done so due to factors that contributed to their superior outcomes. They might have stopped their drugs precisely because they were doing better. One of his findings, however, challenges this hypothesis [15]. He compared the level of psychotic symptoms between two groups who were both diagnosed with schizophrenia. One group was on drug at every assessment point, and the other was never on drug at

any point. The groups manifested similar levels of psychotic symptoms after 2 years. It was only after that time that those who were not on drugs improved and their improvement continued over successive assessment points. The magnitude of psychotic symptoms among the group taking antipsychotic drugs, on the other hand, remained essentially static. If the group off drugs stopped them *because* they had experienced improvement of their symptoms, that would have been apparent at the 2-year assessment point. The recovery they showed seemed to begin after year two. Even when controlling for the presence of positive prognostic indicators, Harrow reported a negative effect of antipsychotic drugs on long-term outcomes.

There are several randomized controlled studies that also suggest that continued use of antipsychotic medications might result in poorer outcomes, particularly with regard to indicators of functioning [16, 17]. Wunderink and colleagues [18] studied a group of individuals experiencing an initial episode of psychosis who were stabilized on drug for 6 months and then randomly assigned to one of two treatment groups: one maintained drug therapy (MT) while the other stopped it (DR), resuming if there was a recurrence of psychosis. The groups were followed for 18 months initially. At that point, the DR group had a higher relapse rate and there was no apparent advantage to this approach [19]. However, the cohort was assessed 5.5 years later. At that time, the DR group had a much higher level of recovery (40%), defined as remission of psychotic symptoms along with engagement in work and social relations, as compared to the MT group (17%). Furthermore, the difference was accounted for by the difference in functional outcome – the ability to work and have friends. The rate of symptomatic recovery – the proportion of each group to achieve an absence of psychotic symptoms – was similar (~67%). In addition, at the 7-year follow-up assessment, the overall rate of relapse was similar between the two groups; early maintenance of drug appeared to postpone but not prevent relapse. These findings support the hypothesis that the drug-induced indifference observed

by Laborit and others and discussed earlier in this chapter might, over time, result in impairments in functioning: being unemployed and having fewer meaningful relationships. These are aspects of life that are deeply valued by most of us.

Our conceptualization of schizophrenia might have made it harder for psychiatrists to consider the negative effects of long-term exposure to antipsychotic drugs, particularly since Emil Kraepelin characterized dementia praecox, now called schizophrenia, as a condition with an inevitably chronic and deteriorating course. However, this conceptualization of the condition has not been consistently borne out in long-term outcome studies. A landmark study of patients who were extremely symptomatic and poorly responsive to chlorpromazine and enrolled in an innovative rehabilitation program in the 1950s [20], found that, 25 years later, 68% of these individuals were living on their own in the community with few or no psychotic symptoms. Other studies have found that outcomes are more varied than predicted by the Kraepelinian model [21]. It therefore seems imprudent to ascribe all poor outcomes to the nature of the psychotic condition itself.

If one is trained in a disease-centered model and observes patients who appear calmer and less bothered by voices after taking antipsychotic drugs, it is easy to conclude that the drugs target some pathophysiology specific to this experience. When the person stops the drug and seems more bothered or influenced by the voices, it is easy to assume that the person is now experiencing a recurrence of the disease that that the drug had once treated effectively. If one is trained in the Kraepelinian model of schizophrenia, it is not a stretch to assume that apathy and the failure to work or have friends is due to the illness. The growing need for more inpatient beds despite the availability of these drugs would not necessarily raise alarm – at least not about the failure of our current treatments.

A drug-centered paradigm, on the other hand, predicts the results of the Wunderink study. Drugs whose major impact is to cause cognitive and behavioral blunting may be expected to impair function when one takes them for many years. A

disease-centered approach, combined with an archaic and unproven notion of the nature of the disease in question, appears to have made it more difficult for the profession to become aware of these potential problems.

A significant problem with these drugs is that many people do not like to take them. Their refusal to accept medical advice has become associated with a failure to acknowledge their illnesses. The term “anosognosia” has been used to describe this phenomenon, and some have argued that this should be incorporated into the diagnostic criteria for schizophrenia [22]. This conceptualization is consistent with a disease-centered approach. A drug-centered perspective allows for the possibility that the cognitive changes people who take neuroleptic drugs experience – the indifference observed by Laborit – might not always be experienced as positive. This topic is discussed in more detail in Chap. 7 in this volume, but it is important to consider it in the context of the drug- versus disease-centered models.

From a drug-centered perspective, a different paradigm of care emerges. First of all, it makes sense to wait, if at all possible, before drugs are started. Psychosis is complex and still poorly understood. Stress, sleep deprivation, and substance use can all contribute to its emergence in a substantial number of young people. Providing them a safe and supportive environment to determine who might emerge from the psychosis without drugs has been demonstrated to be an effective approach [23]. Once on a drug, it seems reasonable to consider stopping them when the target symptoms are less intense. Delineating optimal ways to taper and discontinue the drugs is recognized as a vital arena of investigation. Psychosis is thought of as a condition from which people are likely to emerge – without requiring life-long adherence to drug therapies. The relapse risk associated with drug discontinuation, while continuing to be a serious concern, is considered but one risk to be weighed against those of impaired functioning, weight gain, and tardive dyskinesia associated with drug therapy continuation. Clinicians and others acknowledge that reluctance to taking these drugs can be due

to something other than a lack of awareness that one is ill; it may be related to experiencing the effects of the drugs as unpleasant. Individuals who are prescribed these drugs are invited, along with those who care about them, into careful and considered discussion about these various risks and benefits.

## Antidepressant Drugs

Drugs thought to relieve depression have been in use for decades. Their use increased in the 1970s and 1980s with the introduction of the tricyclic antidepressants and then skyrocketed in the 1990s and beyond with the introduction of the selective serotonin reuptake inhibitors [3, 24]. Along with depression, their indications have broadened to include anxiety disorders, pain, obsessive-compulsive disorder, post-traumatic stress disorder, and bulimia. All of this contributes to an increasingly broad target population for these drugs. One in 9 Americans now takes an antidepressant, compared with 1 in 50 three decades ago, and 25% of these people have been taking it for 10 years or longer [25].

Yet there are serious concerns about short-term efficacy and adverse long-term outcomes associated with these drugs. While in some reviews antidepressant drugs are reported to be more effective than placebo, the impact is a statistically but not necessarily clinically significant one [26]. That is, there are large enough sample sizes to detect small differences between active drugs and placebo on clinical rating scales, but these differences are not likely to have much impact on a person's sense of well-being [27]. The recommendation for long-term use is based on relapse data; however, similar to what was found with neuroleptics, these drugs might also worsen long-term outcome. Vittengyl [28] evaluated 9-year outcomes among people who experienced depression and found that those treated with antidepressants had worse outcomes than those who were not. To examine the competing hypothesis that this result was due to those on drug having

more severe depressive conditions, he used a national sample of individuals that included assessments of symptom severity and socioeconomic status, as well as treatment exposure. He found that even after controlling for illness severity, there continued to be a negative impact of exposure to drug treatment.

Other studies also suggest that individuals who continue on drug do worse over time than those who stopped it or were never prescribed an antidepressant. These findings do not appear to be explained by differences in the severity of the condition being treated. In a World Health Organization study of the efficacy of depression screening tools, researchers found that those who were identified through screening as having depression and were treated with antidepressants did worse than those who were diagnosed with depression but not prescribed drugs to treat it [29]. Baseline severity ratings were the same between the two groups. If a person responds to drug but relapses when it is discontinued, reinitiation of drug might seem the obvious route to follow. However, Posternal and colleagues [30] studied 84 individuals who had initially responded to antidepressant drugs but then relapsed after the drug was stopped. They did not resume drug treatment, but at 1 year 85% were in remission of their depressive symptoms.

Shortly after fluoxetine was introduced, there were case reports that the drug might, in some individuals, be associated with the onset of intense feeling of suicidality or aggression [31]. This risk appears to be of particular concern among children and adolescents [32]. However, the risk was minimized by some experts, and the suicide events were attributed to the underlying condition the drugs were prescribed to treat. Psychiatrists who raised alarms about the potential hazards of the drugs were criticized for frightening people away from taking them. However, when FDA “black box warnings” regarding suicide risk were added, this seemed to have affected prescribing practices only for several years after they were issued [33]. In addition, there is not strong evidence of an association between the rate of SSRI prescribing and reduction in rates of suicide [34]. Fortunately, suicide is a rare event and correlations do not

prove causation. Experts often argue about the relative merits of various statistical analyses. However, there is no reason why this concern cannot be included in the informed consent process when people are prescribed these drugs.

The modest evidence for short-term efficacy combined with the many questions that exist about negative short-term effects as well as poor long-term outcomes support a cautious approach to using antidepressant drugs.

## Benzodiazepines

While it might be more difficult for a psychiatrist to consider neuroleptics from a drug-centered perspective, it is likely less of a challenge with the benzodiazepines. These are older drugs with multiple indications. They are recognized as causing dependence and withdrawal symptoms. Their short-term benefits are obvious to anyone who takes them and are not specific to those with a particular syndrome or disorder; they are sedating for everyone, and, if they do not immediately induce sleep, most will experience the effect as calming. Although different benzodiazepine compounds are in some instances prescribed for different conditions, those differences are entirely due to differential pharmacokinetics, i.e., different rates of absorption, onset and offset of clinical action, and elimination. For example, a drug that is absorbed and eliminated quickly will be better as a sleep aid and a drug that has a slower rate of absorption and longer elimination half-life would be more helpful to someone with persistent anxiety.

The disease-centered paradigm is relevant to our understanding of benzodiazepines because of the impact it has had on our knowledge base regarding these drugs. Similar to other drugs, initial studies focused on establishing efficacy for specific indications in short-term studies with limited assessment of long-term outcomes. While it has long been recognized that they can be addictive and abused, in recent years there is increasing evidence that use of these drugs is correlated with an overall increased mortality [35]. Lembke and



colleagues reported that overdose deaths involving benzodiazepines increased in the USA almost ninefold from 1999 to 2015 [36]. Chronic exposure to benzodiazepines is correlated to increased risk for memory impairment [37]. They are associated with increased risks of falls, depression, infection, cancer, suicide, and overall mortality [35]. Yet despite this, they continue to be commonly prescribed. In the USA from 1996 to 2013, the number of adults who filled prescriptions for benzodiazepines increased by 67% [36].

## Conclusion

The implications for a drug-centered versus disease-centered approach to pharmacotherapy can be examined for many classes of psychoactive drugs. The themes are similar: short-term efficacy with increased relapse risk when drugs are stopped, combined with a conceptualization of mental disorders as chronic, leads to recommendations for long-term drug use. Considerations of withdrawal effects as distinct from relapse are generally ignored as are data suggesting that many people recover without drug therapy. Despite an ongoing attachment to the notion of drug specificity, each class of drugs seems to have ever-widening indications. This results in more people on ever expanding numbers of drugs for indefinite durations. Over time, evidence emerges suggesting that those who remain on these drugs appear to do worse than those who have stopped taking them.

This raises interesting questions about the influences involved in physician prescribing. First of all, it is important to understand the notion of the placebo response. Most consider this to be a manifestation of the impact of expectation; what one expects to happen is more likely to happen. It is incorrect to interpret the data on short-term outcomes as an indication that the drugs are ineffective. The controversy, rather, relates to the question of whether there is a meaningful difference in response between those given placebo and those given active drugs.

In clinical practice we frequently face the dilemma that, although many people report a favorable responses to drug therapies, we have no way of knowing in each circumstance the extent to which such improvements represent placebo responses rather than benefits attributable to specific pharmacological attributes of the drug we prescribed. Let's consider the clinical situation in which a patient has taken a drug, is feeling better, is not having any major problems with the drug, but, based on concerns about the potential risks of long-term adverse outcomes, is considering whether it makes sense to continue to take it indefinitely. There are two likely alternative short-term outcomes the person might experience if the drug is stopped: no change or feeling worse. A doctor and patient who understand the drug-centered approach might be able to weather the period of feeling worse because they are aware that this might pass and that, over time, there might be more benefit to the patient by enduring this period of difficulty. Doctors tend to favor resumption of the drug – or not even attempting to stop it in the first place – and this is likely due to cognitive biases that influence clinical decision-making.

Daniel Kahneman and other cognitive psychologists have studied the kinds of biases that affect decision-making when the outcome is uncertain. In his book, *Thinking, Fast and Slow* [38], he describes common heuristics, or “rules of thumb,” that influence decision-making. While doctors believe themselves to be acting under rational rules that follow evidenced-based guidelines, various biases influence everyone, even those who are well-educated experts in their fields. One powerful bias is that of loss aversion, being “driven more strongly to avoid losses than to achieve gains” (p. 302). Another influence is the availability heuristic; people are influenced by events they can more easily recall. A “relapse” or worsening of symptoms is going to be experienced as a negative outcome – a loss – for both the patient and the doctor. The risks that have been discussed in this chapter that are associated with long-term exposure to drugs are more distant. They are therefore likely to have a weaker impact on a physician's decision-making

process than the short-term and more immediate risk of relapse. These biases favor physicians – and many patients – being averse to drug discontinuation.

Nevertheless, a more modest approach to pharmacotherapy, predicated on a drug-centered approach, seems warranted. Given that we currently live in a culture where psychoactive drugs are widely prescribed and actively promoted, many individuals are likely taking drugs that not only might not be helping them but might in fact be harming them. In addition, there has been a proliferation of polypharmacy prescribing in psychiatry and this is, at least in part, attributable to the disease-centered model and the promotion of the concept of “comorbid” psychiatric conditions.

There are several general recommendations that can be made, based on the drug-centered approach:

1. Begin with a careful discussion of psychiatric diagnosis. It is important to emphasize that psychiatric diagnoses are categories used for identifying common clusters of experiences but that they do not carry information about the causes of the problem or distress they name.
2. Consider non-pharmacologic options including watchful waiting, reducing substance use, and improving sleep and diet before starting a drug.
3. When suggesting a drug, explain that the drug is targeting particular symptoms rather than a disease state.
4. Explain what is known about drug action and how that might affect, in both positive and negative ways, the person’s experience.
5. Offer information on the powerful influences of placebos across the population.
6. When drugs are initiated, discuss the duration of treatment and plans for tapering and discontinuation.
7. After a person starts a drug, remain curious about general psychoactive effects. Avoid focusing only on symptoms.
8. If the drug does not help or if adverse effects emerge, consider reducing the dose or stopping the drug before adding another to target the new problems.

9. Make one change at a time, identify clear target symptoms, and systematically track the impact of the drug. Maintain careful documentation so that progress can be systematically reevaluated over time. Electronic health records need to be designed to support, rather than hinder, this process.
10. After a person is stable, discuss possible drug withdrawal.
11. Even if a person has difficulty at one time with withdrawing drug therapies, this does not necessarily indicate that such treatment needs to be continued indefinitely. Working with a person to minimize withdrawal symptoms is important. In addition, drug tapering can be revisited over time depending on the person's life situation.

Often, people come to us already having been prescribed medications, in many cases, more than one. The next chapter will discuss approaches to withdrawing these drugs.

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# Chapter 6

## Deprescribing and Its Application to Psychiatry



**Swapnil Gupta and Rebecca Miller**

### The Concept of Deprescribing

People are increasingly likely to develop medical conditions as they grow older, and this often results in their being prescribed multiple medications with potential serious adverse effects due to drug interactions, changes in drug metabolism with aging, and/or high dosing of individual medications. With the potential increase in morbidity and mortality due to inappropriate medication prescriptions, geriatric and palliative medicine introduced the term deprescribing to describe the practice of reducing or discontinuing medications whose “current or potential risks outweigh their current or potential

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benefits, keeping in mind the patient's medical status, functioning, and preferences" [1].

