

Introduction

This is a book about stories of schizophrenia—stories written by those living with it and stories written by those who study and treat it. These stories have developed in troubled and troubling dialogue with narratives about schizophrenia that circulate within the larger culture, some of which are explicit, as in popular films about madness (*The Snake Pit*, *One Flew Over the Cuckoo's Nest*, *Girl Interrupted*, *A Beautiful Mind*), and some of which are implicit in the widespread attitudes and assumptions that dominate Western understandings of severe mental illness. In the popular cultural view, schizophrenia means madness and madness invokes any number of images and associations, including raving lunacy, incoherence, homelessness, violence, isolation, pitifulness, staring catatonia, out-of-control sexuality, wild laughter, babbling speech, and just plain meaninglessness. It is these images and associations, as well as the stories that put them into play, that those living with schizophrenia must contend with and write against as they tell their stories.

I've opted to describe the stories discussed in this book as 'life writing' because across a range of genres—memoir, autobiographical fiction, autobiography, case study—the works I explore give shape to the lives and identities of those diagnosed with schizophrenia. These stories were written with deliberation, in an attempt to give written form to life experiences. While I discuss clinician-theorists as well as those living with schizophrenia, as the book unfolds I hope it will become clear that who is

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doing the writing is key. At the center of the discussion of these stories is the question, 'How do those living with schizophrenia write about their lives given that the diagnosis defines them as unable to tell a coherent story?'¹ In looking deeply into this question I've found that it has been taken up—with bafflement, interest, intensity, and longing—not only by writers living with schizophrenia but also by some of the theorists and clinicians who work with, study, and treat them. It is a difficult question to face directly, and over the last hundred years or so the mental sciences have struggled with it, at times only to turn away in the end, finding refuge in the biological psychiatry that risks sacrificing the humanity of those diagnosed as severely mentally ill for the security of neurophysiological explanations that make their story-telling irrelevant. As autobiography theorist Paul John Eakin has pointed out, acceptable identity is tied to narrative coherence, the ability to tell a story that makes sense. Eakin observes that 'the rules for identity narrative function simultaneously as rules for identity. If narrative is indeed an identity content, then the regulation of narrative carries the possibility of the regulation of identity—a disquieting proposition to contemplate in the context of our culture of individualism.'² Yet those living with schizophrenia have continued to find ways to make their voices heard, writing with and against psychiatric and popular narratives that describe them as different beings whose language is at worst unintelligible and at best unreliable, tainted by the incoherent sentences of their psychotic episodes.

As memoirist Lori Schiller writes in *The Quiet Room* of her initial desire to keep secret the fact that she was hearing voices, 'I didn't want to be a crazy person. People shunned crazy people. They feared them. Worse, they called the men in the white coats to come put them in straitjackets and take them away to an insane asylum.'³ She ties her fears to the popular culture representations of madness she was exposed to as a teenager, remarking that 'psychotic meant like the movie *Psycho* and Norman Bates, and the Bates Motel. That was scary and sick. That wasn't me.'⁴ As a writer, she introduces schizophrenia to her reader by highlighting the power of these popular representations, which can similarly skew the reader's understanding of Schiller's narrative.

One of the main challenges these narratives come up against is the fact that, while schizophrenia is associated with incoherence and mean-

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inglessness, at the same time it has come to 'mean' quite powerfully in the twentieth and twenty-first centuries. It has become what we might call a relentless metaphor. It tends always to represent something—contact with the demonic, the dissolution of meaning, the lost self in the face of modernity, the isolation and rootlessness of the post-modern subject. In popular culture, 'madness' is generally understood to be a less sensitive word for schizophrenia, so that the experience of those diagnosed with this label always already carries an excess of associations for their friends and relatives, for clinicians, and often for themselves as well. In the 1948 film *The Snake Pit*, based on Mary Jane Ward's 1948 autobiographical novel of the same name, viewers are signalled that Virginia Cunningham is 'mad' because she hears voices and has a distorted sense of reality. Her diagnosis of schizophrenia affirms for the viewing audience both that they were right (she really is 'mad') and that madness is a real condition known as schizophrenia. The metaphorical resonances of the term spill over into common understandings of what it means to live with the condition.

What Michel Foucault wrote of madness in the modern age—'Madness is responsible only for that part of itself which is visible. All the rest is reduced to silence. Madness no longer exists except as *seen*'⁵—holds true in the sense that madness, and thus schizophrenia, is seen to lie outside the possibility of interpretation. Yet paradoxically the term is everywhere imbued with meaning, brought into service to 'stand' for something other than itself. This is the case not only in popular understandings of schizophrenia but in literary criticism, where representations of madness are, yes, relentlessly, interpreted and reinterpreted. It's the case often in philosophy and literary theory, even when the theorist goes out of his or her way to point out that madness, like psychiatry, is a socio-historical construct and 'real' schizophrenia is different than the cultural schizophrenia of an age or the potentially liberating schizophrenia of a fluid, desiring post-modern subject. Thus even as Foucault traces the genealogy of madness to its sources in evolving historical practices and beliefs, the term often seems, as in the passage quoted above, to float above its material conditions, representing the self-deludedness of an age or a generalized rejected and repressed Other.

Philosophers Gilles Deleuze and Félix Guattari are careful to distinguish in their influential work *Anti-Oedipus* between 'the schizo', a rebellious,

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liberatory figure who revels in the fluid, unbounded interconnectedness of man and nature, in which ‘the self and the non-self, outside and inside, no longer have any meaning whatsoever’,⁶ and ‘the artificial schizophrenic found in mental institutions: a limp rag forced into autistic behavior, produced as an entirely separate and independent entity.’⁷ Nevertheless, even as Deleuze and Guattari argue against metaphor in general, and even though Félix Guattari himself worked tirelessly for the rights of those living with severe mental illness, the figure of ‘the schizo’ is made to stand for something, in this case the deconstruction of those oppressive capitalist structures that benefit from and uphold the restrictive constriction of desire in contemporary society.⁸ In some ways such a division between the figurative ‘schizo’ and the ‘real’ person living with schizophrenia echoes that between the rebellious, insightful McMurphy and the inarticulate, raving Rawler in Ken Kesey’s 1962 novel *One Flew Over the Cuckoo’s Nest*. In both texts, whether ‘limp rag’ or screaming lunatic who castrates himself in his solitary cell, the representation of someone actually living with schizophrenia remains voiceless, described only from the outside, assumed to be unknowable.

For Louis A. Sass, schizophrenia is remarkable for the many ways it corresponds with and is exacerbated by modernism. Sass seeks

to call attention to the special affinity modernity has for self-consciousness and meta-awareness—that is, to its preoccupation with its own underlying assumptions and rules as well as with personal and cultural counterfactuals of all sorts. Here, then, we discover what is perhaps the deepest affinity between schizophrenia and modern society: Each is defined by forms of hyperreflexivity that lie at the core of its decentered, ever self-decentering soul.⁹

In Sass’s view this association ‘may help to account for the fact that schizophrenia seems to be a more chronic and severe condition in modernized than in more traditional cultural settings’,¹⁰ a ‘fact’ established by World Health Organization studies and repeated in many anthropological and psychiatric texts examining the prevalence of schizophrenia worldwide. Kim Hopper has pointed out the discrepancies and faulty assumptions in the WHO studies, not the least of which is the imposition of Western definitions of psychosis in non-Western cultural settings.¹¹ The associa-

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tion between modernism and madness (and the related nostalgic association between sanity and a 'simpler' way of life) is a long-standing one that shows up in, say, Susanna Rowson's portrayal of the city as dangerous and soul-stealing for innocent young women in her 1791 novel *Charlotte Temple*, in F. Scott Fitzgerald's rendering of an early twentieth-century couple's dissolution in *Tender Is the Night*, in Franz Kafka's famous man-turned-cockroach Gregor Samsa, in Samuel Beckett's disturbed main character in his 1951 novel *Malone Dies*, and in any number of other modernist texts. I don't in the least mean to dismiss Sass's work, which offers an important exploration of the sociohistorical contexts within which schizophrenia has emerged in the modern West as both illness and diagnosis. I only wish to highlight how determinedly schizophrenia comes either to represent something sweeping and general, like modernism or post-modernism, or to signify complete meaninglessness, that which lies beyond language and culture, inaccessible to human reach or understanding.

It is this kind of figuration that life writing about schizophrenia writes with, through and against. It's as if the popular, literary, and philosophical representations of madness have to be beaten off with a broom, like bats, as many of these writers unfold their stories. Sometimes those bats are flying around inside the narrators' self-representations, or, in the case of those writing about others, sometimes they blur and obscure narrative possibilities that might otherwise emerge. Through a focus on narrative and narrators, I hope to be able to bring attention to some of the ways that schizophrenia has been written from the inside. I also want to examine the ways that narrative and narrators created by writers in close proximity to those diagnosed with schizophrenia can reveal both assumptions about what 'madness' is and conceptions of living and being that uphold those assumptions. As I'll discuss below, theories developed within illness narrative studies as well as Disability Studies about the relationship among voice, subjectivity, experience and the ethics of narrative provide useful tools for approaching these texts. First, though, I'd like to provide an overview on the diagnosis of schizophrenia in order to give historical context to the discussion that follows.

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Genealogies of schizophrenia as brain disorder

The contemporary diagnosis of schizophrenia emerged out of the earlier designation *dementia praecox* developed by late-nineteenth-century professor of psychiatry Emil Kraepelin, one of the founders of modern diagnostic categories of mental illness. Working at the University of Heidelberg in the 1890s, Kraepelin sought a more scientific basis for the study of 'mental diseases' by constructing systematic pharmacological and psychological studies of large numbers of patients. His work became controversial as it became more widespread and crossed the Atlantic to America; his critics maintained that he emphasized diagnostic categorization over deep psychological theory. Even as he methodically classed *dementia praecox* along with other 'metabolic disorders' (including 'cretinism' and dementia caused by syphilis) that appeared to result from an external or internal 'intoxication' of the system, Kraepelin alluded in his metaphors to the elusive and mysterious nature of the illness, which he characterized as 'an alteration of the cerebral cortex ... which brings about a slow deterioration in a constitutionally weak psychic state ... similar to a tree whose roots can find no nourishment.'¹²

As far as Kraepelin's model is from present-day understandings of schizophrenia as a neurological disease, his descriptions of *dementia praecox* as an incurable illness with a degenerative course in many ways set the stage for conceiving of schizophrenia as primarily a disease of the brain. Late-nineteenth-century reactions to his textbook reveal an incipient debate over the roles and definitions of neurophysiology and environment in severe mental illness. Influential Swiss-American psychologist Adolf Meyer upbraided Kraepelin for promoting distinctions without sufficient evidence on the one hand, and neglecting psychological explanations on the other, even though, as historian Edward Shorter has pointed out, Kraepelin was in many ways rebelling against the stricter biological psychiatry of the previous generation.¹³ In a review of the fifth edition of Kraepelin's textbook *Psychiatrie*, published in 1896, Meyer complains,

The classification of dementia praecox, hebephrenia, katatonia—i.e., of all those acute psychoses which terminate in secondary dementia—in connection with this group is rather hypothetical. It will be necessary, first, to

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demonstrate that they belong together and are not frequently pernicious forms of intoxication (post-febrile, post-typhoid) or of other acute psychoses—this is the easier one of the two problems. Second, it remains to be shown in how much the expression ‘disease of metabolism’ can find a place in pathology with so little substantial evidence.¹⁴

Meyer follows his questioning of Kraepelin’s categories of diagnosis with an assertion of his own position that nosology should not be overemphasized and that

the aim of clinical psychiatry must be the study of the development of specific psychical and somatic events out of specific conditions. The accumulation of nomenclature, of names and descriptions of phases of insanity, are merely preparatory studies of symptomatology; and even Kraepelin’s attempt at giving groups with specific basis, specific course, and specific termination is in many respects a problem, not a solution of the difficulty.¹⁵

By the time of his sixth edition of *Psychiatrie*, Kraepelin had revised and broadened his categorization of *dementia praecox*, distinguishing it from the manic-depressive illnesses. He considered *dementia praecox* to be a disease of cognition, whereas manic-depressive illness was a disease of affect. Significantly, he further emphasized the poor prognosis of *dementia praecox*, defining it as a progressive disease without a cure. While not every psychiatrist or psychologist of the time agreed with this assessment, Kraepelin’s textbook had a powerful impact that is still felt today in popular understandings of schizophrenia. In 1902, the sixth edition of Kraepelin’s *Psychiatrie* was translated into English by psychiatrist A. Ross Diefendorf, who condensed and adapted it for American students and practitioners of psychiatry. In a 1907 revision of this text based on Kraepelin’s seventh edition, Diefendorf comments that ‘In response to a general demand, an abridgment of the chapter on the Classification of Mental Diseases is added to the present edition. Less hampered by restrictions as to size the present edition follows more closely the context of the “Lehrbuch”.’¹⁶ In this English-language edition, Diefendorf reiterates Kraepelin’s various subtypes of schizophrenia (such as catatonia, hebephrenia, and paranoia) as well as his claims that ‘defective heredity is a very prominent factor’, that

'there is a definite disease process in the brain, involving the cortical neurones',¹⁷ and that the course of the disease is degenerative. Also included is Kraepelin's highly influential description of schizophrenia's symptom of 'flat affect', or lack of emotion, in which 'the patients express neither joy nor sorrow, have neither desire nor fears, but live from one day to another quite unconcerned and apathetic, sometimes silently gazing into the distance, at others regarding their surroundings with a vacant stare.'¹⁸ This conception of the supposed effect of the disease on the patient's emotional life, a conception based not on patients' expressed experience but on the evaluation of their behavior and appearance by a psychiatrist, has persisted throughout the twentieth century and into the twenty-first.

In a sense, Kraepelin combined a set of classifications with implicit narratives—presented as nosology—that helped to differentiate them. *Dementia praecox*, and later schizophrenia, became the mental illness with no cure, the sign and enactment of a gradual loss of brain, then mind and self. This early classification may thus have much to do with contemporary fears about schizophrenia, even though the diagnostic description has been substantially changed.

Researchers and clinicians subsequent to Kraepelin helped to revise the diagnosis and the story it told, among them Eugen Bleuler, who in 1911 defined the 'Group of Schizophrenias'. These illnesses, according to Bleuler, were marked by 'the alleged disproportion between affect and cause'.¹⁹ Bleuler thus shifted the division Kraepelin had established between *dementia praecox* and manic depression to posit a 'split' within schizophrenia itself. Like Adolf Meyer, Bleuler also placed emphasis less on the degenerative course of the disease as a major diagnostic factor than on its symptomology, paving the way for subsequent efforts to cure the patient through psychotherapeutic methods. Indeed Bleuler's language in describing schizophrenia reveals his contact with Freud's developing psychoanalytic theories. He remarks,

On the one hand, the loosening of the associations results in the opening up of wrong pathways of thought, pathways deviating from experience; and on the other hand, the patient is forced to operate with fragments of ideas. The latter abnormality leads to displacements, condensations, confusion, generalizations, clang-associations, illogical thinking, and incoherence.

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The weakening of the logical functions results in relative predominance of the affects. Unpleasantly-toned associations are repressed at their very inception (blocking); whatever conflicts with the affects is split off. This mechanism leads to the logical blunders which determine (among other things) the delusions; but the most significant effect is the splitting of the psyche in accordance with the emotionally charged complexes.²⁰

Sigmund Freud at first rejected the term 'schizophrenia', particularly when the patient displayed paranoia, largely because the implication of a split within the psyche was to him misleading. In 1914, Freud wrote that he preferred the term 'paraphrenic' (from Greek *para*, meaning abnormal, and *phren*—meaning mind) because it allowed for his claim that patients 'display two fundamental characteristics: they suffer from megalomania and they have withdrawn their interest from the external world (people and things)'.²¹ Yet despite Freud's argument with Bleuler's term, it became the dominant one, bringing with it the popular misunderstanding of schizophrenia as invoking someone with two or more distinct personalities, represented iconically by the title character in Robert Louis Stevenson's 1886 novel *The Strange Case of Dr. Jekyll and Mr. Hyde*. This popular conception of schizophrenia continues into the present day and is another narrative that the diagnosed individual must contend with in telling his or her own life story. Indeed in Lori Schiller's *The Quiet Room*, in which her family members narrate several of the chapters, her mother Nancy Schiller writes of her response of first being told of her daughter's diagnosis, 'Schizophrenia meant split personality, didn't it? I had heard about schizophrenia, and I had seen some movies about it. To me, schizophrenia was *The Three Faces of Eve*, the film starring Joanne Woodward about a woman who had three different personalities that came and went without warning.'²²