Recently, other branches of medicine, such as primary care medicine, cardiology, neurology, and, specifically of interest here, psychiatry, have begun to question the long-term use of medications. With that in mind, these specialties have begun to adopt the framework of deprescribing to approach the issue of potentially unnecessary medications. For example, in primary care, proton pump inhibitors have emerged as a class of drugs targeted for deprescribing, as the data on their long-term efficacy is insufficient [2–4]. Cardiologists have challenged the established practice of the long-term use of aspirin, statins, beta-blockers, and angiotensin-converting enzyme inhibitors following a myocardial infarction. Gaps in the current guidelines regarding the use of these drugs, problems with polypharmacy, and absence of drug withdrawal trials have spurred on this interest [5]. Similarly, clinical trials demonstrate the feasibility [6] and advantages [7] of reduction of anti-epileptic drugs in individuals who have been seizure-free for a specific amount of time. The Italian League Against Epilepsy, for instance, has proposed guidelines to identify individuals in whom anti-epileptic drugs can be deprescribed and for the management of the process of tapering the medications [8].

## Deprescribing in Psychiatry

In psychiatry, clinical trials have explored the possibility of medication reduction or discontinuation in persons experiencing chronic psychotic disorders [9–12]. These trials almost uniformly concluded that reduction or discontinuation of antipsychotic medications ultimately led to a relapse of the primary psychotic illness, and thus standard guidelines [13] now recommend indefinite treatment with antipsychotic medications. Similarly, in recurrent depressive disorders, guidelines recommend the indefinite use of antidepressant medications following two or more episodes, based on trial data that showed a higher recurrence in persons who stopped taking them as compared to persons who continued to take

them [14]. However, both these groups of trials add a caveat that further research is needed to identify persons who derive ongoing benefit from continued treatment with psychotropic medication (antipsychotics in the case of chronic psychotic disorders and antidepressants in the case of recurrent depressive disorders) versus those who are less likely to relapse after the discontinuation of a psychotropic medication. Antipsychotic medications have serious neurological and metabolic side effects with both long-term and short-term use, while antidepressant medications have been known to cause weight changes and sexual dysfunction that can persist in the long term and cause distress [15, 16]. Thus, for certain patients at a given point in their illness, with consideration of the context and life goals of the patient, the reduction or discontinuation of medication may be indicated. Further, when the patient's preferences, values, and medical status are factored into the choice of treatment, we propose the framework of deprescribing as useful for making collaborative decisions to implement psychotropic medication reduction in the safest possible manner. While some physicians and patients may perceive deprescribing as a withdrawal of care rather than a positive intervention, deprescribing may very well end up being more time- and labor-intensive than the introduction of medication to a treatment plan. The careful consideration of multiple factors, including stakeholders, supports, and interventions, is key to a well-thought-out trial of medication reduction or discontinuation. The following outlines situations in which deprescribing might be considered, recommended steps and practices in deprescribing, and areas of further research.

## Clinical Situations in Psychiatry When Deprescribing May Be Considered

Apart from serious or life-threatening side effects and drug interactions, there are situations which are not as clearly guided by the risk/benefit ratio in which deprescribing may be considered.

*When the Current Treatment Is Misaligned with Patient's Preferences*

Patients may voluntarily choose to experience symptoms from time to time rather than take medication every day. This may not necessarily be due to side effects but relate more to the effect of the medications on their functioning and to the meaning that the medication and the act of taking it every day carries for them.

*Maintenance Phase of Treatment of Chronic Psychotic Disorders or Bipolar Disorder*

It has been shown that the dose of antipsychotic medication required for relapse prevention (maintenance) may be lower than the dose required for acute symptom control [17]. In people with bipolar disorder, an antipsychotic or antidepressant medication may be added to a mood stabilizer to manage acute mania or acute depression. In such patients, it is important to gradually taper the doses of medication to a minimum effective dose or withdraw the medication completely after the acute manic or depressive episode has remitted.

*Unjustified Polypharmacy*

Even if a patient is not experiencing side effects or at risk for known drug interactions, situations where continuous polypharmacy is unjustified may require a deprescribing intervention. Second antipsychotic or antidepressant medications and augmenting agents, such as buspirone or aripiprazole, should be a priority for deprescribing because there are no guidelines for the duration of their use.

*Medications Prescribed for Specific Side Effects*

Medications such as anticholinergics used to treat extrapyramidal symptoms may not be needed beyond a certain period of time due to the development of tolerance to the parkinson-

nian effects of antipsychotic medications [18]. When used for longer periods, they may provide no additional benefit while significantly increasing side effects.

### *Medications Prescribed for Off-Label Uses*

Highly sedating antipsychotic medications such as quetiapine are often prescribed for management of insomnia in patients with psychiatric disorders. Similarly, antipsychotic medications are often prescribed for aggression and other behavioral problems not necessarily caused by psychosis or for the control of transient psychotic symptoms in post-traumatic stress disorder. These off-label uses put the patient at risk for serious side effects when other less risky medications or behavioral interventions such as cognitive behavioral therapy for insomnia [19] may be equally or more effective.

## The Pros and Cons of Deprescribing

In addition to reducing the side-effect burden, drug interactions, and financial burden, deprescribing can have other beneficial effects. When implemented in a collaborative fashion, it may improve the person's adherence to the remaining prescribed medications by increasing patient engagement in their own treatment [20]. It may increase the person's investment in non-pharmacological treatment strategies such as the development of coping skills or the use of individual or group psychotherapy. For individuals who find it stigmatizing to take psychotropic medications, even the possibility of deprescribing can offer hope, empowerment, and a sense of identity different from that of the "career mental patient."

The biggest risk of deprescribing is a relapse of the underlying illness, the effects of which could range from negligible to severe. In some instances, the crisis might warrant hospitalization which may cause suffering that could have been avoided and can be devastating to employment, education, or relationships. The risks of deprescribing must be tailored to

each patient based on past psychiatric history, the timing of the deprescribing intervention and the medication that is being considered for deprescribing. Both the risks and the benefits of the intervention must be discussed with the patient, in terms of available evidence and potentially acceptable and unacceptable consequences.

## The Process of Deprescribing

Reeve and colleagues [21] have reviewed the five essential elements of a deprescribing process described by various research groups. These elements include obtaining a complete medication history, identifying medications that are potentially inappropriate, evaluating the possibility of reducing and/or discontinuing the medication, implementing a plan for reducing and/or discontinuing the medication, and ongoing monitoring, documentation, and support. This process was expanded and adapted for use in psychiatry [22] with an additional focus on the timing of the intervention and bolstering other psychosocial supports. Box 6.1 summarizes the steps of deprescribing in psychiatry.

### **Box 6.1 Deprescribing for Psychotropic Medications [22]**

#### *STEP 1: Choose the right time/review psychiatric history*

- Avoid times of psychosocial crises/acute phase of illness
- Establish strong treatment alliance
- Use caution with active substance abuse

#### *STEP 2: Compile a list of all the patient's medications*

- Dose, route, expected duration, and original indication
- Document current therapeutic and adverse effects
- Estimate potential drug-drug interactions and future risk/benefit ratio

*STEP 3: Initiate the discussion with the patient*

- What is the patient's knowledge and attitudes about their medications?
- What is their perception regarding the benefits and risks of each?
- Explore the meaning of medication(s) to patient

*STEP 4: Identify which medication would be most appropriate for a taper*

- Collaboratively weigh pros and cons of deprescribing each medication
- Solicit preferences

*STEP 5: Introduce deprescribing to the patient*

- Inform about potential indications for and process of deprescribing
- Solicit ideas, concerns, and expectations
- Address any anxieties on the part of the prescriber, patient, family, or clinical care team
- Get family and caregiver buy-in

*STEP 6: Develop a plan*

- Start date and rate of taper
- Is switch to another medication/formulation indicated for taper?
- Reinforce alternative biopsychosocial strategies
- Inform about expected and possible discontinuation effects
- Agree on monitoring/follow-up schedule and crisis plan

*STEP 7: Monitor and adapt, if necessary*

- Adjust rate of taper.
- Treat discontinuation syndrome or relapse.
- Abort/defer deprescribing.

## Persons for Whom Deprescribing Might Be Appropriate

Deprescribing should be considered (but not necessarily implemented) for any person who is exploring the idea of managing their psychiatric illness without medications. An ideal candidate for deprescribing is someone who is engaged in treatment, largely free of symptoms, has not demonstrated risky behaviors such as self-harm or violence in the recent past, does not have active substance use, and has social supports who can assist in the quick identification and management of a relapse. If the prescriber determines that the current medication regimen is problematic in some way (e.g., use of two antipsychotic or mood stabilizer medications, without clear indication and history), the physician may consider approaching the person with the possibility of deprescribing, especially if there are indications that the medications may be contributing to a lower quality of life (e.g., due to sedation).

## Using Shared Decision-Making in Deprescribing

Whether deprescribing is initiated at the request of the patient or prescriber, a model of shared decision-making will support an exchange of information, attitudes, feelings, and preferences and combine best evidence with the individual patient's experience with a given medication [23]. This, in turn, can increase satisfaction with treatment [24] and empowerment of the patient [25]. This strategy may also strengthen the alliance between prescriber and patient and facilitate transparency and communication leading to better life outcomes. The development of a relapse prevention plan, such as Wellness Recovery Action Plan or WRAP [26], can be included in the shared decision-making process. These plans typically include identification of early warning signs, specific preferences in times of crisis, and post-crisis planning to assist the person in returning to home or work. The development of these plans can provide reassurance as well as specific mark-

ers for family and treaters to help prevent or at least identify a relapse in the early stage.

## The Implications of the Psychiatric History for Deprescribing

A past history of relapse or rehospitalization precipitated by medication discontinuation may tempt the prescriber to prematurely dismiss the idea of deprescribing. While such a reaction is certainly reasonable and understandable, there are additional considerations when interpreting the past psychiatric history. These may include the rate of taper, whether it was in collaboration with the psychiatrist, the reason for discontinuation, the context and life situation of the person at the time, substance use, the severity of the previous relapse, and other variables unique to the person. Further, the patient's preferences may have shifted in favor of a willingness to risk relapse in order to try a reduction of medications. In other words, a past history of relapse in response to medication discontinuation may not necessarily mean that deprescribing should never be considered again. Box 6.2 lists some factors to note in the psychiatric history when deprescribing is being considered.

### **Box 6.2 Factors in the Psychiatric History That May Have Important Implications for Deprescribing**

Past history of attempts at discontinuing medications

- Which medication was discontinued and at what dose?
- What was the rate of the taper?
- What were the person's symptoms at the time?
- Was the attempt assisted by the prescriber or not?
- Were there additional psychosocial supports at the time?
- Did any withdrawal symptoms develop?
- If a relapse occurred, when did it occur?



History related to the last hospitalization

- How many months or years ago was the last hospitalization?
- What precipitated the hospitalization?
- What were the main symptoms?

History of risk

- Suicide attempts
- Violence (including homicide)
- Other behaviors that the patient or their family may find concerning such as excessive spending, gambling, reckless driving, or drug use

Legal history

- Mandated medication treatments

## Appropriate Timing of Deprescribing

Ideally, deprescribing would be avoided during times of acute psychological or social crisis, such as loss of a job, unstable housing, bereavement, or separations (including separations from a therapist or prescriber with whom the patient is well-engaged). Each patient may have a preference for timing of the intervention. For instance, some may wish to avoid a holiday season, a busy season at work, or other impending stressors such as an exam or planned surgery.

A different set of deliberations arises when determining the timing of deprescribing in relation to the course of the underlying illness. For instance, would one consider reducing the dose of an antipsychotic medication three months after the full remission of a single psychotic episode? Similarly, would one consider withdrawing an antidepressant medication after a person has experienced two depressive episodes of moderate severity? In such situations, the prescriber should openly discuss the available treatment guidelines and evidence while also upholding patient preferences and safety.

## Managing Withdrawal Symptoms

Many psychotropic medications (beyond benzodiazepines) can cause distressing withdrawal symptoms. Benzodiazepines are widely recognized as causing dependence and potentially severe withdrawal. However, the SSRI withdrawal syndrome is well-described and characterized by flu-like symptoms, dizziness, paraesthesias, mood lability, and even mania [27]. Withdrawal or supersensitivity psychosis [28] has been described following the abrupt discontinuation of antipsychotic medications. It has been proposed that the mechanism of withdrawal psychosis is the upregulation of dopaminergic D<sub>2</sub> receptors due to the prolonged blockade caused by antipsychotics [29]. Although formal scientific literature in the management of withdrawal syndromes is lacking, consumer forums such as the withdrawal project of the Inner Compass Initiative [30] and publications of the Icarus Project provide guidance from first-hand experience of withdrawal syndromes [31]. Table 6.1 describes some of the commonly encountered withdrawal symptoms and suggests strategies for their management.

## The Ethics of Deprescribing

Reeve and colleagues argue that since deprescribing may be considered an error of omission, it becomes even more crucial to bolster its ethical bases [37]. Poor insight and judgment as well as societal interests have been used as arguments in favor of coercive or mandated treatments in psychiatry. However, medical ethics dictate that patient autonomy must be upheld at all times [38]. If patients express interest in deprescribing and are cognizant of the potential risks and benefits, a prescriber may offer them the least distressing methods of reducing the dose of a given medication. In a situation where a patient is unable to make medical decisions due to cognitive deficits, a legal surrogate may participate in the discussion with the prescriber. Further, if a deprescribing

TABLE 6.1 Discontinuation syndromes associated with commonly used psychotropic medications and recommended management

<b>Class/medication(s)</b>	<b>Symptoms</b>	<b>Management</b>
Serotonergic (SSRI, SNRI, TCA, and MAOI antidepressants) [27]	Light headedness/dizziness Vertigo, ataxia Paraesthesia/electric shock-like sensations, numbness Lethargy, headache, tremor, sweating, anorexia Insomnia, nightmares, excessive dreaming Nausea, vomiting, diarrhea Irritability anxiety/agitation, dysphoria	Reduce rate of taper <sup>a</sup> Switch to an agent with a long half-life such as fluoxetine Antihistamines
Antihistaminergic (e.g., hydroxyzine and diphenhydramine)	Irritability, anxiety, inattention Insomnia Mild anticholinergic rebound	Reduce rate of taper <sup>a</sup> Add sleep hygiene and other interventions to address sleep
Anticholinergic (e.g., benztropine and trihexyphenidyl) [32], [33]	Nausea, vomiting, increased sweating, sleeping problems, flu-like symptoms (symptoms of cholinergic rebound)	Reduce rate of taper <sup>a</sup> Antihistamines
Lithium	Recurrences of mania and depression resulting from withdrawal have been described but no literature on physical symptoms Recurrence of suicidality	Reduce rate of taper <sup>a</sup> Consider exercise and additional psychosocial interventions

Valproate	Recurrences of mania and depression resulting from withdrawal have been described but no literature on physical symptoms Seizure	Reduce rate of taper <sup>a</sup>
Antipsychotic medications [34], [35]	Cholinergic rebound (low potency) Hyperthermia (specific for clozapine) Dyskinesia, dystonia, or akathisia Supersensitivity psychosis	Reduce rate of taper <sup>a</sup> Antihistamines
GABAergic (benzodiazepine and “z” drugs) [36]	Anxiety, restlessness Insomnia Agitation, irritability Muscles tension, tremor Seizures, psychosis	Reduce rate of taper using long-acting drug (clonazepam or diazepam) <sup>a</sup>

<sup>a</sup>Reducing the rate of taper may involve using different dose strengths of the same medication, cutting the pills, using liquid formulations when available, and using dosing regimens tailored for managing withdrawal symptoms rather than for treatment of the underlying disorder

intervention potentially leads to the reduction of side effects, improvement in social or occupational functioning, and a reduction in costs, it adheres to the principles of non-maleficence and beneficence.

## Documentation of Deprescribing

Documenting the process of deprescribing is crucial as standard guidelines are not available and this may raise medico-legal concerns. Documenting the original indication (if available), along with benefits and side effects of each medication, will be helpful in justifying an intervention and demonstrating adequate planning before execution. Accurate notes on the decision-making process undertaken before identifying the specific medication for deprescribing, a plan of management for potential relapse, any reading materials provided to the patient, consultations with the pharmacist or primary care physician, and meetings with family and significant others will further establish due diligence. Finally, documenting follow-up visits including phone calls and gathering of collateral information is essential. In addition to addressing medicolegal concerns, thorough clinical notes may assist future treatment of the same patient as well as other patients with similar case histories.