Bleuler's new categorization had other ramifications for the life writing of those diagnosed with schizophrenia. His understanding of mental illness as manifest in affect and rooted in physical disease helped establish the psychiatrist as interpreter and the appearance and behavior of the patient as text to be read. At the same time, the status of the patient's own language as readable text came immediately into question. Theorists and clinicians argued over whether schizophrenic language was interpretable or whether it presented as pure symptom, notable only for the fact of its

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meaninglessness. As Carl Jung pointed out in 'On the Psychogenesis of Schizophrenia', 'In most cases it transcends even the physician's comprehension, so much so that he is inclined to suspect the mental sanity of anybody who sees more than plain madness in the ravings of a lunatic.'²³ While both Jung and Freud attempted to work with patients experiencing symptoms of schizophrenia, Kraepelin's claim that *dementia praecox* was a degenerative disease and Freud's ultimate assertion that patients with paraphrenia 'are inaccessible to the influence of psycho-analysis and cannot be cured by our endeavours'²⁴ have had powerful consequences for those diagnosed with schizophrenia up to the present day. These patients have been written into an already existing story in which their own words have meaning primarily as symptoms of a mental illness with a grim prognosis. Unlike those marked by almost any other diagnosis of mental illness—including the bipolar disease that descended from Kraepelin's category of manic-depression—individuals diagnosed with schizophrenia must contend with the fact that their story-telling becomes suspect and opaque from the moment of diagnosis.

Psychoanalysis, psychotherapy, and narratives of schizophrenia

Despite the fact that Bleuler's new distinctions and definitions laid the groundwork for dismissal of the words and stories told by those with schizophrenia, many psychiatrists of the early twentieth century applied eclectic treatments to psychosis, distancing themselves from the avid biological psychiatry of the nineteenth century and employing interactive methods that often included talking with patients. In the first half of the twentieth century, as Adolf Meyer's version of Freudian psychoanalysis (a version that questioned Freud's focus on early childhood, Oedipal relations, and reliance on deep unconscious processes) influenced American psychiatry, the psychoses were often described as psychological in origin and treatable with 'talk therapy'.²⁵ Particularly during and after the second World War, as many European psychoanalysts immigrated to the U.S., the American Psychiatric Association was increasingly influenced by psychoanalytic thinking that, departing from Freud's own pessimism about using his methods to treat those with schizophrenia, was often applied to psychotic patients. Even before the war, throughout the late 1920s and the

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1930s, psychoanalysts such as Karl Menninger and Harry Stack Sullivan used psychodynamic methods to treat psychotic patients within psychiatric hospitals. Sullivan in particular, developing a social theory of mental illness and prioritizing the social and cultural contexts within which mental health was defined, used interactive methods to treat patients with schizophrenia.²⁶ Working with patients diagnosed with schizophrenia at Shepard and Enoch Pratt Hospital in Towson, Maryland, Sullivan claimed an 80% success rate using treatments based on interpersonal theories of psychic development.²⁷

The eclectic, transnational development of psychoanalytic treatments for psychosis is exemplified in the work of Frieda Fromm-Reichmann, who worked with schizophrenic patients at Chestnut Lodge in Washington, D.C., after emigrating from Germany in 1935 after Hitler's ascendance to power. Fromm-Reichmann adapted Freudian concepts based on her own experience with patients, balancing an emphasis on early childhood sexuality with equal interest in relationships and events throughout the patient's life.²⁸ Fromm-Reichmann, like Sullivan, emphasized the importance of respectful, gentle interactions with patients experiencing schizophrenia, stressing that therapists should listen to patients' words and heed their needs and expressed limitations whenever possible.²⁹ While today these approaches to psychosis are either ignored or dismissed as mistaken, even laughable, at the time they were taken seriously within the pages of the *American Journal of Psychiatry*, the preeminent American psychiatric journal of the time, and psychoanalysts working with schizophrenia claimed moderate rates of success.³⁰

Since the 1970s, psychoanalytic approaches to psychosis by Sullivan, Fromm-Reichmann, and Gregory Bateson (the subject of Chapter Two of this book) have been caricatured as wrong-headed, simplistic enactments of 'blaming-the-mother' theories. While their work could and did lead to practices villifying mothers as responsible for their children's mental illness, in rejecting the research and experience of these theorists outright we may have thrown the baby out with the bathwater. These psychoanalysts developed approaches that were painstaking, time-consuming, and often skewed by misogynist theories of family interaction. Yet they also listened to patient stories and, developing new understandings of the dangers of counter-transference, explored their own role in patient-therapist

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dynamics, thus treating their patients as full human subjects. They also saw the meanings of mental illness as embedded in cultural and social values, norms, and beliefs that had to be understood as context for the patient's experience.

This attention to cultural and social meanings of mental illness would find full expression in the late 1960s and early '70s in the 'anti-psychiatry' writings of Thomas Szasz and R.D. Laing, as well as in Michel Foucault's influential *Madness and Civilization* and the historical studies of David Rothman, whose *Discovery of the Asylum* (1971) posited psychiatry and the mental institution as forms of social control.³¹ Feminist theorists furthered this approach by examining the ways that gender ideologies were part and parcel of the social construction of mental health and illness; Phyllis Chesler's landmark study *Women and Madness* (1972) maintained that women throughout history have been contained and violently controlled by psychiatric ideologies and practices. On the popular front, anti-psychiatry found expression in such anti-institutional works as the 1967 film *Marat/Sade*, based on Peter Weiss's 1963 play about 18th-Century asylum inmates linked to the French Revolution, and the 1975 film of Ken Kesey's novel *One Flew Over the Cuckoo's Nest*. Today these films are seen as representing a period of hot-headed rebellion, while the writings of Szasz and Laing are often characterized as errant blips on the screen of psychiatry's story of progress towards a (more solid) neurophysiological science.³²

In the creation of these caricatures and the dismissal of what admittedly may have been one-sided critiques of the profession of psychiatry, present-day theorists and historians obscure values and practices that could be of use to contemporary psychiatric practice: a respect for the experiences and words of those diagnosed with severe mental illness; an insistence that those living with schizophrenia have the same ontological status as the rest of humanity; an attention to the social construction of mental sciences; and an interrogation of medical authority exercised in the description, research, and treatment of psychosis. These messages are of continuing value in an age when psychiatric treatment, even more so than theory, has turned almost exclusively to neurophysiological explanations of schizophrenia.

The new biological psychiatry and stories of schizophrenia

In the late twentieth and early twenty-first centuries, schizophrenia has for the most part been represented as existing in a realm apart from story-telling. In both popular and medical representations of schizophrenia, the words people diagnosed with schizophrenia speak or write are not heard as story but as jumbled, random linguistic units disconnected from meaning and from the kind of social interrelatedness that gives sense to story-telling. The person in recovery or remission from schizophrenia must invariably struggle against this approach to his or her language, repeatedly placed in the position of having to prove him or herself capable of coherence and sense.

It is perhaps not surprising that in the 1970s, at the same time that historians, filmmakers, and psychologists were critiquing overcrowded and often abusive mental institutions and the professions that sustained them, the mental sciences began a pronounced turn from psychoanalytic explorations to biological psychiatry, a turn that has been steadily reinforced up through the present day. As historian Edward Shorter so adroitly puts it, in the 1970s 'biological psychiatry came roaring back on stage, displacing psychoanalysis as the dominant paradigm and returning psychiatry to the fold of the other medical specialties.'³³ Charles E. Rosenberg remarks on 'the cultural pervasiveness of somatic, mechanism-based ideas of disease specificity'. For Rosenberg, 'it is no accident that today's advocates for the mentally ill state again and again that "it" is a physical ailment no different from diabetes or cancer—and no more deserving of censure or less-than-equal insurance coverage.'³⁴ While psychotherapy still plays a role in the treatment of schizophrenia, its focus is primarily on the patient's everyday coping skills rather than the deep engagement with patient language that characterized the treatments of Sullivan, Fromm-Reichmann, and others. In other words, the stories told by experts about schizophrenia have changed; they no longer explore the effects of traumatic social, political, and familial interactions on the individual psyche but instead focus on the transmission of genetic material, the malfunction of chemical receptors, the deviation from the norm of neurological structures and processes.