## Future Directions

Discussion and research regarding deprescribing are only starting to emerge in psychiatric literature. Randomized controlled trials of antipsychotic medication discontinuation need to be conducted again in selected individuals with the use of newer modalities such as neuroimaging and genetics to potentially identify individuals who are less likely to relapse. Evaluation of the effectiveness of different tapering strategies is warranted. Further, new technologies such as mobile applications for tracking mood and behaviors can be harnessed in early identification and management of relapses. It

is also crucial to determine the needs, attitudes, preferences, and experiences of the consumer both through surveys and qualitative interviews. “Deprescribing clinics” are a promising development as a part of a larger outpatient psychiatric service or even as a consultation service. Studies that combine medication management and specifically medication tapering, along with a personal treatment plan, are required in the field of deprescribing.

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# Chapter 7

## Coercion and the Critical Psychiatrist



**Nicolas Badre, Shawn S. Barnes, David Lehman,  
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### Introduction

Psychiatrists in many parts of the world play a role in society not only in defining what it means to have a mental illness but also in determining the fate of those so afflicted. This authority can have profound effects on people; psychiatrists have authority to compel hospital admissions, seclusion and restraint within hospital, and administration of psychoactive drugs. Psychiatrists are called upon to offer opinions

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regarding people's capacities to make financial and medical decisions and to determine who should be sent to a hospital rather than a jail. The many concerns explored in this book raise urgent questions for critical psychiatrists regarding the underlying justification and wisdom for the assumption of these responsibilities. While many psychiatrists can avoid this dilemma by choosing to practice in settings where these issues do not arise, this is not an option for psychiatrists who work with people who experience psychosis or other extreme states where behavior may be so affected that individuals pose risks to themselves or others or are not able to behave in ways that comport with societal expectations.

There are several questions that critical psychiatrists need to address. Each one, if answered affirmatively, leads to the next question. By examining these questions sequentially, psychiatrists can determine the extent to which they can participate in coercive practices. First, is force ever necessary? Second, if one concludes that force might sometimes be necessary, is there a role for the medical profession in this process? Third, if one accepts that there is a role for physicians, how does one accept this responsibility in an ethical and intellectually coherent manner?

## Is Force Ever Necessary?

Even in states where individual liberty is highly valued, governments may sometimes put the public interest over those of the individual. Those functions include not only managing financial and territorial rights but also promoting social benefit and legal order. To achieve those latter two goals, some societies have instituted the death penalty, policies for removing children from parents' control, and involuntary confinement, be it civil or criminal. Doctors have been involved in many of those tasks. Some functions carry moral ambiguity and can put a physician at odds with professional ethical obligations, for example, administering death penalty drugs, diagnosing and treating slaves, making recommendations for how to make torture more effective, or promoting euthanasia.

There are varying opinions on the extent to which involuntary psychiatric hospitalization and treatment raise questions about professional ethics.

During the nineteenth and twentieth centuries, Social Darwinism posited that purportedly heritable, undesirable traits of individuals posed public health and even national security risks and warranted involuntary sterilization of those deemed unworthy of procreation. Those ideas, widely accepted in medical, psychiatric, and popular culture at the time, have since fallen in disrepute after the horrors of the Holocaust, which was framed by the Nazis as a public health response to the national security threat posed by genetically inferior Jews and others – including the disabled and mentally ill – compromising the health of the Aryan population.

As the state took an interest in the mental health of its workers and consumers in order to maintain a healthy, functioning economy, the psychiatric profession was there to claim powers to address the problem. The horrible and unintended result was that the state discovered that psychiatric care of the mentally ill is an expensive undertaking and perhaps not worth the effort; the Sonnenstein Clinic in Germany, where Ernst Pienitz attempted to create a therapeutic asylum [38], eventually came under the influence of the Nazi's infamous T4 Program and became one of the world's first gas chambers [22]. Most countries discovered, over the course of approximately a century of developing inpatient treatment, that asylums are extremely expensive and that mental illness can be frustratingly difficult to understand and treat. It became tempting to make the problem disappear using a variety of tragic solutions, including murder. The United States never resorted to murder, but neglect (and certainly not of a benign kind) and euthanasia were employed [3, 39]. While the Nazis might be held up as an extreme, their connection to once popular, albeit now-discredited, theories is widely cited by those critical of psychiatry and, at the very least, is a cautionary tale for the profession.

Nevertheless, it is generally accepted that governments have a legitimate role in enforcing community safety. When

an individual cannot comport themselves in accord with community standards, law enforcement intervenes. Such a person can be charged with a crime and, if convicted, face punishment. The challenge is how to address those who behave in irrational ways. In Western cultures, mental health professionals have been called upon to be the arbiters of the “mad vs. bad” question. Those deemed “mad” are sent to mental institutions and those deemed “bad” to prisons. Even those most critical of psychiatry’s role in coercive practices do not necessarily argue against some response to those who are violating the law.

In 1961, Thomas Szasz published the *Myth of Mental Illness*. He argued that mental illness is an inherently incoherent combination of medical and psychological concepts. He opposed the use of psychiatry to forcibly detain, treat, or excuse what he saw as mere deviance from societal norms or moral conduct. He “insisted that mental hospitals are like prisons not hospitals, that involuntary mental hospitalization is a type of imprisonment not medical care, and that coercive psychiatrists function as judges and jailers not physicians and healers.” He was not against force, but he was against psychiatry’s participation in the use of force; he opined that dangerous people should be incarcerated if they break the law and that medical professionals should not participate in this police function [35].

Organizations such as the Bazelon Center were established to protect the rights of those with mental disabilities. While they argue for improved protections, they have not argued for a complete elimination of force. Some of their most important legal successes have been to enforce the right to treatment. MindFreedom International is an organization whose members are primarily drawn from those who have experienced psychiatric treatment, often against their will, and want to protect others from coercion. Among their goals: “Support the self-determination of psychiatric survivors and mental health consumers” and “Promote safe, humane and effective options in mental health.” [23]. Their challenge to the profession also addresses fundamental premises of

psychiatry. Similar to Szasz, they challenge the legitimacy of psychiatric illnesses as well-defined entities that fall within the legitimate purview of medicine. These arguments against force do not ultimately hold that there is never a need to use force to intervene when a person is behaving in a dangerous or erratic manner. Rather, they question the legitimacy of psychiatry's role in this endeavor. They argue for alternative approaches and promotion of the civil rights of those at risk for involuntary treatment.

## What Is the Role of the Medical Profession in This Process?

Philippe Pinel, at the end of the eighteenth century, argued for more humane approaches to those residing in asylums. Pinel and Pussin introduced concepts and practices that were radical for an era when internment of the mentally ill in asylums represented punishment more than therapy. The so-called moral treatment replaced shackles, endless seclusion, and corporal punishment with kindness, increased social engagement, participation in daily activities, and minimization of restraints. This period has been memorialized by the long tradition of teaching psychiatrists in training about Pinel's unshackling of the mentally ill at the Bicêtre Hospital. This humanization of mental health treatment has been at the cornerstone of subsequent attempts by psychiatrists and others to reform the approach to involuntary commitment.

Psychoanalysts have long called into question mainstream approaches to the conceptualization of psychosis by postulating that psychosis might be a psychic defense in response to a stressor. An extension of this belief is to argue that psychosis is sometimes natural or even beneficial. In his doctoral thesis, Jacques Lacan [20] discussed the case of Aimée. He argued that she represents a case in which the psychotic experience was meaningful and useful to her recovery. Aimée's psychosis, he claimed, served a need for self-punishment. When her psychosis led her to commit a crime and she was subsequently

found guilty, her psychosis disappeared as it no longer was needed to serve the purpose of reprimanding her. Lacan's and other psychoanalysts' teaching can be used to theorize that, in certain cases, psychosis was a manifestation of a psychological need and not simply a meaningless detachment from reality. The concern would be that forcing someone to stop communicating in this manner may be more psychologically harmful than therapeutic.

In the 1960s, psychiatrists R. D. Laing and David Cooper spearheaded the Philadelphia Association. Their work was based on the idea that mental suffering, including psychosis, is best dealt with by living in ordinary settings with people who can relate using their own personal experience. This resulted in the use of Kingsley Hall as an open and voluntary treatment household where there was no distinction between patient and professional. Patients came to Kingsley Hall to live rather than to be treated. This form of repudiation of standard mental health treatment was seen as so controversial as to be considered a precursor of the anti-psychiatry movement [5].

Michel Foucault has been one of the most notable critics of psychiatry. His book *Madness and Civilization* [12] has influenced many on the subject of the limitations of modern society's approaches to the treatment of those deemed mentally ill. He argued that history shows us examples of different and less stigmatizing treatments. During the Renaissance, he pointed out that psychotic patients were considered to have wisdom and a role within society. However, as societies evolved, psychotic patients were deemed to be a burden and exiled from the rest of the population. Modern society's attempt to repair this harm has been to assign their care to doctors. Having worked in asylums, Foucault argued that this was simply an improved rationale for the continued internment of the mentally ill. Foucault claimed that asylums and the involvement of psychiatry in involuntary treatment have rendered psychiatrists officers of the state and no longer at the service of their patients.

Foucault argued that capitalist economies require healthy populations to maintain both steady production and

consumption of goods and services. The state, therefore, has an economic interest in the health of the population; the medical profession assumes the role of nurturing the populace in order to maintain the economic health of the wider society. It is from this relationship that the treatment of mental illness becomes of such crucial interest to the state. Mental illness is a serious problem to address in a capitalist economy. Addiction, depression, psychosis, and dementia are expensive disruptions to the style and schedule of work that originated with the industrial revolution and modern conceptions of time. Agrarian economies had more flexibility in terms of allowing for lateness, intoxication, and impaired social skills. Factory work, in contrast, cannot tolerate these infractions.

These arguments underlie prohibitions against the use of psychiatric authority in a coercive fashion or as cause for a cautious approach to the use of force. The challenge is that some individuals act in irrational ways that appear to be distinct from what is typically considered criminal behavior. Even if one attributes the causes of such behavior to the ravages of neoliberalism or other societal factors, one nevertheless faces the quandary of how to respond to people who act erratically or seem unable to use reason. For centuries, most societies have felt it cruel to treat these individuals as criminals and have wanted to offer treatment rather than punishment. This has led to the establishment of guidelines for determining criminal culpability.

Judge Bazelon, in *Durham v. United States* [9], expressed the moral justification for the insanity defense by noting: “Our collective conscience does not allow punishment where it cannot impose blame.” Most jurisdictions in the United States base the assignment of guilt on the M’Naghten Rule of 1843 [24]. This involves establishing if a person, at the time of the offense and as a result of mental illness, lacked the ability to understand the nature of the act committed or, if such ability were present, lacked the capacity to distinguish between right and wrong [14]. Mental health professionals are called upon to make these determinations. In some instances, they are called to intervene even when there have not been

unlawful behaviors but when people appear to pose risks to themselves or others because of mental disorder.

Recognizing that some critical psychiatrists (among others) might disagree, the authors of this chapter believe there is a legitimate role for a society to attempt to make these kinds of determinations and for some individuals to be offered alternatives to criminal sanctions or to be forced into what is essentially protective custody when they appear to pose significant risks. We consider that it is reasonable to assign this task to mental health professionals, including psychiatrists. This leads to the next question regarding the role of critical psychiatrists in this process.

## Can Forced Treatments Be Effective in Reducing Harm?

In psychiatry, there can be an illusion of certainty pervading our discussions of both diagnoses and treatments. The Diagnostic and Statistical Manual implies to many a sense that there are discrete illnesses delineated by scientific inquiry. The problems with this assumption are discussed in detail in Chap. 2 in this volume. The medications psychiatrists prescribe are often explained to patients as correcting a chemical imbalance, “just like insulin for diabetes.” Forty-six of fifty states have enacted involuntary outpatient commitment laws on the assumption that long-term antipsychotic medication is effective. Unfortunately, as discussed earlier in this book, these assumptions have been challenged. When involuntary treatment is considered, we would want strong evidence in support of the efficacy and safety of treatment administered against a patient’s will. We will focus on some of the illusions of certainty surrounding involuntary treatment and examine the evidence.

Involuntary psychiatric treatment has been on the rise in recent years [30], but does the evidence support its use? Psychiatrists can involuntarily hospitalize a person on the basis of assessing there to be a significant risk of suicide or harm to others. However, the idea that suicide or future



dangerous acts can be accurately predicted is contrary to empirical evidence. Prevention of the death of a patient is one of the most fundamental goals of medicine. In the face of poor predictive abilities, physicians need to weigh the risks of errors of omission versus errors of commission. It is imperative for physicians to weigh the relative harm in admitting individuals to a hospital over their objections as compared to the risk of not admitting individuals who might go on to harm themselves or others.

### *Suicide*

To our knowledge, there is no randomized controlled study or systematic review that has found any reliable evidence that involuntary intervention reduces or prevents suicide [1]. While there are potential harms of admission (physical isolation, restrictions on personal items, stigma, social isolation from friends and family members, etc.), there is little evidence to suggest that involuntary admission alters risk of death by suicide. Huber and colleagues [17] compared outcomes for nearly 150,000 patients admitted to locked versus open psychiatric units in Germany. Controlling for severity of symptoms, they found that locked units were associated with a slightly higher rate of eventual death by suicide compared to open, voluntary units. Fulton County, Georgia, was forced to reduce admissions to its locked psychiatric hospital in 1996, due to budgetary constraints. Patients with substance use disorders, personality disorders, and recidivism were not admitted during that year, resulting in a 56% decline in admissions. However, the suicide rate in the county remained essentially unchanged, suggesting that hospitalization, forced or not, does not seem to reduce suicides [13].

### *Dangerousness*

Another area in which there are distorted beliefs relates to the dangers posed by people with mental illness. The mass murders in the United States committed in Aurora, Newtown,

Santa Barbara, and Charleston have magnified attention paid to mental illness and violence despite none of those crimes having been judged to have been consequences of psychosis. Politicians on all sides have promoted the belief that patients with mental illness cause violence. Donald Trump once said, “This isn’t a gun problem; it’s a mental health problem ... these are sick people” [41], while Barack Obama has stated that “incidents of violence continue to highlight a crisis in America’s mental health system” [10]. This message has been amplified by the media with headlines like, “Get the violent crazies off our streets” [6] and “They threaten, seethe and unhinge, then kill in quantity” [11].

Despite this common public belief in a high rate of dangerous behavior among those identified as mentally ill, the scientific evidence contradicts those views. Most reviews of the topic come to conclusions similar to those of Pinals and Anacker [27], who wrote: “Despite media accounts to the contrary, persons with mental illness account for only a small percentage of persons who commit acts of violence.” Swanson and colleagues studied more than 10,000 people with and without mental illness over the course of a year and found that serious mental illness could only be attributed to 4% of the aggressive acts. They found three factors that predict its occurrence: whether the perpetrator was male, poor, or abusing drugs [34]. “That study debunked two myths,” Swanson reported, “One: people with mental illness are all dangerous. Well, the vast majority are not. And the other myth: that there’s no connection at all. There is one. It’s quite small, but it’s not completely nonexistent” [19].

The problem of violence and the role of psychiatry in its prevention presuppose an ability to predict future acts of aggression. Encouraged by financial incentives, tests and tools that predict violence have proliferated. The popular actuarial approach involves using weighted risk and protective factors found to be statistically associated with criminal behavior to assign scores to individuals. However, in a meta-analysis, Singh and colleagues [31] found that studies done by the authors of a predictive instrument found a twofold greater ability to predict future violence than studies done by

independent researchers. Hart and colleagues [16] report that the validity of such tests at the individual rather than the population level is limited.

### *Antipsychotic Drugs*

As discussed in Chaps. 4 and 5 of this volume, long-term use of antipsychotic drugs is recommended as essential for the optimal treatment of people with psychotic disorders, yet there is substantial evidence that challenges this convention. It is, therefore, worrisome that long-term antipsychotic drug treatment can be administered involuntarily in many places. Outpatient commitment laws in the United States (referred to euphemistically as assisted outpatient treatment (AOT)) can be used to compel individuals to comply with treatment, including medications, as a condition of maintaining freedom in the community [2]. These commitments are usually long term. In New York State, which has the most data collected on its AOT program, 61% are involuntarily committed for over 1 year, and 25% are committed for over 2.5 years [28]. While there is strong evidence that antipsychotic drugs reduce symptoms during the acute phase of psychosis, evidence for the efficacy of long-term antipsychotic drug therapy is lacking.