While the connection of mental illness to organic causes and manifestations may take the blame off individuals and families and feed the

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hope for chemical cures funded by insurance, it also implies there is an ontological difference in those diagnosed with schizophrenia. The wider socio-cultural belief in such a difference is supported by studies showing that, when research subjects think schizophrenia is a brain disease, they blame those diagnosed with it less but treat them worse than they do when they think it stems from psychosocial causes.³⁵

In the area of diagnosis, which, as I shall discuss below, is a narrative practice intimately tied on the one hand to wider societal practices and beliefs and on the other to decisions about treatment, psychiatric clinicians and researchers continue to reproduce and rely on Kraepelin's categories of symptoms. In the widely used *DSM-IVTR (Diagnostic and Statistical Manual of Mental Disorders)*, in order for a patient to receive a diagnosis of schizophrenia, he or she must exhibit delusions, hallucinations, disorganized speech, grossly disorganized behavior or catatonia for most of a one-month period. In line with Kraepelin, while two of these symptoms are usually required for diagnosis, only one is sufficient if delusions are severe or the patient is hearing voices.³⁶ In addition, the patient must display what are usually referred to as 'negative symptoms', such as depression, failure to function in society, or inability to care for one's self. Thus evaluation of symptoms for schizophrenia is based overwhelmingly on the assessment of a person's behavior and appearance, with little attention paid to his or her experience of what's happening either internally or in the clinical interview or to his or her language as producing meaning.

Interestingly, the *DSM-V* section on schizophrenia, which is still in the process of being revised as of the writing of this book, removes the subtypes, such as paranoid schizophrenia, that appeared in earlier versions of the *DSM*. Rather than divide the diagnosis into various sub-categories or differentiate dramatically between positive and negative symptoms, the current editors propose a 'spectrum' of schizophrenia disorders in which symptom 'dimensions' (such as 'hallucinations' or 'restricted emotional expression') vary in number and degree but can nevertheless be applied to a range of diverse patients.³⁷ This editorial gesture effectively removes the trace of Freud's distinction between paranoid schizophrenia and other types, a distinction based on developmental socio-familial factors.³⁸ The creation of a schizophrenia 'spectrum' thus opens the diagnosis to a wider, less differentiated group of patients at the same time that it focuses diag-

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nosis even more acutely on symptomology rather than context and history. While the substitution of 'restricted emotional expression' for 'flat affect' or 'restricted affect' seems to allow that the person may be experiencing emotion and just not revealing it to others, thus focusing some attention on the patient's internal life, the editors return to the previous terminology in their rationale, stating that 'restricted affect better describes the range of abnormalities in affective experience and expression in schizophrenia than flat affect.'³⁹ This gesture preserves from past editions an imagined prefiguring of patient-clinician encounters in which the 'patient' is observed, evaluated, and described as an isolated unit and the clinical encounter itself is erased as a crucial factor in the individual's behavior, internal feelings, and responses. Such inconsistencies present in the *DSM* as it undergoes revision bear the traces both of debates among the volume's editors and advisors and of the genealogy that goes back to Kraepelin's focus on the behavior and appearance of the patient. This emphasis on nineteenth-century symptom categories over and against patient experience supports representations of schizophrenia as a disease or condition of the brain with organic causes that will eventually be revealed.

Contemporary psychiatrist and trauma specialist Colin A. Ross has pointed out, 'within psychiatry, there is virtually unanimous adherence to the biopsychosocial model of mental illness.'⁴⁰ Yet at the same time, writes Ross, 'in clinical practice in North America, *psychotic* means that the person has a biomedical brain disease or a chemical imbalance, requires medication, and cannot be treated with psychotherapy.'⁴¹ This is particularly the case when the patient is indigent; such a patient will have minimal contact with psychiatrists beyond receiving a prescription and will be monitored by case workers for 'compliance' with medication orders.

While researchers repeatedly assert that genes play only a partial role in the etiology of schizophrenia and that environment is an equally important factor, considerable research efforts—such as one underway for the last decade spearheaded by an international, interdisciplinary group of researchers from UCLA and the University of Helsinki—currently go towards confirming the centrality of genetics and establishing links between identified gene markers, patient behavior, and brain morphology. Increasingly, 'environment' is defined not as socio-cultural contexts but as physiological phenomena, such as exposure to toxins or viruses, that are

not clearly genetic in nature. In this research there is little room for the words or stories of those living with schizophrenia.

I hesitate to critique important studies such as these, which promise to bring answers and eventually new treatments to thousands of individuals experiencing severe mental illnesses. At the same time, I think it is useful to place such work in the context of the history of treatments and understandings of schizophrenia and to examine its relationship to larger cultural narratives about the disease. As disability studies scholar Lennard Davis points out, 'Our problem comes when we try to deny that diagnosis is a complex process that aims to freeze in a moment the moving target of individual bodies and their processes interacting with psyches, environments, and social, institutional, and cultural milieus.'⁴²

Along these lines, when I read about the results obtained through neuroimaging studies or questionnaires tracking verbal memory and recognition, I can't help but wonder how the study subjects experienced the collection of such 'data'. For the 'proband', those experiencing schizophrenia, did having images taken of their 'gray matter' touch on fears and delusions? Did questions about memory and recognition lead them to feel interrogated, inadequate, defective?

In the reporting of study results, these individuals necessarily become the objects of narrative, sacrificing their existence as speaking subjects. One might argue that this fact is a necessity of the research genre and merely fulfills the conventions of scientific study, in which the individuality of research subjects is less important than obtaining generalizable results. Yet I wouldn't want to think that a genre or set of conventions should remain unquestioned simply because the rules historically established for its practice have defined it in a certain way.⁴³ The interdisciplinary studies mentioned above, which make use of a large cohort of Finnish monozygotic (identical) and dizygotic (fraternal) twins, at least one of which has been diagnosed with mental illness, employ narrative devices that help establish relations among researchers and subjects—devices such as the manipulation of narrative time, with its expansion and contraction, its focus on some events and not others.

For example, in a 2004 article on 'Hippocampal Volume in Schizophrenic Twins', van Erp et al. relate that 'high-resolution magnetic reso-

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nance images were acquired on 252 of the 260 twins. Two images were excluded because of technical problems with the magnetic resonance imaging, and 1 was excluded because of a large frontal lobe lesion, leaving 249 images on which hippocampal volumes were measured.⁴⁴ A use of passive voice here facilitates the temporal collapse of story events that the reader may nevertheless imagine—technicians gathered around malfunctioning machines or blurred screens, doctors meeting with family members to explain the unexpected lesion in a patient's brain, graduate students staying late in their labs in order to finish taking measurements. It's not that all these details should necessarily be included, but their absence helps draw attention to the narrative qualities inherent in a research report, including the portrayal (justified as convention) of research subjects as faceless, acted upon, the amorphous sum of procedures, measurements, body parts. As illness narrative theorist Arthur Frank remarks, 'the master text of the medical journal article needs the suffering person, but the individuality of that suffering cannot be acknowledged.'⁴⁵

As much as any novelist or teller of fables, the researcher is engaged in constructing imaginary worlds, imaginary not in the sense of 'made up' or disconnected from any reality altogether but in the sense of being created on the page and in the minds of readers.

Implicit in these narratives are the desire and longing that propel the studies themselves, impulses that themselves represent a yearning after a story that makes sense, a story with cause and effect, the following of one thing from another. When Cannon et. al. write that 'there is an urgent need to decipher the complex nature of genotype-phenotype relationships within the multiple dimensions of brain structure and function that are compromised in neuropsychiatric syndromes such as schizophrenia',⁴⁶ even though they are careful to name 'relationships' rather than causes, they express a desire to pin what can be seen and measured to something conceived of as immutable—DNA. For, while genes can and do mutate, it is precisely the concept of mutation that helps reinforce the representation of an ideal genome, a reliable biological foundation that connects the past to the present and future. Mutation, in both its scientific and popular connotations, is often figured (as in Cannon et. al.'s comment above) as abnormal deviation in relation to the normal stasis of unmutated DNA.

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As Lennard Davis points out,

Somewhere, in some empyrean there exists the platonic human genome. This genome is a book or text made up of letters sequenced in the right order without 'mistakes.' As such, it is in fact a sacred text and our correct reading of it is not unlike the vision that the fundamentalist has that his or her sacred text is infallible. However, the problem is that, as it stands now, the human genome is in need of fixing to make it perfect. Errors of transcription have ruined the primal perfection of the text.⁴⁷

As scientists work to link that stable foundation to human life and behavior, they strive to identify that behavior as 'phenotype', an expression of genetic coding that can be measured and assessed.⁴⁸ While such research into genetic expression, with its stated longing for a story that makes sense, may in some future time lead to useful treatments, the representation of schizophrenia as part of a narrative of 'genetic' causes and effects can also contribute to a conception of those with schizophrenia as ontologically different, as abnormal, as fundamentally 'other'.