A 2012 Cochrane review found diminishing effects of antipsychotics through time with relapse prevention rates approaching zero after 2 years [21]. Sohler and colleagues [33] evaluated studies that compared outcomes among those who had been exposed to antipsychotic drugs for longer than 2 years with those who had not. They found most studies were of poor quality and concluded that the data were inconclusive. In a randomized study, Wunderink and colleagues [40] studied 128 people after they were treated for a first episode of a psychotic disorder. For 2 years, one group remained on antipsychotics continuously, and another group was tapered off drug when stable and restarted on them if psychosis recurred. They subsequently reevaluated 103 of the initial cohort 5 years after the first study had ended.

Although those in the dose reduction/discontinuation group were more likely to have an initial relapse within the first 2 years, both groups were found to have roughly equal rates of relapse over the course of 7 years; drugs appeared to postpone but not entirely prevent relapse. While groups were similar with respect to the presence of psychotic symptoms at 7 years (about 30%), there was a striking difference, in functional recovery (returning to work, maintaining relationships). The group initially randomly assigned to dose reduction/discontinuation had a functional recovery rate that was twice that of the continuous treatment group (40% compared with 18%). The outcome correlated to dose; those on low doses of antipsychotic drug had much better functional outcomes than those on higher doses.

The data challenging existing treatment guidelines prompted a recent expert review [15]. The authors could only conclude that there was no definitive evidence that long-term antipsychotic exposure results in a worsening of psychosis. The article cited the increased risk of relapse as a reason to continue current guidelines but was notably silent on other benefits of long-term antipsychotic drug use [15]. They do not challenge the observation that relapse risk is only established to be higher early in treatment. While some individuals might choose to take antipsychotic drugs indefinitely, such data raise questions about forcing individuals to remain on them against their wishes.

## Informed Consent and Capacity

Modern medicine requires *informed consent* of patients to participate in medical treatment. This involves advising patients about the nature of their conditions, the proposed treatments, and the risks and benefits of both agreeing to and declining the treatments proposed. Participating in this process requires patients to have *capacity* to make decisions regarding their medical conditions. Capacity refers to an individual's ability to make rational decisions.

Capacity determinations are clinical evaluations, often a component of psychiatric assessments, that involve determining a person's ability to:

1. Demonstrate an understanding of the situation: e.g., "I was brought to the hospital because the police thought that I was acting strange" versus "The CIA brought me here because they want to do experimental brain surgery on me."
2. Express a choice: e.g., "I would like to leave the hospital because I prefer being at home" versus "This is the devil's den, take me out of here to somewhere safe."
3. Express the risks, benefits, and alternatives of treatment: e.g., "The psychiatrist recommends risperidone to improve my behavior but it might cause me to gain weight; alternatives include psychotherapy, waiting, and other medications" versus "You are trying to poison me, the water is poisoned in here, I am scared, I am going to stop eating altogether."
4. Express a coherent rationale for the decision being made: e.g., "I refuse treatment because I have seen others in similar situations do fine without medical treatment" versus "I refuse treatment because I think that if I take haloperidol, my mother will die."

The examples listed above underscore that when individuals are psychotic, their fundamental perspectives on their situations may be altered. Individuals with delirium might not be able to attend adequately to understand they are in the hospital. The inattention will make it difficult for physicians to explain the nature of the recommended treatment. Individuals who are psychotic might be perfectly attentive but lack a shared sense of consensual reality. Because capacity requires a person to demonstrate an understanding of the condition for which the physician offers treatment, capacity will by definition be impaired when an individual considers the problem to be external (e.g., related to aliens inserting thoughts into one's head) rather than internal.

This is an important consideration because the issue of "insight" has been a prominent one in psychiatry with regard

to decision-making capacity. Some have appropriated from neurology the term anosognosia which refers to the striking lack of awareness associated with neurological damage. This is most commonly observed in people who have had right hemisphere strokes who become oblivious to their left-sided hemiplegia. The use of the term to describe those who do not accept they have a mental illness implies that there is a similar, specific neurological abnormality. Critical to this discussion is that some organizations that promote the use of forced treatment use the concept of anosognosia to buttress their arguments [37]. They assert that differences found in brain imaging between those who have psychiatric symptoms including anosognosia, as compared to those who do not prove these conditions, are the result of a disease process which legitimizes the use of force. Variability in imaging, however, is not synonymous with brain pathology; people who are right-hand dominant, for example, may have different findings in an imaging study from those who are left-hand dominant, but this is not evidence of a disease process. In addition, although brain abnormalities have been found in those identified as having anosognosia, studies do not report consistent findings [36]. While the term might be an apt description of a person who has sustained frostbite but is oblivious to the damage and insists on continuing to sleep outside in subfreezing weather, inadequately dressed for the conditions, it is less helpful when considering a person who declines the drugs because the side effects of sedation and weight gain do not outweigh the benefits. We caution against using this term to provide validity to arguments for coercion. It not only implies a type of brain dysfunction that has yet to be substantiated by the evidence but also implies that the presence of a brain difference is an adequate rationale for forced treatment.

There are often differing opinions about the observed benefits of treatment. The clinicians might notice significant calming and coherence of thought which the individual might discount. These are complex conversations which do not seem well served by inaccurately using a sophisticated neurological term. While the decision to accept that someone has capacity

is subjective and should be subject to strict and thorough oversight by the legal system, it is an important and often overlooked topic in the involuntary treatment debate. We understand that involuntary treatment is polarizing, but failing to notice a difference between involuntary treatment with and without capacity simplifies the problem unnecessarily.

The term *nonvoluntary* has been advocated to separate those types of commitment for patients without capacity, using the term *involuntary* only for commitment of patients with capacity [32]. This type of nomenclature risks sanitizing a serious and important act of committing someone. Nonetheless the distinction is useful. Societies have long permitted the medical treatment of patients with diminished capacity. In most jurisdictions, when patients enter the hospital delirious, or severely incapacitated, treatment decisions are guided by advanced directives, designated medical powers of attorney, next of kin, or, if the former are not available, the clinical judgment of the treatment team. Medical decision-making capacity is returned to patients as soon as they regain capacity. When decisions regarding treatment occur in the context of psychiatric care, court orders supersede these other mechanisms, and patients often are required to return to court for restoration of their rights to make medical decisions.

## Coercion and the Critical Psychiatrist

A physician who accepts a role in coercive interventions is not likely to be perceived as helpful to those who are forced into hospitals or forced to take drugs. In some situations, such as forensic or guardian evaluations, the person conducting an evaluation is not treating the individual. However, in civil commitment hearings in many countries, psychiatrists serve a dual function; they may petition the court for commitment and testify in a hearing while also serving as the person's psychiatrist. This is a difficult situation that will be explored in the context of the critical psychiatric perspective.

Interfering with a person's liberty and right to self-determination is probably the most serious and difficult act

for any psychiatrist. It is particularly vexing for a critical psychiatrist who may question many basic tenets of the profession. The authors find judicious use of coercion the least bad alternative in certain situations. When a person has broken the law or is at risk of being charged with a crime due to an inability to conform behavior to accepted societal norms, psychiatric hospitals can be a better option than jail for individuals who are in the midst of extreme mental distress such as psychosis. When a person appears to pose a serious risk of violence to others, psychiatric hospitalization may benefit not only that individual (who is at risk of committing acts that the person might regret when in a different mental state or might result in incarceration) but also others who could be the targets of the aggression. When someone expresses serious intent to self-harm, hospitalization may give that person time to reconsider the act. The commonly cited study of people who survived jumping from the Golden Gate Bridge suggests that some people who have near-death experiences through acts of attempted suicide express relief that they survived [29]. When a person seems so incapacitated as to lack the wherewithal to attend to the most basic needs for food and shelter, we believe forced hospitalization is more humane than a strict respect for individual choice. At the same time, we recognize that there is judgment in each of these decisions; errors of commission will be made. Individuals will be hospitalized who might never have harmed others or themselves. Individuals who seem extremely impaired might have the ability to survive. A high level of judicial oversight in these processes is warranted, including the provision that those subjected to involuntary hospitalization and medication are provided with adequate legal counsel.

An important role for critical psychiatrists is to use their authority to acknowledge the risks and harms that our interventions may confer as well as advocating for societal progress that reduces the need for involuntary treatment. In studies of forced outpatient commitment, it can be hard to determine if improved outcomes are the result of the force or the enhanced services offered as part of the commitment [26].



This increased access to care should be offered without force prior to pursuing involuntary care. Developing and funding programs that offer a flexible array of treatment, including non-medicalized approaches to care, is important. Soteria, peer respite, and wet shelters are examples of these kinds of programs. Mental health courts are another alternative that give individuals the ability to avoid both hospital and jail.

Voluntary, non-medicalized centers such as peer-run respites will offer some a welcomed alternative to traditional services. One of these programs is the Western Mass Recovery Learning Community's Afiya. Their director, Sera Davidow, asserts "'stigma' happens when someone is unable to confess the magnitude of their pain without facing the consequence of involuntary incarceration (aka hospitalization)" [7]. She acknowledges the difficult position one is in when someone expresses a strong intent to die. She describes a person who stated that he was planning on killing himself during his stay at Afiya. "I had to explain to him that actually attempting to kill himself while staying at the house felt like an angry act toward us, as well...I had to explain how it wouldn't be fair of him to go there specifically to ask us to sit by while he dies." In discussing their evolving relationship, she describes a turning point when "instead of asking if there's anything I could do to support him to consider living, I simply said, "Okay, I hear that you want to die. That you are going to die. But, is there anything you want to do before that happens?" [8]. This person goes on to find a way to live in this world and make meaningful contributions to his community. Davidow and colleagues have developed "Alternatives to Suicide" which include peer support groups and trainings so that these groups can be available in other communities. In describing this training, she writes, "What we offer is more unlearning than anything else; more self-exploration so that you're better positioned to explore with others without needing to sound alarms." This approach focuses less on whether people will or will not act on their suicidal thoughts but more on the validation of and curiosity about their experiences as well as building community and connection.

Although developed as an alternative outside of the traditional system of care, these are approaches that can be incorporated into conventional settings. Other perspectives on this topic are discussed in Chap. 8 of this volume. Psychiatrists have much to learn from those who have been the recipients of our care.

Critical psychiatrists can also promote research that is informed by those who have been the recipients of our treatments. A growing body of literature offers a different perspective than that of randomized controlled trials (RCTs) which historically are most commonly conceived of and conducted by those who prescribe (and market) rather than ingest the drugs psychiatrists prescribe [25]. RCTs are considered the gold standard for evidenced-based medicine and have a great influence on not only treatment guidelines but also the medical opinions offered in commitment hearings. Research informed and, sometimes, conducted by those with lived experience offers a rich understanding of the experience of taking these drugs. This is valuable in all domains of psychiatric practice and is an important addition to the process of seeking informed consent but has particular salience when psychiatrists are forcing people to take medications.

Sometimes we meet a person for the first time in a crisis, but often we meet people before a crisis has occurred. We advocate for honesty and transparency in all matters including the potential use of coercion. Informed consent is as relevant to the use of involuntary actions as it is for voluntary treatment. Patients can be educated about when a psychiatrist may be compelled to resort to involuntary interventions. Encouraging individuals to complete an advanced directive or a tool such as the Wellness Recovery Action Plan [4] can be helpful to increase a person's sense of agency as well as encourage a person to express what kind of treatments are considered helpful. This may be particularly important when a person has already been subject to involuntary interventions. It can be a way to help the person address the trauma of the experience and reduce the sense of powerlessness in

the face of psychiatric authority. People admitted to the hospital can be informed about the use of seclusion and restraint and the criteria for discharge. Those should be based on objective behaviors and not questions of diagnosis or engagement in treatment, including adherence to prescribed medication regimens. For instance, refusal to take a pill from a physician who is forcing a person to stay in a facility should not, in and of itself, be grounds for continued hospitalization. However, behaviors such as ongoing violence toward self and others, lack of eating, lack of grooming, and lack of ability to communicate a plan for self-care are more appropriate reasons for extending inpatient hospitalization. The damage caused by not attempting to build a relationship based on trust and humility may outweigh the benefits of protective confinement.

Transparency is a key aspect of optimizing relationships with all patients, but it is considered especially important when a person is subject to coercion. This includes sharing with the person the limitations of our knowledge about the benefits of treatment as well as acknowledging that interventions that might have some benefit may also simultaneously do harm [18]. Using terms, such as anosognosia, does not advance transparent and honest discussions of these complex issues. Acknowledging the limitations of our predictive powers is preferred over unfounded certainty. For instance, telling a patient, “Based on what you have told me today, I do not want to take responsibility for letting you leave. If something were to happen to you, I would have to answer to others – your family, my supervisors, and myself – and I would not be able to justify not keeping you here where I think you will be safe.” That is a very different kind of conversation from stating, “I am keeping you here because you are ill and you are not safe.” When we commit a person to a hospital, we admit that we are making a judgment that could be wrong. This cognitive dissonance – understanding an act can be simultaneously beneficent and harmful – can be hard to sustain and that might be why many psychiatrists appear to retreat to a more certain and

less ambiguous position. However, we suspect that greater transparency improves our ability to work in a therapeutic manner with those who are forced into our care.

Coercion in psychiatry is arguably the reason why the anti-psychiatry movement exists. The authors offer some guidelines but are under no illusions that what is offered here will resolve fundamental questions and differences of opinion. At the very least, we hope our colleagues acknowledge the power society bestows on us and exercises it with judiciousness and humility.

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# Chapter 8

## Listening to Those with Lived Experience



**Emily Sheera Cutler**

### Introduction

One of the most important critiques of the dominant model of biomedical psychiatry comes not from psychologists or other mental health professionals but from individuals who have experienced emotional distress and have been given psychiatric diagnoses and/or psychiatric treatment. In the critical psychiatry academic discipline and activist community, these individuals are often referred to as “people with lived experience.”

Many scholars, advocates, and activists with lived experience have spoken or written about psychiatry’s colonizing effect on their identities. According to the American Psychiatric Association, psychiatry is “the branch of medicine focused on the diagnosis, treatment and prevention of mental, emotional, and behavioral disorders” [3]. Arguably, psychiatry constitutes a system of categorizing individuals as mentally disordered or mentally healthy; the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) serves as a framework to define the types of internal experiences and

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outward expressions that are pathological. Within this framework, psychiatrists and other mental health professionals are seen as the experts on the value, meaning, normality, healthiness, and rationality of their clients' experiences. The mainstream model of psychiatry is one in which clients tell their psychiatrists about their experiences and then are provided with the diagnostic terminology, language, and paradigm through which to understand them. Clients are taught to see their experiences as symptoms that need to be managed through one or more forms of treatment.

Scholars, advocates, and activists have critiqued this model of psychiatry on the basis that it provides little room for people with lived experience to come to their own understandings and conceptualizations of their internal states and outward behaviors. Many people with lived experience find meaning or value in their so-called symptoms and prefer to approach their distress and/or differences in a non-pathologizing way. Clients may, for example, view their experiences not as illnesses in need of treatment, but instead as positive aspects of their identities, rational reactions to traumatic circumstances, temporary states that will pass with time, or all of the above.

People with lived experience have developed a number of alternative frameworks for conceptualizing distress and difference. Two frameworks that this chapter will focus on are the principles of Mad Pride and the field of neurodiversity. The field of neurodiversity seeks to redefine thoughts, feelings, characteristics, and traits categorized as symptoms of mental disorders as naturally occurring, valid forms of human diversity. Similarly, the Mad Pride movement is made up of people with lived experience who find value and even pride in their experiences that have been constructed as madness or mental illness. Central to both of these paradigms is the notion of people with lived experience deciding for themselves what terminology and meaning they would like to ascribe to their own states and characteristics.

This chapter will discuss some of the primary principles, ideas, and tenets of both the Mad Pride and the neurodiversity movements. It should be noted that not all Mad Pride and

neurodiversity activists share the same views; in fact, both movements could be described as loose coalitions of individuals and organizations rather than unified campaigns. This chapter does not aim to capture the views of all Mad Pride and neurodiversity activists but instead some of the principles behind the development of both movements. It should also be noted that there are significant differences between the Mad Pride and neurodiversity movements, but this chapter will focus on similarities.

## Questioning Dominant Assumptions

Both the Mad Pride movement and neurodiversity field radically question some of the fundamental assumptions underlying the traditional model of psychiatric care. Both paradigms call upon mental health professionals, researchers, advocates, and the public to re-examine some of their beliefs about what we consider madness or mental illness. Below are some of the assumptions the two paradigms seek to challenge.