Again, while I don't wish to imply that such work should be discontinued, I think an awareness of the sociocultural desires that fuel it can help draw attention to attitudes and unspoken values that can lead to the erasure of those living with schizophrenia as the feeling, perceiving beings that they are, beings with their own stories to tell, as fragmented as those stories may at times be. The focus on genetic and neurophysiological research within neuropsychiatry coupled with a public fascination with the human genome can obscure psychiatry's own claim to a biopsychosocial model of mental illness in which patients' words about their own lives weigh in equally with the idiosyncracies of their DNA.

Psychiatrists as well as patients at times call on the profession to recognize and practice its claim that schizophrenia is about more than gray matter and genetic markers. Colin A. Ross calls for recognition of a subset of schizophrenia diagnosis in which trauma is seen as both possible cause and framework for narrative-based treatment. Returning to psychology-centered approaches to psychosis from the early twentieth century, Ross states that Bleuler 'considered trauma to be a primary cause of the dissociation he observed in his patients, and he considered dissociation to be the

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fundamental phenomenon in schizophrenia.⁷⁴⁹ Far from rejecting neuro-physiological approaches altogether, Ross calls for ‘a model of the brain-mind field that allows for causality of serious mental disorders to run in two directions: brain to mind and mind to brain’ (xviii), thus placing the mind—along with self and language—more at the center of schizophrenia research and treatment.

Life writing about schizophrenia

Because I’m a literature scholar and not a psychiatrist or psychologist, I can’t provide evidence for what schizophrenia is or isn’t, nor can I make specific recommendations for how it should be treated. What interests me is rather how it is represented—within the specialized fields that investigate and treat it, within non-specialist popular media, and in the writings of those diagnosed with the disease—and the meanings it carries both for individuals and the social and cultural worlds they inhabit. It’s one thing for psychiatrists to say that the words of schizophrenics are meaningless, merely a sign of disease, but it’s something else again for a human being, any human being, to be treated as if what he or she says has no signifying power. Thus I’m interested above all in how those diagnosed with the disease write about meaning, the search for meaning, and the absence of meaning, as well as how they connect writing and story-telling to the on-going shaping of identities seen by others, and often by themselves, as severely disrupted, even destroyed.

Writing about the ethics inherent in autobiographical discourse, Paul John Eakin reflects that

we inhabit systems of social intercourse in which the ability to articulate an identity narrative—whether written, related orally, or simply dropped piece by piece into the social discourse of daily life—confirms the possession of a working identity. Accordingly, when brain disorders of various kinds impair or prevent our saying to others who we are, our claims to recognition as persons may suffer irreparable harm.⁵⁰

Eakin recognizes that the disruption of one’s ability to tell a life story can place that individual at risk of being seen not simply as ‘not normal’

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but as without personhood. It is this risk that lies behind my exploration of both the narrative methods of researchers and clinicians and those who are themselves living with schizophrenia; an individual living with schizophrenia who enters a research trial or becomes the subject of a case study is always already on the edge of being regarded as at best a 'different' kind of person and at worst not a person at all, so that eliding his or her identity into a generalizable research subject can inadvertently commit an erasure that is already expected.

The interdisciplinary fields of disability studies, illness and narrative, and medical humanities have gone far towards providing ways of understanding life writing as an undoing of that erasure.⁵¹ Theorists in these fields often draw on their own experience as they explore the relationship among narrative, identity, and social constructions of illness and medicine. In his powerful memoir *Intoxicated By My Illness*, Anatole Broyard writes,

My initial experience of illness was as a series of disconnected shocks, and my first instinct was to try to bring it under control by turning it into a narrative. Always in emergencies we invent narratives. We describe what is happening, as if to confine the catastrophe.⁵²

Arthur Frank's research and writing, based to a large extent on his own experiences as a patient, similarly focuses on the power of narrative to gain control over illness and rewrite derailed identities. In Frank's view, 'stories have to *repair* the damage that illness has done to the ill person's sense of where she is in life, and where she may be going. Stories are a way of redrawing maps and finding new destinations.'⁵³ His analysis of the functions of storytelling goes further to show how writing by those experiencing illness and disease can counter dominant models of illness stories as redemptive, restorative, and always focused on overcoming adversity. Because 'restitution stories bear witness not to the struggles of the self but to the expertise of others, their competence and their caring that effect the cure',⁵⁴ they tend to simplify and deny the complex, multi-layered lives of those experiencing illness, lives that can find expression in narratives that resist the desire for the expulsion of suffering and a return to safe and known identities.

In his classic work *The Illness Narratives*, anthropologist Arthur Klein-

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man has done invaluable work in examining how active listening to patient narratives on the part of medical practitioners can help patients rebuild identities shattered by traumatic illness, disease, and accident. In her analysis of occupational therapists' interactions with their patients in *Healing Dramas and Clinical Plots*, anthropologist Cheryl Mattingly shows that collaborative life story-telling in such a therapeutic setting can help patients reshape identities damaged by catastrophic medical events.⁵⁵ Indeed, much recent work in medical humanities theorizes storytelling as a collaboration between patient and practitioner in which the clinician is encouraged to listen actively rather than imposing medical judgments on patient experience. Narrative medicine theorists Laurie Zoloth and Rita Charon, like Arthur Frank, turn to philosopher Emmanuel Levinas to examine the nature of self–other relations in ways that can help facilitate a truly collaborative patient–practitioner exchange. Because the work of Levinas ‘illuminates the transformative and disconcerting implications of listening to the other, hence taking responsibility for the other’,⁵⁶ his philosophy provides a way for physicians and other health care practitioners to value listening and collaborative story-making as central to good medical care.

Yet as useful as these approaches are to the positive valuation and understanding of patient life writing, it can be difficult to apply them to stories by patients diagnosed with severe mental illness. In an understandable effort to see empowerment in patient story-telling, theorists often stress the ability of patients to take conscious control of their life stories, using narrative to reform new lives and identities. Such an approach relies on an understanding of narrative as, on the one hand, primarily a conscious process and, on the other, an enterprise entered into within a community of tellers and listeners who share an epistemic common ground, for whom story-telling itself is not a mine-field full of gaping holes and secret dangers. In contrast, for many people diagnosed with schizophrenia it is their language itself, the things they say and the way they say them, that is often the basis of their diagnosis. What illness narrative theory might posit as the means of their empowerment thus lies at the very center of their diagnosed illness.

Disability studies has contributed greatly to an understanding of both mental and physical disabilities as sociohistorically constructed differences

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whose stigmas are a product of ideology rather than measurable medicalized conditions. Disability studies calls into question the notion of 'disease' itself as an objective bodily state, positing that medical representations of the body are always informed by social, cultural, and political values and preconceptions. In the words of Rosemary Garland-Thomson and Martha Stoddard Holmes,

The New Disability Studies thus explores disability as a historical system of thought and knowledge that represents some bodies as inferior, as in need of being somehow changed, so as to conform to what the cultural imagination considers to be a standard body. In other words, this critical perspective considers 'disability' as a way of thinking about bodies rather than as something that is wrong with bodies.⁵⁷

Applying this view to mental illness goes far towards challenging the pathologizing and objectification of those diagnosed with schizophrenia. Disability studies scholars have questioned the use of disability as metaphor throughout Western literary history. As Michael Davidson points out, 'A common recent criticism among disability scholars is that metaphoric treatments of impairment seldom confront the material conditions of actual disabled persons, permitting dominant social norms to be written on the body of a person who is politely asked to step offstage once the metaphoric exchange is made.'⁵⁸

Personal narrative has emerged as a central genre within disability studies in ways that go beyond previous conceptions of illness narratives. Through personal narrative, writers with disabilities have given voice to their experience, developed epistemologies based on that experience, and turned a critical lens both on the social construction of illness, diagnosis, and medical treatment, and on 'ableist' scholarly methodologies. Lennard Davis remarks in *Bending Over Backwards: Disability, Dismodernism, and Other Difficult Positions* on 'the specter haunting normality in our time. That specter may be crippled, deaf, blind, spasming, or chronically ill—but it is clearly no longer willing to be relegated to the fringes of culture and academic study'.⁵⁹ Writers with disabilities have made their voices heard by publishing in a number of important anthologies (such as Fries's *1997 Staring Back: Disability Studies From the Inside Out* and Black, Bartlett and