### *That Which We Consider Madness Is an Illness That Needs to Be Cured or Managed*

Many Mad Pride and neurodiversity advocates argue that the states and characteristics that we categorize as madness are not illnesses that need to be prevented, treated, or cured, but rather part of the human experience. They often view feeling emotions intensely, experiencing auditory or visual hallucinations, and being highly sensitive as part of the continuum of differences that make humans uniquely themselves. These experiences are seen as just some examples of the characteristics that make up each person's idiosyncratic way of responding to the world around them.

Rather than referring to themselves as "mentally ill," many neurodiversity advocates refer to themselves as "neurodivergent," i.e., having a brain or personality that differs from what is perceived as normal. People who do not have traits or characteristics

categorized as mental illness may be referred to as more “neurotypical” or “neuroconforming” to reflect the notion that their cognitive styles, emotions, and behaviors are perceived as being more typical or more conforming to societal norms, rather than mentally healthier with better functioning brains. In the Mad Pride and neurodiversity frameworks, divergence from the norm and diversity of thoughts, feelings, and internal states are seen as positive, just as we generally view cultural, racial, ethnic, and gender diversity as positive.

In speaking about the value of her own lived experience, neurodivergent activist Darien Rachel Welch says, “I think the value in neurodivergence is being afforded the opportunity to experience life on the other side of acceptance. Having to play with what that means while constantly being taught that you are broken, on a regime to be fixed. Being impervious to the standard glyph of human behavior and recognizing how flawed and dangerous it is. I see people labeled as neurodivergent sustaining what makes them unabashedly human in a society that demands their conformity” [37].

### *Madness Is an Objective, Discrete Category. People Can Be Proven to Be Either Mad or Sane*

Mad Pride and neurodiversity advocates also emphasize the culturally constructed, rather than objective or binary, nature of madness and neurodivergence. They seek to challenge the notion that a person is either mentally healthy or mentally ill by pointing out all of the social and systemic factors that shape a person’s likelihood of being placed in one of these two categories. For example, in some geographical locations and time periods, being queer or questioning one’s sexual orientation is or has been seen as a sign of mental illness; in other contexts, queerness is not or has not been pathologized. Additionally, in some cultures, experiencing auditory hallucinations is seen as a religious experience and a sign that a person may be spiritually gifted; in other cultures, experiencing auditory hallucinations is seen as a sign of schizophrenia.

Mad Pride and neurodiversity advocates also highlight the ways that a person's individual life circumstances may intersect with broader societal factors to shape whether they are or are not considered mentally ill. For example, in a variety of cultures and contexts, mental health clinicians would not diagnose a parent who has just recently lost a child and is experiencing sadness with major depressive disorder. Yet, a parent who continues to experience a predominantly sad mood after 5 years may or may not receive a diagnosis depending on contextual factors, such as cultural customs and definitions of appropriate grieving, as well as a clinician's individual views and diagnostic preferences. What about a situation in which a parent who has just recently lost a child has begun to experience auditory hallucinations? Whether or not this parent is categorized as mentally ill would also depend on contextual factors and a clinician's individual judgment. The same factors apply to situations in which an individual meets the diagnostic criteria for a mental disorder after a breakup, divorce, job loss, or other major life transitions. Mad Pride and neurodiversity advocates point out these various contextual factors in order to demonstrate that whether someone is deemed mentally ill does not depend on objective, discrete pathology but on clinical and societal judgments around what constitutes rationality and normality.

### *That Which We Consider Madness Is Dangerous*

Many dominant psychiatric and societal ideas about the experiences categorized as madness assume that these experiences are dangerous. The notion of just letting people experience the so-called symptoms of mental illness without receiving treatment often leads to the question, "But what if someone ends up getting hurt?"

Mad Pride and neurodiversity advocates point out that people diagnosed with mental illness are no more likely to be violent than anyone else. In fact, people diagnosed with mental illness are more likely to be victims of crimes than perpetrators [15]. Additionally, there are many traits and experiences

that *are* associated with a risk of danger – such as extreme sports, sleep deprivation, and risky sexual activity – and are not categorized as signs of mental illness or madness. While some individuals do commit violence precipitated by hallucinations or extreme states, this is not a reason to categorize all hallucinations or extreme states as signs of mental illness, any more than engaging in extreme sports should be seen as a sign of a mental illness due to motorcycle racing deaths.

### *That Which We Consider Madness Is Uncommon or Abnormal*

One of the underlying assumptions of the psychiatric paradigm of care is that the traits and experiences categorized as mental illness are uncommon. Part of a psychiatrist's or mental health professional's job is to determine whether a client's experiences are phenomena shared by the majority of people or whether they are abnormal. While neurodiversity advocates do not focus as much on challenging this particular assumption, Mad Pride advocates and scholars seek to show the ways in which that which we consider madness is, to some extent, a universal experience.

For example, many Mad Pride advocates have spoken about the ways in which hearing voices is more or less a universal phenomenon. Whether we experience horrifically self-critical internal voices or antagonizing external voices, many of us relate to the experience of being told insulting messages by different parts of ourselves. Additionally, everyone experiences life hardships, losses, and obstacles that can lead to intense sadness and pain as well as even apathy, mania, and hallucinations for some [1, 32]. Mad Pride activists point out that in finding meaning and value in that which we consider madness, we are not only making the world more inclusive to those diagnosed with mental illness, we are also giving everyone a bit more freedom to experience and express emotions and idiosyncrasies without being stigmatized or pathologized. A core principle of the Mad Pride

movement is that rather than conceptualizing distress and difference as a justification for othering a person or categorizing them as abnormal, we can view a person's distress or difference as an opportunity to connect with and relate to them. In accepting and embracing our shared vulnerability, we can pave new paths to forming more meaningful relationships and communities.

### *That Which We Consider Madness Is Irrational*

Another underlying assumption of the traditional model of psychiatric care is that the experiences categorized as mental illness represent an irrational way of thinking, feeling, or behaving that needs to be corrected and adjusted. Many Mad Pride and neurodiversity advocates seek to convey that which we consider madness as a natural, rational reaction to external circumstances. Numerous written and spoken testimonies by people with lived experience speak to the roles that trauma, oppression, and life hardships play in causing emotional distress and extreme states [14, 18, 21, 22, 35], [25].

Mad Pride and neurodiversity advocates tend to support trauma-informed care, a paradigm whose core principle is to ask not “What’s wrong with you?” but “What happened to you?” In the paradigm of trauma-informed care, the definition of trauma is not limited to physical acts of violence and sexual abuse, although these forms of violence can certainly play a major role in leading to distress and extreme states. Trauma-informed care also considers the role of societal oppression and systemic injustices in affecting our well-being; individuals who practice and advocate for trauma-informed care recognize that not only overt forms of discrimination and hate but also more subtle forms of bigotry, such as microaggressions and social exclusion, can drive individuals to experience what we consider madness. Additionally, they recognize the role that economic hardships and class factors can play, ranging all the way from the burden of living in poverty to the pressure upper middle-class individuals might feel to be successful and

maintain their status. Furthermore, trauma-informed care acknowledges the impact of life hardships, including not only death and loss but also breakups, divorce, unemployment, and workplace stress.

In short, Mad Pride, neurodiversity, and trauma-informed care recognize that life is difficult for everyone, and any reaction or response to life's hardships is understandable and can be seen as rational. Mad Pride and neurodiversity advocates usually do not see it as helpful or constructive to judge which kinds of reactions and coping styles are valid and which are disproportionate to an individual's circumstances. Instead, their goal is to validate all reactions to our often painful and burdensome existence.

### *That Which Is Uncommon Is Unhealthy*

Another assumption underlying the psychiatric paradigm is that a trait's abnormality or rareness in society potentially signifies that it is a symptom of mental illness. While some amount of suffering, quirkiness, or divergence is to be expected, one of the purposes of the DSM is to capture those whose differences veer unacceptably or unhealthily far from the norm. Abnormality in of itself is seen as pathological.

The Mad Pride and neurodiversity frameworks argue that just because one trait might occur less frequently than another trait in society, that does not necessarily correlate with the healthiness of either trait. English speakers are not any healthier than French or Italian speakers; white people are not any healthier than people of color. One prime example of this, of course, is people who identify as LGBTQ. Although homosexuality was once pathologized in the DSM due to its rareness or minority status, we now know that being queer is not necessarily associated with increased suffering, apart from the societal oppression LGBTQ individuals experience as a marginalized group.

Mad Pride and neurodiversity advocates often pose the question: What else might the DSM pathologize that is not

necessarily correlated with suffering, apart from societal oppression? While the DSM no longer pathologizes homosexuality, many people with low sex drives are diagnosed with hypoactive sexual desire disorder or inhibited sexual desire. Yet, one can easily discover in the literature about, and activism of, the asexual community that for many people, having a low sex drive is not at all problematic in of itself [6]. Theoretically, the diagnoses of hypoactive sexual desire disorder or inhibited sexual desire do not apply to asexual people; the DSM states that these diagnoses cannot be given to people who identify as asexual or to people who feel their low sex drive is not interfering with their lives or causing them any suffering. However, for many individuals, it may be nearly impossible to separate the effect of societal biases against a particular trait from inherent suffering correlated with that specific trait. For example, people who have been told that they need to have a high sex drive in order to conform to their prescribed gender roles or be good spouses might experience low self-esteem and negative effects on their well-being. They may not wish to identify as asexual and may instead hope that their low sex drive is fixed or changed. For this reason, a diagnosis of hypoactive sexual desire disorder or inhibited sexual desire might be given, despite the fact that some people's low sex drives might not have caused them problems apart from societal pressures and biases.

The Mad Pride and neurodiversity frameworks strive to examine all diagnoses through this lens. For example, experiencing hallucinations might not in of itself be problematic or cause suffering. Some accounts from people who experience hallucinations, however, speak to the content of their hallucinations worsening and becoming more distressing as a result of societal stigmas and biases against these experiences [9, 21]. Similarly, many autistic people report not experiencing distress resulting directly from their autism, but have experienced significantly increased levels of distress resulting from discrimination, exclusion, and societal pressure to act less autistic [20, 28, 34]. Numerous accounts written by autistic advocates focus on the trauma that has resulted from their experiences of applied



behavior analysis (ABA), a therapy designed to reduce the behaviors associated with being autistic [5, 29].

As mentioned above, Mad Pride advocates often acknowledge that the traits that are constructed as madness or mental illness are actually much more common (or even universal) than we are led to believe by the psychiatric paradigm. Growing acceptance of the LGBTQ community has led more people to come out and identify as queer; even those who identify as straight may view their own orientations as more fluid than people did in the past, and the public is generally more open to a range of experiences with and conceptualizations of gender and sexuality. Similarly, destigmatizing and depathologizing mental distress and differences may lead to more people “coming out” and identifying with these phenomena as well as recognizing how even some of the experiences that we do not consider mental illness – such as internal voices – can be viewed along the continuum of mental diversity.

At the same time as recognizing and promoting this message of universality, though, both Mad Pride and neurodiversity advocates emphasize that the healthiness or validity of a given experience or trait should not *depend* on its universality or commonality. Even if only a very small percentage of the population identified as LGBTQ, being queer would not be pathological. Correspondingly, even if only a very small percentage of the population experiences the traits and characteristics considered to constitute madness, those traits and characteristics are not necessarily pathological. A trait’s prevalence within the general population should be considered separately from its healthiness.

## Mad Pride and Neurodiversity in Action: Examples

Individuals with a variety of different mental, cognitive, emotional, and behavioral experiences have conceptualized their own identities in alignment with the Mad Pride and neurodiversity frameworks. Below are four examples of how these frameworks have been employed.

### *A Mad Pride/Neurodiversity Approach to Auditory and Visual Hallucinations and Extreme States*

As mentioned above, many people who experience hallucinations and extreme states, such as mania and depression, do not consider these characteristics to be inherently pathological, instead viewing these phenomena as positive aspects of their identities. Some view their hallucinations as helpful influences on their lives, guiding and encouraging them and/or ensuring that they never feel alone. Others take a more trauma-informed approach, conceptualizing distressing hallucinations as reactions to trauma; while these experiences may not be framed as positive or enjoyable, they are still seen as valuable and helpful because they may alert the individual to unresolved trauma. Still others have a more spiritual perspective on hallucinations and extreme states, conceptualizing them as part of being spiritually awakened; for example, some people find that the state we call “mania” allows them to feel more spiritually connected.

The Hearing Voices Network (HVN) is an international organization that provides and advocates for non-pathologizing approaches to hearing voices, seeing visions, and other unusual perceptions. Although many HVN members have been diagnosed with schizophrenia or bipolar disorder, they may not identify with their diagnosis and instead refer to themselves as “voice hearers” or “people who experience extreme states.” One can find Hearing Voices groups across the USA and abroad in which voice hearers and people who experience extreme states come together to talk about and find meaning in these phenomena as well as provide one another with support. People hearing distressing voices, for example, may be supported in listening to and engaging in dialogue with those voices to better understand what their experiences might mean. They may find that the voices represent perpetrators of trauma that has not yet been processed, intense emotions they have been too afraid to speak about, or friends or family members whose deaths they have not fully grieved.

Additionally, some HVN members may interpret their hallucinations or extreme states as coming from external sources such as deities, spiritual entities, or extraterrestrial beings. While not all HVN members share the same spiritual belief systems, group members are respectful of one another's beliefs and understandings of their experiences. Hearing Voices groups support members in coming to whatever interpretations of their voices is most helpful and feels most truthful to them.

### *Autism: Divergence, Not Disorder*

The neurodiversity paradigm was developed primarily by autistic advocates and scholars who view autism as a way of being and existing in the world that is not pathological or disordered. Many autistic advocates point out that the traits and characteristics categorized as autism do not inherently cause suffering apart from the demands of the society in which we live. For example, autistic styles of communication – such as not making small talk, employing more blunt or direct expressions of needs, and using text-to-speech technology or sign language in the place of oral speech – can be viewed through the lens of cultural differences rather than deficit or disorder. If an immigrant has difficulty grasping the norms and customs surrounding communication in the USA, we would not conclude that the immigrant is disordered, but rather is accustomed to a different cultural style of communication. Similarly, the neurodiversity paradigm recognizes autism as a different cultural style of communication with its own norms and customs. In fact, some autistic advocates even capitalize the word “Autistic” when describing themselves to emphasize the notion of Autistic as a culture and identity, not a disorder.

The Autistic Self Advocacy Network (ASAN) is just one example of many organizations led by and for autistic people that advocate for increased acceptance and accommodation of autistic individuals. ASAN states on their website that their organization “promotes social acceptance of neurological difference as part of the broad landscape of human diversity and

seeks to bring about a world in which Autistic people enjoy the same access, rights, and opportunities as all other citizens. Acceptance of difference is essential to understanding, accomodating, and benefiting from the contributions of everyone in our society, thus allowing all people to live up to their potential” [4]. While ASAN does not advocate in favor of treatments that aim to make individuals less autistic and more neurotypical or neuroconforming, the organization does advocate for services that accommodate autistic individuals’ unique needs such as facilitated communication and occupational therapy, as well as therapy and support groups that assist autistic individuals in coping with the harmful effects of discrimination and bigotry.

In speaking about her own identity and culture, neurodivergent activist Christa Mullis shares some of the positive aspects of her experiences as an autistic person: “Something important to me is a greater sense of self-awareness. Ironically, people think we [autistic people] lack that. But ‘neurotypical’ people have no reason to have to think about how their brain works, to intimately explore how and why they react to things a certain way, why something makes them uncomfortable, why they like or dislike certain things, etc. And while it’s awful that the world isn’t already built for us, I think I’ve also come to a better understanding of who I am by having to build a more accomodating world for myself, in what adaptive equipment I use or how I communicate with others. I know who I am and what I need because I have to” [24].

### *Multiplicity: Divergence, Not Disorder*

Another community that often views their identities and experiences through a lens of cultural and neurological difference, rather than disorder or deficit, is the community of multiple or plural systems. Being a multiple or plural system, or system for short, means existing as multiple people in one body. Although this way of being is commonly diagnosed as dissociative identity disorder, the neurodiversity and Mad Pride paradigms hold that there is nothing inherently disor-

dered or pathological about existing as multiple people. Just as it is perfectly valid and healthy for an individual born in a male body to identify as a woman, it is also valid and healthy for multiple individuals who exist in a singular body to identify as more than one person.

There exist many variations within the community of multiple systems on how each system conceptualizes their experience and identification of systemhood. For example, some systems identify as having been born as one person and experiencing the emergence of other members of the system as a result of trauma or other factors, while other systems identify as having been born as a multiple system. Some systems conceptualize members as fictional characters, aliens, or other types of beings. Regardless of each system's origin story or members' individual characteristics, many advocates agree that multiplicity is an important form of diversity that should not be cured or treated.

In a blog for the critical psychiatry web magazine *Mad in America*, neurodiversity activists Missy and Skylar Freels, who exist as a multiple system, wrote, "We're not dysfunctional or bad just because there are two of us in here. What's more important than being a socially acceptable single person is that we know how to get along and manage our trauma and our life together. Knowing this, we now strive to advocate for other systems and reach out to those that may not understand systems, to show that existing as we do is okay and that we can learn to navigate the world by cooperating. We don't need the psychiatric system or its labels to allow us to exist, or to try to fix us. We just need to be accepted as we are" [17].

Many systems view their multiplicity as a similarly positive experience. Pride, a plural activist of the system Nu Upsilon Xi, lists a variety of positive aspects that have come with the system's plurality. For her, being a member of a plural system has led to a greater understanding of inter- and intrapersonal dynamics, a profound sense of insight and awareness, and heightened empathy. She says that members of her system are "able to draw on each other's strengths to complete necessary

tasks we otherwise would not, or could not do” and that existing as a system has created a more stable and solid sense of identity for each member [2].

### *A Mad Pride/Neurodiversity Approach to Suicide*

As stated previously in this chapter, the Mad Pride and neurodiversity paradigms acknowledge that life is difficult for everyone and recognize all reactions to life’s hardships and traumas as valid. In these paradigms, desiring to die is a natural and rational reaction to experiencing violence, oppression, exclusion, abuse, and life hardships including death, loss, illness, breakups, divorce, and unemployment. Suicidal ideation, therefore, is not a sign that an individual is thinking irrationally and needs mental health treatment. Rather, it is a sign that a person’s life circumstances have become unbearably painful. It is a sign that whatever circumstances have driven such a person to experience suicidal thoughts are, for them, worse than death.

David Foster Wallace [36] once wrote the following about suicide: “The so-called ‘psychotically depressed’ person who tries to kill herself doesn’t do so out of quote ‘hopelessness’ or any abstract conviction that life’s assets and debits do not square. And surely not because death seems suddenly appealing. The person in whom Its invisible agony reaches a certain unendurable level will kill herself the same way a trapped person will eventually jump from the window of a burning high-rise. Make no mistake about people who leap from burning windows.”

“The terror of falling from a great height is still just as great as it would be for you or me standing speculatively at the same window just checking out the view, i.e. the fear of falling remains a constant. The variable here is the other terror, the fire’s flames: when the flames get close enough, falling to death becomes the slightly less terrible of two terrors. It’s not desiring the fall; it’s terror of the flames. And yet nobody down on the sidewalk, looking up and yelling ‘Don’t!’ and

‘Hang on!’, can understand the jump. Not really. You’d have to have personally been trapped and felt flames to really understand a terror way beyond falling.”

In the case of a person about to jump out the window of a burning building, it would be absurd to shut the window and celebrate having “prevented suicide” without making some attempt to put out the flames; the Mad Pride and neurodiversity paradigms posit that it is absurd to focus on the goal of “treating suicidal ideation” or “restoring sanity to a suicidal person” without addressing the cruelty and hardships in our world that drive people’s desire to escape.

The Mad Pride movement and neurodiversity field pay close attention to all of the subtle and overt forms of prejudice and oppression that neurodivergent people and people diagnosed with mental illness experience. For many neurodivergent people, being constantly stereotyped as violent, perceived as weird or sick, discriminated against in hiring and housing processes, excluded socially, subjected to forced psychiatric drugging, or confined against their will are just some of the consequences they have faced merely for expressing who they are. Many neurodivergent people also experience or have experienced other intersecting forms of oppression such as economic inequality, sex- or gender-based violence such as sexual assault, institutional racism, and sizeism and lookism. This is their reality. And for many people, this reality feels like a burning building from which desiring to escape makes complete logical sense. Mad Pride and neurodiversity advocates often believe that suicide prevention efforts should focus on systemic and cultural change rather than individual treatment programs.

Of course, sometimes suicidal ideation may result from factors independent of systemic oppression or social issues. For example, severe chronic pain is commonly associated with suicidal ideation. Sometimes individuals may not even wish to die due to any unbearable pain or suffering at all; for example, some have reported wanting to kill themselves as a means to reclaiming control over their deaths instead of suc-

cumbing to unpredictable or involuntary ends. Like other traits and characteristics categorized as “mental illness,” the desire to die should not be seen exclusively as a sign of incompetence or pathology but rather viewed as rational and justified. At the heart of the Mad Pride and neurodiversity movements lies the notion that individuals’ decisions about their own bodies, minds, and lives should be respected.

## The Social Model of Disability

It is not the intention of the Mad Pride movement or neurodiversity field to suggest that the experiences constructed as madness, mental illness, or neurodivergence do not come with suffering or limitations. Taking pride in one’s “madness” or neurodivergence is not the same as claiming that these characteristics are solely positive. In fact, the Mad Pride movement and neurodiversity field both advocate for societal acceptance of limitations.

Both the Mad Pride movement and neurodiversity field are aligned with the social model of disability. The social model of disability posits that individuals are disabled by societal barriers to access and exclusion rather than by medical conditions. For example, many deaf advocates have expressed that while their ability to hear is indeed limited, deafness would not be disabling or problematic if every deaf individual had access to sign language interpretation, closed captioning, and other accommodations. Similarly, most wheelchair users indeed have limitations on their ability to walk, but this would not be disabling or problematic (or at least significantly less disabling and problematic) if every building were wheelchair accessible and every environment accommodating to wheelchair users. For this reason, many disability activists refer to themselves as “disabled people” rather than “people with disabilities” to convey that disability is something that actively happens to people as a result of systemic injustices, rather than medical conditions or physical differences.



Disabled advocates often recognize that every individual has limitations and is accommodated in some way. For example, most people in contemporary society cannot grow their own food or build their own shelter; they rely on others to do this for them. Additionally, most people in the USA are reliant on their employers for their income and benefits, including health insurance and retirement. We consider it normal to rely on external sources for these needs; why should needing other types of accommodations be considered pathological?

There is no denying that many autistic people do experience difficulty with executive functioning such as limitations in memory, attention, and time management. Many people who experience extreme states may be limited in their ability to perform self-care tasks and activities of daily living while in those states. Many people who feel suicidal or depressed are limited in their ability to get out of bed and work at full-time jobs. But according to the social model of disability, these limitations are only problematic because individuals are not accommodated. Instead of focusing on curing or eradicating these limitations, the social model proposes solutions that provide accommodations, such as personal care attendants, work schedule flexibility or the ability to work from home, and/or disability payments to relieve individuals from work responsibilities.

Sometimes, accommodations can even include having access to different types of drugs and substances that reduce physical or emotional pain and improve individual functioning. Just as almost everyone has used coffee or some other caffeinated beverage to be more alert, some neurodivergent people may wish to use mind-altering drugs to improve daily functioning. Just as the limitation of needing to drink coffee every morning to function at one's best is not pathologized, the limitation of needing psychotropic drugs to function at one's best should not be pathologized. Neurodiversity and Mad Pride advocates do maintain, however, that all individuals deserve the right to informed consent about whatever substances (or other accommodations) they choose to use, and accommodations should never be forced upon anyone.

Disability rights activist Cal Montgomery speaks of the importance of providing a model in which the strengths and limitations of neurodivergent identities can coexist: “We talk a lot about traits people – ourselves and others – have that we don’t like, but we never seem to investigate how they are connected to traits we value. For instance, I know people who don’t always show up when you want them to, and if you follow the threads, this seems largely connected to what we call depression and anxiety.”

“And, fair enough, it would be nice if they came to things when I wanted them to, so there is a temptation to think I would be happier if they had less of those issues. But, those same traits are also connected to some of my favorite things about them. Anxiety often seems to be related to a deep concern with behaving ethically. Depression often seems connected to empathy. Not always. But often.”

So then when I evaluate how personally annoying I may find it that So-and-So wasn’t at Event, I start asking myself, do I care enough about what a profoundly kind and considerate person So-and-So is to gladly accommodate that sometimes they can’t be there? The answer is usually yes. [23]

## Why Mad Pride and Neurodiversity Are Incompatible with Coercion

Central to the frameworks of Mad Pride and neurodiversity is the idea that distress and difference should be accepted. Sometimes the characteristics that are categorized as mental illness are embraced and celebrated. Other times, celebration is not called for, such as when these characteristics cause suffering or result from trauma. However, even in these latter instances, they can be accepted as valuable and rational. The Mad Pride and neurodiversity paradigms propose that under no circumstances should people be punished for their differences or distress.

Numerous accounts from people with lived experience speak to the traumatic and harmful nature of involuntary com-

mitment, forced drugging, and forced electroshock treatment [7, 8, 13, 16, 19, 23, 26, 27, 33]. Many people who identify as “psychiatric survivors” have spoken out about the violent nature of having these acts forced on them. The author, a victim of involuntary commitment and forced treatment, has contributed several such accounts [10–12, 30, 31]. Underlying the principles of Mad Pride and neurodiversity is the notion of Mad and neurodivergent autonomy: people should be considered the experts and sole proprietors of their own minds and bodies; no matter how much distress individuals are in and how different they are from what is considered “normal,” they still deserve the right to make decisions about their own brains and bodies.

One conceptual framework that is closely related to Mad Pride and neurodiversity is the notion of cognitive liberty. Cognitive liberty advocates support the right of each individual to experience any and every thought, feeling, belief, state, and expression of such as long as it does not violate another person’s bodily autonomy. Another way of saying this is that cognitive liberty activists support the right of all people to alter their minds and consciousness however they choose (including the decision to cease being conscious) and not have their consciousness altered against their will. Cognitive liberty encompasses the right to experience “madness” and be neurodivergent; it also encompasses the right to use mind-altering drugs.

Many psychiatrists, including some who identify as critical psychiatrists and have contributed to this book, argue that coercion may be justified for individuals in instances in which all nonrestrictive alternatives have been attempted and they appear to be at legitimate risk of harming themselves or others. While Mad Pride and neurodiversity activists recognize this as an improvement upon current practices of coercion in mental healthcare, the movements tend to support abolitionist, not reformist, stances on coercion. They believe that individuals should retain full autonomy over their bodies, even if this results in death or bodily injury; the choice to value liberty and autonomy over life should be a choice an individual – regardless of mental state – has the right to make.

As a Mad Pride and neurodiversity activist and a survivor of forced psychiatric treatment, I am not fully safe from psychiatric coercion unless all of us – all Mad and neurodivergent people, people labeled “mentally ill,” and all people in general – are safe from psychiatric coercion. Just a few members of this group being subjected to this kind of violence has an effect on the entire community; not only do community members experience the vicarious trauma of their friends’ and comrades’ loss of autonomy, but they also experience the fear that if they reach a certain degree of perceived madness or departure from societal norms, they, too, may lose their liberty. Although I remain free from force and coercion, I am not free from its threat – and I am certainly not free from witnessing the pain of my friends and comrades whose autonomy continues to be violated.

At the same time, I have also experienced the pain and trauma of losing a friend and comrade to suicide, and I can empathize with the instinct to prevent suicide at all costs. I do not minimize the pain resulting from the death of any loved one. However, the Mad Pride and neurodiversity communities privilege the values of liberty and personal autonomy; to experience a loved one’s loss of liberty can also involve a process of mourning and pain.

Chapter 7 of this volume, “Coercion and the Critical Psychiatrist,” places emphasis on conversing with clients in a transparent way when discussing coercive practices. While increased honesty about the intentions of these practices is certainly an improvement, countless survivors of psychiatric coercion would argue that no words or language can take away the violent and traumatic nature of this act. I was forced to miss my college graduation due to being involuntarily committed; even having been committed by a compassionate and transparent psychiatrist would not have made up for the fact that I was forced to be absent at a milestone event I had spent years working arduously to achieve. While I was hospitalized for passive suicidal thoughts, my ideation became active as soon as I experienced the intensity of the regret, guilt, and shame resulting from being excluded from this occasion.

### *But What if Someone Gets Hurt?*

As mentioned earlier in this chapter, people diagnosed with mental illness are far more likely to be victims of violent crimes than perpetrators. However, there are instances in which the experiences categorized as madness can lead to violence toward others. For example, people may hear voices or experience hallucinations telling them to harm others.

Many Mad Pride and neurodiversity advocates recognize that violent impulses are often shaped by systemic and contextual factors. Sometimes, individuals are driven to violent impulses and actions by being made to feel fearful and powerless; repeated victimization in the form of abuse, ostracization, or trauma can lead a person to use violence or aggression as a recourse to regain power. Many psychiatric survivors and victims of involuntary commitment report becoming more aggressive after being confined or forcibly drugged, as these acts led to intense fear and panic. In the Mad Pride and neurodiversity paradigms, it is important to recognize the factors in people's lives that may contribute to their thoughts of harming others. In this way, we can humanize those whose actions seem irrational and incomprehensible at first glance. Sometimes, the recognition that violent impulses are coming from feelings of powerlessness and abuse along with working to address ways to change a person's circumstances is enough to prevent violence and resolve any potentially dangerous situation.

This does not mean, however, that society should be unprotected from actions that put them in danger by violating their bodily autonomy. The majority of Mad Pride and neurodiversity advocates believe that detention or confinement is called for when a person has made an active threat to harm others. However, Mad Pride and neurodiversity advocates would maintain that such confinement or detention should not be dependent on an individual's neurodivergence or psychiatric diagnosis. Instead, we should seek to protect society from potentially violent acts in the most humane, compassionate way possible that considers the contextual

and systemic circumstances surrounding the threat or act of violence that has occurred. Many Mad Pride and neurodiversity advocates support the development of alternative methods for addressing violence besides the criminal justice or psychiatric systems. The proposed alternatives often focus on addressing systemic inequality and injustice rather than attributing violence to an inherent characteristic within an individual such as criminality or mental illness.

## Going Forward

Although the Mad Pride and neurodiversity movements represent a radical shift from the dominant paradigm of psychiatry and mental healthcare, these movements are not irreconcilable with the practice of psychiatry. As mentioned previously in this chapter, psychiatrists and mental health professionals once pathologized queer identities and practiced forms of conversion therapy; now, many psychiatrists and mental health professionals practice LGBTQ-affirming therapy, respect their clients' queer identities, and validate the trauma of experiencing queer antagonism. In the same way, it is possible to practice psychiatry and psychotherapy that is affirming of madness, neurodivergence, and all of the traits and phenomena categorized as "mental illness."

Such a practice could include introducing clients to paradigms like Mad Pride and neurodiversity and assisting clients in deciding what traits they want to change or alter and what traits they would prefer to accept and embrace as part of their identities. Psychiatrists and mental health professionals could help clients explore the positive or valuable aspects of these characteristics and support clients in developing greater self-acceptance. Therapy may also include an exploration of how clients' particular traits or phenomena may represent valid responses to systemic issues or external circumstances and how they may be helpful, not harmful, coping mechanisms.

One major role that a psychiatrist or therapist can play in affirming, rather than pathologizing, a client's identity can be

determining what kinds of changes could be made to the client's external environment in order for the client to feel more accepted and included on a day-to-day basis. For example, many young neurodivergent clients may face family rejection or peer victimization; they may be bullied by their classmates due to being perceived as different or seen as burdensome by their parents. Psychiatrists and mental health professionals can help young clients' families and schools shift their negative attitudes toward neurodivergent youth by providing educational information about the importance of inclusion and the traumatic impact of exclusion or sanism, i.e., prejudice or discrimination on the basis of a person's mental or emotional characteristics. Psychiatrists and mental health professionals can also advocate for their clients to receive accommodations from their workplaces, schools, or housing or assist their clients in finding support groups or other social settings that are inclusive toward people with their particular characteristics.