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Northern's 2011 *Beauty is a Verb: the New Poetry of Disability*), in the genre of memoir (such as Michael Berube's 1996 *Life As We Know It: A Father, A Family, an Exceptional Child*) and in scholarly books and articles, many of which include personal narratives (such as Robert F. Murphy's 1987 *The Body Silent*, Nancy Mairs's 1997 *Waist-High in the World: A Life Among the Non-Disabled*, Eli Clare's 1999 *Exile and Pride: Disability, Queerness, and Liberation*, and Davis's 2002 *Bending Over Backwards*). In his 2009 *Signifying Bodies: Disability in Contemporary Life Writing*, Thomas Couser examines the literary significance of narratives by those living with disabilities, exploring the complex ways that such narratives confront and counter standard cultural representations of disability in gothic, sentimental, and other rhetorical modes.⁶⁰

At the same time, with its primary focus on the physical body, a disability studies approach can run the risk of reproducing twentieth and twenty-first century representations of severe mental illness as neurophysiological difference grounded primarily in genetics and brain function and structure. The often useful distinction between impairment (a limiting physical difference) and disability (the prejudice and social construction of living that excludes, ignores, and demeans those with impairments) can become fuzzy when applied to schizophrenia. As Davis points out, 'impairment is not a neutral and easily understood term. It relies heavily on a medical model for the diagnosis of the impairment.'⁶¹ While, as I discuss in the final chapter, such a focus on neurophysiological and genetic difference can lessen the stigma of blame historically associated with mental illness, it can simultaneously reinforce another historical stigma—the labelling of mentally ill persons as both ontologically different and unintelligible. The important insights of narrative theory and disability studies challenge us to push definitions of 'disability' beyond 'the disabled body' to find new ways of thinking and talking about severe mental illness that respect the minds and words of those living with schizophrenia.

Memoirs by those diagnosed with and living with schizophrenia, such as those discussed in this book, have long countered the representations of 'the mentally ill' as ontologically different. From John Perceval's early-nineteenth-century autobiography to asylum memoirs by mid-nineteenth-century American writers Elizabeth Packard and Clarissa Lathrop and twentieth-century stories of institutionalization (such as those discussed

in this book), writers have told their stories of both severe mental and emotional distress and the treatments that sometimes helped and more often exacerbated their suffering. More recently, interdisciplinary work in disability studies, both literary and theoretical, has begun to contribute significantly to understandings of the lived experience of severe mental illness and diagnosis as well as the ways that mental illness narratives can offer new literary strategies that challenge constructions of the normal'. The 2007 collection *Unfitting Stories: Narrative Approaches to Disease, Disability, and Trauma*, which emerged out of an interdisciplinary, collaborative project funded by the Peter Wall Institute for Advanced Studies at the University of British Columbia, contains several articles that address narrative strategies by writers diagnosed with mental illness.⁶² Gail Hornstein's groundbreaking 2009 book *Agnes's Jacket: A Psychologist's Search for the Meanings of Madness*, whose title refers to a nineteenth-century patient in a German mental institution who sewed intricate messages into her jacket, highlights the importance of first-person narratives, both written and oral, to a deeper understanding of schizophrenia. Citing her work with the now widespread Hearing Voices Network and other sources of first-person stories, Hornstein remarks that 'published patient narratives, oral histories like those in the Testimony Project, the artworks in Hans Prinzhorn's collection, and hearing voices groups were all essentially saying the same thing. Agnes Richter's jacket embodied their core insight: *Madness is more code than chemistry*. If we want to understand it, we need translators—native speakers, not just brain scans.'⁶³ Similarly, Marius Romme and Sandra Escher's 2009 anthology *Living With Voices: Fifty Stories of Recovery*, offers first-person narratives by those who interpret their own experiences, often giving meaning to what their voices have to say rather than dismissing them as indecipherable symptoms. Margaret Price's 2011 *Mad at School: Rhetorics of Mental Disability and Academic Life*, published as part of a University of Michigan series on disability studies, adroitly examines the construction and policing of 'normal' mental and intellectual functioning in academic contexts.⁶⁴ Equally significant is the fact that over the past few years the internet has offered unprecedented ways for those living with schizophrenia to connect with one another, sharing their stories and transforming the meanings of their narrated experiences in international on-line communities.⁶⁵

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I offer this book as a further contribution to an understanding and appreciation of life writing engaged with schizophrenia. As a literary scholar rather than a psychologist or anthropologist, I examine these works as literature embedded in sociocultural contexts that help shape its parameters and within which it struggles to create something new and distinctive, to express experiences that have historically and repeatedly been represented as inexpressible. I want to highlight the ways that these narratives offer not only new ways of seeing into what it means to live with schizophrenia but new literary strategies given that they must work against the powerful presence of ‘madness’ in the history of literature in the West as either metaphor for meaninglessness or trope overburdened with meanings.

The Narratable Self

Adriana Cavarero’s conception of the ‘narratable self’ provides a useful framework for thinking about life writing by those living with schizophrenia in that it posits a self—born into the world as a relational being—that is always already engaged in telling a life story even if the actual text of that story is fragmentary and chaotic. Writes Cavarero,

The narratable self finds its home, not simply in a conscious exercise of remembering, but in the spontaneous narrating structure of memory itself. This is why we have defined the self as *narratable* instead of *narrated*. Indeed, the particular contents—the pieces of story that the memory narrates with its typical and unmasterable process of intermittence and forgetting—are inessential. What is essential is the familiar experience of a narratability of the self, which, not by chance, we always perceive in the other, even when we do not know their story at all.⁶⁶

If we think about the person with schizophrenia as having a ‘narratable self’, then, whether or not his or her language seems to make sense, it is understood to be working towards meaning, towards a story of a life that is unique to that person. In this model, the individual diagnosed with schizophrenia is not ontologically different but exercises a very human desire for a unifying life story. As Cavarero states it, ‘Even if the precise contents of such a story are inessential to the narratable self, there is no narratable

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self that is not always already and forever immersed in these contents and in this autobiographical text.⁶⁷ The processes of memory begin to create this life story soon after the moment of birth, acknowledging and recording the existence of the individual within a social world of relationships. Thus even if the words of those living with schizophrenia seem locked in a private world of impenetrable meaning, they are reaching for an already-known, deeply human experience of connectedness.

Works by psychotherapists and other clinicians, as fraught as they may be, can help highlight the relational nature of life writing, which involves the telling of one's story to a listener, to someone else. Part of my goal here is to highlight the ways that life writing by those living with schizophrenia can blur the lines constructed between those who tell (patients) and those who listen (psychotherapists) and between those who learn (unknowledgeable patients) and those who teach (knowledgeable psychiatrists). At the same time, psychiatrists or other clinicians do not write about schizophrenia from the same social and experiential location as those who live with it day in and day out. The differences between the contexts within which each narrative was written are crucial, as are the differences between the epistemological lenses of each narrator. As feminist philosopher Elizabeth Grosz has pointed out, once knowledge is seen to be constructed, to have a history and a relation to power (as Foucault has shown psychiatric knowledge to have), then other forms of knowledge can emerge.⁶⁸ Those living with schizophrenia, such as the writers of the Personal Accounts from *Schizophrenia Bulletin* that I discuss in this book, bring an informed kind of knowledge to their writing, a knowledge that is not just based on experience but on the synthesis of experience with thought over time. Many of them write in conversation with mental health professionals who have become part of their lives, wielding narrative authority that recasts these professionals from experts to collaborators, from knowledge-deliverers to knowledge-receivers.

For those, such as Freud and Bateson, who try to interpret texts written by those living with schizophrenia, the knowledge of their 'subjects' often comes out to meet them. It is here where the line between clinician-theorist and patient can blur, as the theorist sees reflected back his (or her) own status as narrator constructing a story about a story about a story. What emerges from such an encounter is the ontological continuity be-

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tween narrators, the analyst/interpreter's realization, sometimes implied, sometimes explicit, that his or her own mind is capable of schizophrenia.