Another way psychiatrists and mental health professionals can practice this "mad-affirming" or "neurodiversity-affirming" care is by validating the trauma of the discrimination and prejudice clients face on account of their "madness" or neurodivergence. Too often, clients are blamed for the prejudice and exclusion they experience. They are told that they should act more "normal" and "healthy" in order to not be victimized. Additionally, they are often told that they should be grateful for having been involuntarily committed or forcibly treated or that they should forgive the well-intentioned people who carried this out against them. Critical psychiatrists and mental health professionals can instead recognize the real, tangible effect of involuntary commitment and sanism on the brain and body and assist clients in healing from, coping with, or addressing this trauma in whatever way they choose.

Underlying "madness-" and "neurodiversity-affirming" mental healthcare would be the principle that clients reserve the right to their own conceptualizations and interpretations of their experiences, traits, characteristics, and phenomena. Their voices, experiences, and wishes regarding their minds, bodies, identities, and course of care would be respected above all.

Clients would always be presumed to be competent to make their own decisions, including the decision as to whether a particular trait or internal experience (including suicidality and self-harm) should be celebrated, embraced, accepted, managed, treated, cured, or some combination of all of the above. This form of mental healthcare would involve a collaborative, non-authoritative relationship – an equal partnership between psychiatrist and client that is free from coercion.

While it is unlikely that coercion can immediately be eliminated from the practice of psychiatric care, one way to reconcile current legal requirements with practicing “mad-affirming” and “neurodiversity-affirming” care could be to be as open and honest with clients as possible about when commitment or other reporting would become necessary. This gives clients the option to choose not to disclose any information that might result in involuntary commitment or forced treatment.

Psychiatrists and mental health professionals can also choose to support the principles of Mad Pride and neurodiversity outside of the therapy room. They can speak out about these ideas in both informal and academic writing as well as introduce these ideas to their colleagues, students, and professional organizations they may belong to. They can always look for ways to center the voices and perspectives of people with lived experience in their research, writing, and speaking.

As a final note, attention should be paid to the privilege and power afforded to psychiatrists and mental health professionals. Within society and the healthcare system, they are assumed to be the experts on the cognitive and emotional characteristics categorized as “mental illness.” This idea does not apply to any other marginalized group: white race studies scholars are not assumed to be the experts on what it is like to be a person of color, and straight queer studies scholars are not given the authority to define and theorize the queer experience. Yet psychiatrists and mental health professionals carry significantly more credibility and weight when speaking about “mental illness” than do people who have been diagnosed with mental illness, who are often discredited and dismissed as “crazy” or “irrational.”



Until this changes, psychiatrists and mental health professionals have tremendous power and authority to legitimize and validate the perspectives of people with lived experience, such as neurodiversity and Mad Pride. They have the ability to be taken seriously when introducing these ideas into the conversation, and that ability should be considered heavily. It is imperative that, going forward, critical psychiatrists closely examine how they can use the power they have to elevate and center the voices of those who are taken less seriously due to being perceived as mentally ill, pathological, or incompetent. In this way, critical psychiatrists and mental health professionals can add a great deal to the Mad Pride and neurodiversity movements by striving to bring rights-based, madness-affirming, context-informed care into a field that has historically been paternalistic and oppressive.

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# Chapter 9

## A Path to the Future for Psychiatry



**Sandra Steingard**

This book began with a review of the history of critical psychiatry. Early critiques tended to focus on the quality of care (or lack thereof) for people treated in psychiatric asylums. In many parts of the world, closure of large mental institutions has created different challenges as we struggle to understand how best to support those who experience mental distress while living in our communities. As outlined in this book, the problems transcend the impediments posed by underfunded community systems. Fundamental assumptions including the concept of diagnosis and the nature of drug action are challenged. Serious questions are raised regarding conflicts of interest that pervade the field. Vaswani and Cosgrove, in Chap. 3 in this volume, argue that this runs deeper than the personal conflicts of any individual psychiatrist; it involves institutional corruption that results from economies of influence posed by both guild and commercial interests.

Some might conclude that the profession is so flawed that it is beyond reform. Others might choose to practice within a niche, for instance, working outside of the public system of

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care where entities such as governmental bureaucracies and insurance companies exert less constraint over practice. Others might limit their practices to those who have experienced and then rejected standard care and come seeking an alternative. However, there may be ways to remain within the dominant medical and public institutions of care while practicing with integrity. The suggestions that follow are directed toward those psychiatrists who chose to practice within the mainstream structure, as this is where most people will continue to seek access to care. If critical psychiatrists practice in the public system, they can be agents of change.

Proposals for reform are often predicated on the assumption that the problem is fundamentally one of access; increasing screening for psychiatric disorders and providing greater availability of psychiatric care are considered of primary importance. There are recommendations that psychiatrists (and their surrogates) see ever more patients<sup>1</sup> in shorter intervals. In the collaborative care model advanced by the American Psychiatric Association, intermediaries consult with psychiatrists and share results of screening. These intermediaries report back to the primary care clinicians with the psychiatric recommendations [9]. In this scenario, the psychiatrist, who has not met the patient, opines on optimal treatment as if the problem can be characterized adequately with rating scales and the like. Alternatively, some who share the concerns raised in this book suggest that the solution is for psychiatry to return to the era when psychiatrists worked primarily as psychotherapists.

This book takes a different stance, positing that there is a distorted demand for psychiatric care that is based on an ever-expanding notion of what constitutes psychiatric disorder compounded by an inaccurate gauge of the efficacy of psychiatric treatments, particularly pharmacological ones. Rather than increasing access, psychiatrists should constrain their purview. Many people who experience emotional dis-

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<sup>1</sup> Some might object to the use of the term “patient,” since it can be interpreted as an implicit endorsement of a medicalized view of the problems under discussion. Here and elsewhere in this chapter, it is used merely to denote a person who consults with a physician.

stress do not require medical attention. They can often be helped by the many others who have considerable expertise in this area. Access to food, housing, and employment and the development of meaningful social connections are not medical interventions but can be enormously important in reducing emotional distress. Working with people who have their own lived experiences of such distress is another valuable resource.

At the same time, there are people who benefit from psychiatric evaluation, and many will seek out pharmacologic remedies, as they have for millennia. Psychoactive drugs will remain on the market. In recent years, there has been a resurgence of interest in hallucinogenic drugs, and society may turn to psychiatrists to determine who might benefit from these agents. It not only makes sense but is imperative for there to be a branch of medicine that includes expertise in all psychoactive drugs – those that are legal and illegal and those that require access to someone with prescribing privileges as well as those that can be grown in one's backyard. The challenge is that psychiatrists are currently charged with being the gatekeepers to psychoactive drug use through employment of a flawed diagnostic system. This was described in Chap. 5 in this volume in the discussion of psychostimulants. Psychiatrists are asked to distinguish those who “need” drugs to treat what they have determined to be “illness” from those who merely “want” them. This is problematic for anyone who recognizes the ambiguities inherent in the construct of “illness,” as outlined in this book.

Nevertheless, expertise in psychopharmacology needs to remain a core proficiency for psychiatrists. Our suggestion is to contract the scope of psychiatric concern, use a drug-centered approach to psychopharmacotherapy, and, when psychiatrists do become involved, allow the time necessary to understand those seeking consultation and their social contexts. The problems experienced by the people psychiatrists are asked to evaluate, as well as the considerations psychiatrists face regarding the conceptualizations and suggested therapeutic approaches to those problems, are complex. This process requires thought, care, and time.

Good care needs to incorporate the following principles:

1. Acknowledge the limitations of psychiatric diagnosis while working in a system that demands the use of DSM or ICD labels.
2. Determine, through the thicket of research and marketing, which, if any, psychiatric treatments have value.
3. Explain to patients and their families why one might have reached conclusions about psychiatric drugs that are at odds with commonly held and highly promoted opinions.
4. Employ a drug-centered rather than a disease-centered paradigm in conceptualizing drug action. Uncouple the need for a label from understanding when and if a drug might provide some benefit to an individual.
5. Study not only how to initiate treatment with drugs but whether and for how long they need to be continued.
6. Acknowledge that some form of withdrawal is an expected consequence of drug discontinuation. Develop an understanding of withdrawal effects and the impact of accommodation to a drug.
7. Acknowledge the biases that might influence psychiatric decision-making and increase aversion to drug discontinuation.
8. Incorporate patients' preferences and values into clinical decision-making.
9. Acknowledge that coercion – even when used to prevent harm – can nevertheless also cause injury.
10. Determine how to bring into the consultation room the valuable perspectives of those with lived experience of psychic distress.
11. Acknowledge the epistemic authority that is granted to psychiatrists, and actively work to privilege other kinds of knowledge and understandings, specifically those of the people we are asked to treat.

The challenge with any set of principles is that it is easier to state them than to incorporate them into everyday work. The framework of need-adapted treatment (NAT) is suggested as a model that can help critical psychiatrists incorpo-

rate these values into their practices. A way forward for the field is to integrate a drug-centered paradigm of prescribing with the need-adapted frame of engagement. NAT offers a way in which the challenges and uncertainties of the field can be openly acknowledged, discussed, and integrated into care. It is a more democratic way of working that allows for multiple epistemic perspectives to be both acknowledged and respected.

Need-adapted treatment was developed in Finland in 1970s and 1980s. At that time, multiple theoretical frameworks were considered helpful [1]. That posed a dilemma: how to determine which treatments would be most helpful to any given individual. The Finnish clinicians made the revolutionary decision to discuss this openly with both patients and their families as part of a plan to determine collaboratively how to proceed. When they did this, they found that such meetings often led to clinical improvement. This approach was the forerunner of Open Dialogue that evolved in Tornio, Finland. Seikkula and colleagues have written extensively about this work [11]. Over time, a broader array of practices has evolved in Scandinavia and northern Europe. Tom Andersen and colleagues were simultaneously working on reflecting therapies [2]. Carina Håkansson started the Family Care Foundation, which incorporated these principles into their work [6]. They found homes for people who were struggling and offered support to individuals in these home settings. Currently, there is increasing interest in these approaches around the world. In the discussion that follows, the expressions “need-adapted treatment” and “dialogic practice” will be used as to refer to this growing movement.

While there are variations in practice, what is shared among them are common values. Chief among them is a deep appreciation of the importance and worth of social networks in helping to both develop understandings of human problems and support people through their crises. Diagnosis – and the diagnostic process – is held lightly in these models. Uncertainty is not only acknowledged but valued. Treatment proceeds from individual and network needs rather than



from expert-derived diagnoses. Treatment remains flexible, and the system evolves in its understanding of problems. This psychotherapeutic attitude is considered at least as important as the technical aspects of the treatment. In keeping with the value placed upon relationships, there is also a recognition of the benefit of psychological continuity. Thus, to the extent possible, the team involved remains constant. At the same time, there is nothing in this model that precludes the introduction of other therapeutic interventions. Pharmacologic treatment, cognitive behavioral therapy, and supported employment, for example, can all be incorporated. The distinction is how they are introduced and suggested. The clinician may bring them up and network members can talk together about their potential benefits and risks. If professionals disagree, they share these perspectives openly with other members of the network.

This contrasts with the more traditional medical approach in which there is a focus on the individual who is presumed to be experiencing some sort of psychopathology that the experts seek to characterize through the evaluative process. Families are a source of further history and support. When they are involved in treatment, it is often in the form of psychoeducation: they are educated about the expert-derived diagnosis and given information on how to support their afflicted family member. This has the tendency to reify diagnosis rather than reinforce the fundamental uncertainties of the diagnostic and prognostic process. The treatments that are offered are based on this evaluative process. Treatments are considered in a technical way, and it is often tacitly assumed that they work in a way that is independent of the relationship.

A drug-centered approach aligns with NAT because it is not predicated on expert-assigned diagnosis. It acknowledges that we understand more about drug action than we do about the underlying causes of peoples' troubles, although our knowledge is certainly incomplete on the former subject as well. A need-adapted approach provides a framework in which we can talk about psychiatric drugs, acknowledge the many uncertainties, and support a person in deciding whether to take them. It

acknowledges that this is likely to be an ongoing process that may be revisited from time to time. It allows for the person's own values and understanding of the problem to be both recognized and respected, and it offers the space for many views to be heard. It acknowledges that what psychiatrists consider "symptoms" might not be the most important focus for a person. It provides opportunity for people to identify what is most important to them and places the discussion of drug treatment, or indeed any treatment, within that context. It allows for a physician to be on the team but not necessarily as the leader. There may be discussion of drugs, the brain, what the physician has observed in others in similar situations, and whether there are studies relevant to the patient's situation, but it does not require that the physician be the only expert or authority. If there is discussion of brain function and dysfunction, this in no way precludes a person finding additional sorts of meaning in the experience. It allows for a frank discussion of what psychiatric nosology is (a classification system) and is not (a reflection of deep understanding of the nature of the problems it classifies). And it accepts that all of this occurs in the context of a relationship – usually multiple relationships – that will exert their influences on this process.

In the principles discussed above, there is a need for critical psychiatrists to manage the risks of working in a way that does not fully adhere to accepted community practice. For instance, the decision to delay initiation of a drug or to suggest a drug taper may be considered controversial. Two core principles of clinical practice are informed consent and standard of care. Informed consent refers to the process of explaining the nature of a clinical condition (typically framed in the context of diagnosis), discussing recommended treatments, and outlining risks and potential benefits of accepting or rejecting those recommendations. Standard of care refers to what an average physician in a given time and place might recommend under similar circumstances. Although standard of care is a legal construct, it exerts significant influence over physicians' actions because of its application in medical malpractice cases. NAT allows for extensive discussion of risks,

including those of both starting and stopping drugs. Families are invited into the process and thus are also informed and have a venue for expressing their concerns. NAT provides a setting for critical psychiatrists to outline the ways in which some recommendations might differ from those of more conventional colleagues and to allow individuals – along with their families when they are included – to decide which treatments to accept. This is the essence of informed consent and allows psychiatrists to be honest and open.

Shared decision-making (SDM) is promoted as a way of working with patients that respects and honors their wishes and preferences [5]. The values reflected in SDM overlap substantially with the principles outlined above in that SDM privileges patients' knowledge and experiences. Common Ground is an online clinical support tool developed by Patricia Deegan, a researcher who is both a person with lived experience and leading academic in this field [3]. When used in clinical practice, a patient, with assistance from a peer, completes the online decision-making tool prior to meeting with the psychiatrist. The patient is then empowered to bring this information into the consulting room. While finding great value in this approach, it remains nevertheless incumbent on the psychiatrist to actively demonstrate that the patient's perspective is valued. In addition, it is important that critical perspectives are incorporated into the information the patient receives, regardless of whether it is from an online support tool, a peer, or a psychiatrist.

Philosopher Nancy Potter [10] has elucidated the process of "giving uptake" as a form of communication that allows the speaker to understand that not only has the listener heard his words but acknowledges "the speaker as a subject whose communications are worthy of consideration." Potter argues that giving uptake is crucial for psychiatrists as a means of restoring some balance to the power differential inherent in the psychiatrist-patient relationship. She describes giving uptake as a virtue that can be learned: "[G]iving uptake well is a disposition to attend carefully, actively, and openly to the communication of another. As with other dispositional states, it has to be learned."

Because psychiatric assessment relies on verbal communication, psychiatry as a profession has long valued clinical interviewing skills. Dialogic practice and giving uptake challenge the notion that psychiatrists are as careful at attending to their patients as they might believe themselves to be. When psychiatrists enter the room as experts and move quickly to characterizing the patients' experiences as symptoms, that might interfere with the opportunity to help patients fully communicate experiences in their own ways. Even with therapeutic practices that value careful listening while employing interpretation, such as psychodynamically oriented psychotherapy, giving uptake can be missing. Responding to a person's utterances with interpretation transforms what has been said into the structure of the therapist's theoretical framework.

In contrast, NAT and dialogic practice can be considered ways of interacting with others in which giving uptake is a value that has been embedded into the very core of the work. Careful attention is given to the nature of communication, but clinicians try to avoid imposing their own implicit or explicit models – be they biological, psychoeducational, psychodynamic, or anything else – upon the patient or the network. Therapists are encouraged to listen to each person's utterances, use each person's language, and stay in the present moment. Multiple perspectives and viewpoints are elicited. These are forms of giving uptake, to use Potter's language. Training in dialogic practice trains one to embody a spirit of giving uptake.

In the principles listed above, there is mention of the value of including the perspectives of those with lived experience. In recent years, some models of NAT have incorporated individuals with lived experience into their teams. The presence of peers as valuable team members – and not just surrogates of the professionals – signals another important aspect of this way of working. In NAT, epistemic authority is shared among team members. While the psychiatrist is acknowledged as having a certain kind of expertise, it is accepted that the psychiatric conceptualization is not the only way to make sense of the situation. Similar to the process of Common Ground, where a peer assists the patient in completing the online

decision tool, the peer in the NAT setting may be able to help the person in the patient role to articulate his own understandings of the problem. By including the peer in the meeting, the psychiatrist demonstrates that other perspectives are valued.

In dialogic meetings, those in the therapist or facilitator roles talk to each other in the presence of members of the network. These discussions can include disagreements. One clinician might advocate that a person requires hospitalization, while another might hold a differing opinion. One might suggest that a drug could be helpful while others might not. Having respectful and considered discussions of disagreements in the company of patients and family members demonstrates, without needing to explain explicitly, that there is room for different perspectives. It can relieve pressure from family members who might themselves have differences of opinion on how best to proceed.

There are other advantages to having discussions among clinicians in front of the network. In clinical practice, there are many conversations happening daily about patients and their families that occur behind closed doors. By having these conversations with the network, it minimizes the tendency in clinical practice to blame patients or family members when treatment does not go well. Under such circumstances clinicians commonly conclude that people have “treatment-resistant” conditions or that their failure to respond to recommended therapies has revealed underlying personality disorders. In dialogic practice, we are forced to find ways of talking that avoids objectifying a person or using pejorative language. We share the responsibility and disappointment if a person is struggling; we are more likely to acknowledge our own limitations and consider how we might improve our means of gaining understanding and connection.

People who experience and have been labeled with psychiatric disorders have often experienced epistemic injustice. This is a concept that has been applied to those whose worldviews are often discounted as a reflection or consequence of their membership in marginalized groups. Their

complaints or perceptions of their experiences are often discounted by those in more dominant positions. Crichton and colleagues [4] discuss how this affects psychiatric patients. However, they tend to focus on ensuring that because people diagnosed with schizophrenia might, for example, hold false beliefs, we should be careful not to discount all of their beliefs. In dialogic practice, however, therapists are careful to honor and respect all beliefs. Therapists are slow to label ideas as delusional, although they might share with patients that their own experiences and interpretations might differ. In this way, dialogic practice could be said to place a high value on epistemic justice. The network is approached with respect and an assumption that there is knowledge and wisdom held by all members, even those who express ideas others consider to be unusual or even false. This empowers all members of the team and may be critical to maximizing the likelihood that individuals remain open and engaged with the network.

SDM was developed, to some extent, to address the matter of nonadherence to treatment recommendations, and Potter discusses the value of giving uptake in situations in which a patient is defiant. However, many people accept the main narratives of modern psychiatric discourse. Acceptance of the dominant psychiatric paradigms does not begin in the consultation room. People are exposed to these ideas through the media and the general culture. Many patients walk into the office not complaining of sadness but of “depression,” not of distractibility but of “ADHD.” They look to psychiatrists as the sanctioned deliverers of diagnoses and pharmaceuticals, and this is often both their hope and expectation. Working with people who accept the predominant psychiatric narrative can pose more challenges for critical psychiatrists than working with those who reject it. There are patients who insist on finding a drug cure even in the face of having experienced many failed drug trials and negative consequences of drug treatment. There is no easy solution to this dilemma, but the model of interaction remains the same. The psychiatrist does not discount the

patient's belief system but is honest and transparent when there are different perspectives.

This problem is particularly challenging when drugs that are used recreationally are adopted into the psychiatric pharmacopeia. Benzodiazepines are sought-after drugs, and in our current system, the psychiatrist is asked to determine who has the "real" condition that warrants their use. Cannabis is now characterized in some states as either "recreational marijuana" or "medical marijuana." While varying strains may have different psychoactive effects, there is not a fundamental, principled distinction between medical and recreational cannabis. Hallucinogenic drugs are once again garnering interest in a variety of settings. Psychiatrists and other physicians may be called upon to be the gatekeepers to legal access. They are most likely to do this by determining who has the "appropriate" diagnosis to justify their use. This is problematic for a critical psychiatrist who questions the validity of the psychiatric diagnostic process.

David Healy [8] has pointed out problems that arose after physicians were giving prescribing authority. It was thought that medical knowledge and training would inoculate the profession against fads and commercial influences, but, as discussed in Chap. 3 in this volume and Healy's book, *Pharmageddon*, this has not always been the case. While it is unlikely physicians will lose this privilege in the foreseeable future, we urge caution in using prescriptive authority as a vehicle for restricting access to psychoactive drugs. This is another context in which a drug-centered approach is of great value. Rather than putting psychiatrists in the role of determining who can and cannot have legitimate access to such drugs, psychiatrists can be the experts on drug action. They can advise people on what drugs do, including their risks and the associated uncertainties, and then allow people to make informed decisions on their use.

Recently, there has been a call for psychiatrists to have training in structural competency. As developed by Helena Hanson and colleagues [7], this approach acknowledges that psychiatrists need to both acknowledge and become educated in the ways in which social determinants – poverty, various

forms of discrimination, for example – affect our patients. While explorations on how psychiatrists can act on both an institutional and community level are beyond the scope of this book, these efforts are not at odds with the thrust of this book and suggest crucial areas of future development for the profession. Oppression, in its many forms, will continue to occur and wreak havoc on people’s lives. This book attempts to offer guidelines at the level of the interaction of the psychiatrist and the patient.

Practicing with humility while openly and actively loosening the epistemic authority society has given to psychiatrists is a core recommendation for reform. This is not anti-drug or anti-psychiatry but pro-humility. Psychiatrists need to be active in exercising that humility. They need to relinquish or, at the very least, share epistemic authority, and NAT gives a frame in which to do that. Integrating a drug-centered approach with NAT allows a psychiatrist to work comfortably within a network that values humility, uncertainty, and respect for multiple perspectives.

The healthcare system is complex, and there are limitations on the extent to which any individual can reform practice within it. The suggestions offered in this book, in the spirit of this chapter, are offered with humility and the knowledge that change is difficult. They do, however, offer an alternative to capitulation to the status quo.

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# Index

## A

- Abilify, 75
- Alcohol, 99
- Alternative services, 7
- American Psychiatric Association (APA), 2, 20
- Amphetamines, 104, 117
- Anosognosia, 125, 168, 173
- Antidepressant drugs, 126–128
- Antipsychiatry, 5–7
- Antipsychotics, 100, 101, 103, 165–167
- Assisted outpatient treatment (AOT), 165
- Attention-deficit/hyperactivity disorder (ADHD), 117
- Attenuated psychosis syndrome (APS), 49
- Autism, 190, 191
- Autistic Self Advocacy Network (ASAN), 190

## B

- Beck Depression Inventory (BDI), 47
- Benzodiazepines, 99, 128, 129, 147
- Binge eating disorder (BED), 77, 118

- Biological reductionism, 24–27
- Biomedical psychiatry, 179
- Bipolar disorder, 140

## C

- Cannabis, 218
- Capacity, 167–169
- Cartesian dualism, 25
- Civil commitment, 45, 170
- Clinical practice guidelines (CPGs), 82
- Clozapine, 104
- Coercion, 156, 170–174
  - forced treatments, 162, 163
    - antipsychotic drugs, 165, 166
    - dangerousness, 164, 165
    - informed consent and capacity, 167–169
    - suicide, 163, 164
  - functions, 156
  - medical profession, role of, 159–162
  - mental illness, 158
  - organizations, 158
  - Social Darwinism, 157
  - therapeutic asylum, 157
- Cognitive liberty, 198
- Corruption, 73, 74
- Critical consciousness, 21, 52

- Critical psychiatrist, 170–174  
 forced treatments, 162, 163  
 antipsychotic drugs, 165, 166  
 dangerousness, 164, 165  
 informed consent and capacity, 167–169  
 suicide, 163, 164  
 functions, 156  
 medical profession, role of, 159–162  
 mental illness, 158  
 organizations, 158  
 Social Darwinism, 157  
 therapeutic asylum, 157
- Critical psychiatry movement, 4, 10  
 alternative services, 7  
 antipsychiatry, 5–7  
 critical psychiatry movement, 10  
 Marxist theory, 8, 9  
 postmodernism, 7, 8  
 service user movement, 9, 10
- D**
- Dangerousness, 164, 165  
 Dementia praecox, 3  
 Deprescribing, 137, 138  
 appropriate timing of, 146  
 clinical situations in psychiatry, 139–141  
 documentation of, 150  
 ethics of, 147, 150  
 managing withdrawal symptoms, 147  
 persons for, 144  
 process of, 142, 144  
 pros and cons of, 141, 142  
 psychiatric history, implications of, 145  
 in psychiatry, 138, 139  
 for psychotropic medications, 142, 143  
 using shared decision-making in, 144, 145
- Depression, 102, 107, 108  
 Dexamyl, 115, 117  
 Diagnostic and Statistical Manual (DSM-III), 3, 4  
*Diagnostic and Statistical Manual of Mental Disorders (DSM)*  
 biological reductionism and explanatory gap, 24–27  
 critiques, ecological approach to, 22  
 ecological model, critiques of, 18–20  
 exo-level critiques, 32–39, 41  
 individual-level critiques, 49–52  
 macro-level critiques, 23, 24  
 madness, measuring, 27–32  
 meso-level critiques, 41–45  
 micro-level critiques, 46–49  
 structural and conceptual competence, 20–22
- Disability, social model of, 195–197  
 Discontinuation syndromes, 148–149  
 Disease-centred model, 100, 105, 106  
 depression, 107, 108  
 psychosis, 106, 107  
 Dopamine, 104, 121  
 Drug action, evidence on, 101  
 animal studies, 104  
 comparisons with non-specific drugs, 102–104  
 mental disorders, research on neurochemical origins, 101, 102  
 Drug action, models of, 97–101  
 Drug treatment  
 drug-centred model, 105, 106  
 depression, 107, 108  
 psychosis, 106, 107  
 models of drug action, 97–99  
 evidence on, 101–104  
 history, 100, 101  
 Drug-centered approach, 98, 99

- antidepressant drugs, 126–128  
 benzodiazepines, 128, 129  
 neuroleptic drugs, 119–126  
 psychostimulants, 117–119  
 recommendations, 131
- E**  
 Ecological model, DSM, 18  
   biological reductionism and  
   explanatory gap, 24–27  
   critiques, ecological approach  
   to, 22  
   DSM-5, 18–20  
   exo-level critiques, 32–39, 41  
   individual-level critiques, 49–52  
   macro-level critiques, 23, 24  
   madness, measuring, 27–32  
   meso-level critiques, 41–45  
   micro-level critiques, 46–49  
   structural and conceptual  
   competence, 20–22  
 Ego-dystonic homosexuality, 35  
 Epistemic injustice, 50, 216  
 Evidence-based psychiatry, 88  
 Exo-level critiques, 32, 33  
   DSM diagnoses, 37–41  
   social production of disorders,  
   33–37  
 Explanatory dualism, 29  
 Explanatory gap, 24–27
- F**  
 Family Care Foundation, 211  
 Financial conflicts of interest  
 (FCOI), 76  
 Fluoxetine, 127  
 Food, Drug, and Cosmetics Act,  
 115, 116  
 Functional, 5
- G**  
 Global Summit on Diagnostic  
 Alternatives (GSDA),  
 20
- H**  
 Healthcare system, 54,  
 203, 219  
 Hearing Voices Movement, 10  
 Hearing Voices Network (HVN),  
 189, 190  
 Hierarchical Taxonomy of  
 Psychopathology  
 (HiTOP), 53  
 Homosexuality, 31, 35, 45, 186,  
 187
- I**  
 Individual-level critiques, 49–52  
 Informed consent, 167, 213, 214  
 Intentional Peer Support, 10  
 Involuntary commitment, 169,  
 198, 200, 203
- K**  
 Key Opinion Leaders (KOLs),  
 79  
 Kraepelinian model, 9, 124
- L**  
 Labelling theory, 51  
 Lisdexamfetamine, 117, 118  
 Lithium, 103, 104  
 Lived experience  
   Mad Pride and neurodiversity,  
   188, 193, 194  
   auditory and visual  
   hallucinations and  
   extreme states, 189  
   autism, 190, 191  
   incompatible with  
   coercion, 197–201  
   multiplicity, 191, 192  
   social model of disability,  
   195–197  
   suicide, 193–195  
 questioning dominant  
 assumptions, 181–188

**M**

- Mad Pride, 180–188
  - auditory and visual hallucinations and extreme states, 189, 190
  - autism, 190, 191
  - incompatible with coercion, 197–201
  - multiplicity, 191, 192
  - social model of disability, 195–197
  - suicide, 193–195
- Mad-affirming, 202, 203
- Madness, 182–183, 202
- Maintained drug therapy (MT), 123
- Major depressive episode, 76
- Major tranquilisers, 100
- Marxist theory, 8, 9
- Medicalization, 34, 35, 52
- Mental health professionals, 162
- Mental illness, 6, 161
- Meso-level critiques, 41–45
- Micro-level critiques, 46–49
- Mind-body dualism, 53
- Modified labelling theory, 51

**N**

- National Institute on Health and Clinical Excellence (NICE), 82
- Need-adapted treatment (NAT), 210, 212
- Neo-Kraepelinians, 115
- Neoliberalism, 9, 35, 52, 161
- Neoliberalism shifts policies, 35
- Neurodivergent, 181, 182, 194, 197–199
- Neurodiversity, 181–188
  - auditory and visual hallucinations and extreme states, 189, 190
  - autism, 190, 191
  - incompatible with coercion, 197–201

- multiplicity, 191, 192
- social model of disability, 195–197
- suicide, 193–195

- Neurodiversity-affirming care, 202, 203
- Neuroleptic drugs, 119–126
- Nominalist position, 29
- Nonvoluntary, 169

**O**

- Open Dialogue, 14, 211

**P**

- Pharmacotherapy, 114, 116, 119, 129, 131
- Pimozide, 104
- Placebo-controlled trials, 107
- Postmodernism, 7, 8
- Premenstrual dysphoric disorder (PMDD), 43
- Psichiatria Democratica*, 7
- Psychiatric drugs, 97, 106
- Psychiatric research and practice
  - institutional corruption in, 73, 74
  - psychiatric evidence base, distortions in, 75, 76, 78–85
- Psychiatry, 2
  - advantages, 216
  - American Psychiatric Association, 208
  - cannabis, 218
  - deprescribing in, 138–141
  - epistemic authority society, 219
  - healthcare system, 219
  - model of, 180
  - NAT, 211, 212, 215
  - principles, 210, 213
  - profession, 207
  - psychiatric evaluation, 209
  - psychostimulants, 209

- SDM, 214, 215, 217  
 traditional medical approach, 212
- Psychoactive drugs, 19, 99, 114, 129, 209, 218
- Psychopharmacology, 89, 209
- Psychosis, 104, 125, 160  
 disease-centred model, 106, 107
- Psychostimulants, 117–119, 209
- Q**
- Qualitative discursive approach, 50
- R**
- Randomized controlled trials (RCTs), 7, 41, 80–83, 150, 172
- Reliability, 46–48
- Restoring invisible and abandoned trials (RIAT), 79
- S**
- Schizophrenia, 5, 9, 21, 36, 49, 102, 103, 124, 189, 217
- Scientific Therapeutic Initiatives (STI), 79
- Sedative drugs, 103, 106
- Selective serotonin re-uptake inhibitors (SSRIs), 78, 83
- Sequenced Treatment Alternatives to Relieve Depression (STAR\*D) study, 80
- Service user movement, 9, 10
- Shared decision-making (SDM), 144, 145, 214, 215, 217
- Social model of disability, 195–197
- Suicide, 163, 164, 193–195
- T**
- Transparency, 52, 73, 144, 172, 173
- Tricyclic antidepressants, 107, 126
- U**
- Unjustified polypharmacy, 140
- V**
- Violence, 164, 165, 170
- Vortioxetine, 84, 85
- W**
- Wellness Recovery Action Plan (WRAP), 144, 173