It might seem strange to analyze as stories writings by those who study and treat schizophrenia. After all, they are clinicians, researchers, and theorists trained in the strict objectivity and precision of scientific method. More often than not, like the writers of *The DSM-IV Case Book*, they have devoted their lives to the careful study of an illness that seems to bring unbridled suffering to those who experience it; they seek an understanding of schizophrenia through scientific methods. And yet, as they describe their research or their clinical experience, submerged narrators provide glimpses of themselves and buried narratives often emerge that reach beyond the procedures of science.⁶⁹ These implied stories take shape in the metaphors the writers use, in their (at times) shifting narrative voices, and in the telling moments—often moments of puzzlement or doubt—when their inquiry seems to burst the constraints of scientific study.

The story of schizophrenia can be a difficult one as both memoirist and clinician struggle to interpret it, at times joined in a kind of collaboration that reminds the theorist that his own thoughts and theories can also be just that recalcitrant, fragmented, and even at times terrifying. As I hope the chapter on Freud and Bateson will especially demonstrate, often the more closely experts listen, the more their carefully built worlds begin to crumble and they face the possibility of a new kind of learning.

The first chapter of the book examines four late-twentieth-century North American memoirs by young women institutionalized in mental hospitals: *Still Sane* (1986) by Persimmon Blackbridge and Sheila Gilhooly, *Girl Interrupted* (1994) by Susanna Kaysen, *The Quiet Room: A Journey Out of the Torment of Madness* (1994) by Lori Schiller and Amanda Bennett, and *The Last Time I Wore a Dress* (1998) by Daphne Scholinski. In particular, this chapter examines the ways that these narratives substitute place for time, deploying the wards and buildings of the hospital as an organizing principle in their stories. For these narrators, time stands still, refusing to follow the forward trajectory into the future familiar in the outside world. Inside the hospital, life is ordered according to the patient's location, which thus becomes a focal point for the narratives themselves. These writers expose their own diagnoses and treatment as 'cases'—here in

the form of staff notes and diagnostic reports included in the text—then write counter-narratives that reveal the limitations of the ‘official story’ of diagnosis. By examining the film *Girl Interrupted* along with the written autobiography, I show that the memoir works against the popular version of schizophrenia and related disorders as either beyond cure or the result of moral weakness. These writers choose narrative forms that appear as memoir but work against a coherent, standard story of illness, crisis, treatment, and recovery. While not all the writers were diagnosed unequivocally as schizophrenic, schizophrenia plays a key role in all the narratives as a worst case scenario held up before every patient, a diagnosis—sometimes temporarily given, as in Kaysen’s story, sometimes seen in fellow patients, as in Scholinski’s—that represents true madness, and a central organizing principle of time and place within each institution.

Chapter Two analyzes ten years’ worth of First-Person Accounts taken from *Schizophrenia Bulletin* (1997–2007), looking at the narrative choices made by these patient-authors asked to write one-page accounts of their lives for an audience of clinicians and researchers. As it explores the writers’ attempts to establish themselves as credible narrators, the chapter shows that they are well aware of the expected narrative of illness-crisis-treatment-recovery, but tend to write anything but that, countering what they see as the expected trajectory of their lives and illness and, like the memoir writers in Chapter One, working against the presentation of their lives as ‘cases’. They represent themselves as suffering individuals who try however possible to take control of their lives and to write stories that explain what is happening to them, even when they are in the midst of delusions. These narratives challenge any easy polarization between meaning-making and incoherence, in both narrative form and content.

The third chapter moves back in time to establish contexts and genealogy for life writing by those living with schizophrenia. This chapter examines two literary case histories written at crucial periods in the history of treatments and explanations of schizophrenia—Sigmund Freud’s 1911 study of Daniel Paul Schreber’s *Memoir of a Neurotic* and Gregory Bateson’s 1961 preface to John Perceval’s nineteenth-century memoir of madness and institutionalization, a text that Bateson rediscovered and published with his own introduction and analysis. Juxtaposing Bateson’s analysis of Perceval’s memoir to Freud’s reading of Schreber’s (available to American

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psychiatrists mid-century in the Hogarth edition), the chapter examines the ways that both psychologists inadvertently developed complex, multi-layered narrative voices as they struggled to come to terms with each memoirist's rendering and interpretation of his own schizophrenic experience. Both Bateson and Freud establish narrative voices that at times represent analyst-narrators and at other times represent baffled readers whose own interpretations pale before not only the experience but the acknowledged analytic ability of their subjects.

Chapter Four examines the early novels and autobiographies of mid-twentieth-century New Zealand writer Janet Frame. A comparison between three of Frame's early novels (*Owls Do Cry*, *Faces in the Water*, *The Scented Gardens of the Blind*), published between 1957 and 1963, and her autobiographical writings reveals the ways that these different genres taken together allow Frame to present the often untranslatable experience of schizophrenia while maintaining narrative authority. On the one hand, by creating a controlled, rational voice within a structured chronological narrative in her autobiography, Frame distances herself from the diagnosis of schizophrenia that led to her eight-year institutionalization and stereotyping as a 'mad writer'. On the other hand, her fiction allows her freedom to delve deeply into the consciousness of characters diagnosed with schizophrenia and to construct time and identity as fragmented, disrupted, hidden, frozen. This fictional approach enables her to portray dehumanizing treatment by psychiatrists and hospital staff members as an inextricable part of the patients' experience of schizophrenia. Like the memoir and 'First-Person Account' writers, Frame's narrators protest their treatment as 'third person' mental patients and take on first-person voices that build a sense of personhood regardless of silences and disruptions in the narrative.

Chapter Five examines a series of case histories in the *DSM-IV Case Book*, a diagnostic manual designed to assist clinicians and medical and psychology students in learning how to apply the diagnostic categories of the *DSM-IV*, the international 'bible' of mainstream psychiatric diagnosis. Through close readings of these case histories, I show that the psychiatrist-narrators as well as the clinical contexts of the scenes reported are assumed to be irrelevant to the 'cases' discussed. I examine what it means to construct a person as a 'case', presenting him or her as an objectified whole through the selection of details that reflect gender and race assumptions as

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well as assumptions about what is important to the scene and what isn't. Through an examination of 'third-world' cases meant to show the *DSM* editors' cultural sensitivity, I further show (with reference to Frantz Fanon's analysis of mental illness in Algiers and its relationships to colonial oppression) that colonial relations persist between psychiatrists and patients in the cases discussed and that local, alternative explanations for mental illness (spiritualism, for example) are rendered either as quaint local color or part and parcel of the symptomology of the patient. My analysis reveals a tension between representations of schizophrenia 'cases' as objective collections of data on the one hand and as compelling human stories on the other. This chapter helps establish the problematic ways that 'case history' can overshadow the patient's own narrative.

In the final chapter, which also serves as a conclusion for the book, I examine my mother Eunice Wood's story as told to me over ten years' time, juxtaposing her narrative of living with schizophrenia to the life writings in the previous chapters. In a close reading of her story, I examine the ways that she shaped and reshaped that story over time, as each period of her life demanded, with a conscious awareness of her various audiences: intake clinicians, prescribing psychiatrists, outpatient clinic psychologists, psychodynamic therapists, her various neighbors, friends, and family members. She was always aware that to carry a diagnosis of schizophrenia meant that she always already had a story written about her that others would read over and against whatever she had to say. I don't tell her story as any kind of personal revelation or confession, but because I think listening to her story and her approach to telling it has given me some insight, limited yet potentially useful, into the extent to which those living with schizophrenia must constantly and repeatedly create life stories over and against psychiatric and popular representations of their experience, representations embedded in larger socially constructed ideas of what it means to be mentally and emotionally 'normal'. These constructions in turn are inextricably connected to social and economic relationships and expectations. For example, my mother made clear that the stories she told about herself to psychiatrists in clinical settings were always shaped in part by such factors as whether or not the clinician had control over her medications or her custody of her children. As a tentative and cautious interpreter, I've learned to accept the inconsistencies and gaps in her stories as well as

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her only partial successes in fitting her delusional episodes into the story of her life. As with other writers living with schizophrenia whose work I examine in this book, regardless of such inconsistencies and periods of intense confusion, her desire to use language, and particularly dialogue, to make sense of her life never faltered.

Throughout these chapters I employ analytical categories of race, gender, class, and nationality as they emerge, sometimes intersecting, sometimes separately, in close readings of each text. While such analyses can be brought to bear on virtually any literary work, given the limitations of space and argument I've tried to take my cues from the text, employing the analytical lenses that seemed not necessarily most obvious but most compelling. For example, in the chapter on Freud and Bateson, I examine the apparent class similarities between psychologist and memoirist that seem to give the 'patient' authority and draw the analyst into the text. In the chapter on *The DSM-IV Case Book*, I examine prejudicial sociocultural assumptions about race, ethnicity, and nationality that emerge in narratives and descriptions of particular 'cases' both in the US and in Africa. In the chapter on twentieth-century memoirs of institutionalization, I look at the ways that social hierarchies from outside the mental hospital are both preserved and transformed inside its walls. In the chapter on Eunice Wood, an understanding of her life story relies on an exploration of the meanings of Euro-American Jewishness in mid-twentieth-century Los Angeles and the consequences of the patient's economic condition for psychiatric treatment.

Like many works in disability studies or medical humanities, this book straddles multiple disciplines and seeks to address various reading audiences, including literary scholars, historians, psychiatric clinicians, researchers in neurobiology, and mental health care consumers. Some readers may be more interested in reading about first person accounts from *Schizophrenia Bulletin* while others are drawn to the literary analysis of Janet Frame's novels and autobiography. In any case, I've tried to make each chapter accessible to readers from any discipline who might be interested in that topic.

I subtitled this book 'Encounters at the Edge of Meaning' because all of these texts are engaged in encounters of various kinds: encounters between narrators and between texts; encounters between writers and readers; encounters between individuals and social, political, and medical

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worlds; encounters between narrators and vast or constricted inner spaces as well as natural or built outer ones. My use of the word 'meaning' is perhaps a little misleading; I intend the word less as a noun, a substance, and more as a gerund, an evolving and fluid process. The texts here discussed are at the edge of meaning in quite an active way, teetering on that edge but always tilting over in the direction of meaning-making. I want to emphasize that while I, as a reader, engage with the meaning-making activity these texts extend to me, I also think it's important to allow that activity to remain inconclusive, undefined. As Richard Ingram observes, "The concept of "making sense" of illness, which has gathered all the force of a regulative ideal for people with all types of illness, is particularly oppressive when it comes to hold sway over people who are judged to be 'mentally ill' on the basis of their alleged failure to "make sense".⁷⁰ For writers living with schizophrenia, the constantly shifting ground, barrages of unanchored sounds and images that can flood perception may upset the meaning-making the reader expects or desires. The reader might ask then, 'Am I capable of staying with this narrative that may stop in time and confuse me without reading it as something I already think I know, such as post-modern play, poetry, or nonsense? Can I read it with all of these in mind, as they may be in mind for the writer, and still hear what this writer has to say?'

Through narrative, these writers struggle to give form to experiences that often appear as language (voices spilling commentary or everyday occurrences taking the form of pre-written plots) but push against or even refuse the boundaries of a singular coherence. In a life that has become at times disoriented, floundering, and isolated, a search for meaning, for a story that makes sense and for an identity that can take shape, however amorphous, within such a story, can itself be a welcome relief and even a source of strength.

In discussing the title of his book *Concerto For Left Hand*, Michael Davidson asks, 'How might a consideration of works written for a one-armed pianist resituate both music and disabled performer?'⁷¹ Davidson suggests that writing with a disability in mind opens up not only new fields to understanding but new aesthetic possibilities. In life writing by those living with schizophrenia, one basis for such a new aesthetic might be an always evolving search for meaning, for identity, a search undertaken through

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literary strategies that claim the right to include the at-times delusional self and to offer forms of knowledge based in both intellect and experience.

Notes

1. Throughout this book I've chosen to use the terminology 'living with schizophrenia' or 'diagnosed with schizophrenia' rather than 'schizophrenic' in order to avoid labelling those with mental illness as belonging to a 'type' whose 'disease' defines who they are. At times I use 'mental illness' or 'schizophrenia' in the sense of illness when the writer views it this way. My intent is to expose 'schizophrenia' as a psychiatric construct while respecting that some of the writers I discuss use the term in their own way.
2. P.J. Eakin, 'Breaking Rules: The Consequences of Self-Narration', *Biography: An Interdisciplinary Quarterly*, 24:1 (2001), 113–27: 113.
3. L. Schiller and A. Bennett, *The Quiet Room: A Journey Out of the Torment of Madness* (New York: Grand Central, 1994), 16.
4. *Ibid.*, 90.
5. M. Foucault, *Madness and Civilization* (London: Tavistock Publications, 1967), 250.
6. G. Deleuze and F. Guattari, *Anti-Oedipus* (London: Continuum, 2004), 2.
7. *Ibid.*, 5.
8. I maintain this claim even though I appreciate Angela Woods' observation that many readings of Deleuze and Guattari's *Anti-Oedipus* 'sanitize' their readings of schizophrenia and miss the subversive, depathologizing potential of their reframing of 'schizophrenia' in Schreber's memoir. I find Deleuze and Guattari's reading of Schreber and division between 'schizo' and 'schizophrenic' very useful but still problematic in its relation to living people. See A. Woods, *The Sublime Object of Psychiatry: Schizophrenia in Clinical and Cultural Theory* (New York: Oxford, 2011), 150–161.
9. L.A. Sass, "Negative Symptoms," Commonsense, and Cultural Disembedding in the Modern Age,' in J.H.Jenkins and R.J. Barrett (eds.), *Schizophrenia, Culture, and Subjectivity: The Edge of Experience* (Cambridge: Cambridge University Press, 2004), 323.
10. *Ibid.*, 320.
11. K. Hopper, 'Interrogating the Meaning of "Culture" in the WHO International Studies of Schizophrenia', in J.H.Jenkins and R.J. Barrett (eds.),

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- Schizophrenia, Culture, and Subjectivity: The Edge of Experience* (Cambridge: Cambridge University Press, 2004), 63–6.
12. Quoted in G. Roccatagliata, “Classical Concepts of Schizophrenia,” In J.G. Howells, M.D. (ed.), *The Concept of Schizophrenia: Historical Perspectives* (Washington, D.C.: American Psychiatric Press, Inc., 1991), 2.
 13. Shorter, Edward. *A History of Psychiatry from the Era of the Asylum to the Age of Prozac* (New York: John Wiley and Sons, 1997), 106–7.
 14. A. Meyer, “Rev. of *Psychiatrie: Sin Lejrnbuch fur Sttidirende und Aerzte by Dr. Emil Kraepelin*,” *American Journal of Insanity* 53 (October 1896), 296–302: 299.
 15. *Ibid.*, 400.
 16. A.R. Diefendorf, *Clinical Psychiatry: A Text–Book for Students and Physicians* (New York: The MacMillan Co., 1912), vii.
 17. *Ibid.*, 220–1.
 18. *Ibid.*, 226.
 19. S.P. Fullwinder, *Technicians of the Finite: The Rise and Decline of the Schizophrenic in American Thought, 1840-1960* (Westport, Connecticut: Greenwood Press, 1982), 52.
 20. E. Bleuler, *Dementia Praecox or The Group of Schizophrenias*, trans. Joseph Zinkin (New York: International Universities Press, 1950), 351.
 21. S. Freud, ‘On Narcissism: An Introduction’ [1914], in *Collected Papers: Vol. IV* (London: Hogarth Press, 1950), 30–59: 31.
 22. Schiller, *op. cit.* (note 3), 70.
 23. Jung, Carl Gustav, ‘On the Psychogenesis of Schizophrenia’, in *The Psychogenesis of Mental Disease*, Bollingen Series 20, trans. R.F.C. Hull (Princeton, N.J.: Princeton University Press, 1960), 233–49: 236.
 24. Freud, *op. cit.* (note 21), 31.
 25. N. Hale, Jr., *The Rise and Crisis of Psychoanalysis in the United States: Freud and the Americans, 1917–1985* (London: Oxford University Press, 1995), 169–71.
 26. *Ibid.*, 176–7.
 27. D.K. Freedheim (ed.), *History of Psychotherapy: A Century of Change*. (Washington, D.C.: American Psychological Association, 1992), 46. Historian Donald K. Freedheim remarks that ‘Sullivan is one of the least understood and least credited theoreticians in the history of psychotherapy. Although his thinking appears to have influenced or anticipated many current psycho-

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- therapies, he is rarely given the credit he deserves.' *Idem.*, 45.
28. Hale, *op. cit.* (note 25), 266–8.
 29. Shorter, *op.cit.* (note 13), 176.
 30. *Ibid.*, 176, 269.
 31. Another influential writer in this vein is sociologist Andrew Scull, whose 1979 *Museums of Madness* and 1981 *Madhouses, Mad-doctors, and Madmen* examines mental institutions as vehicles of ideology and social control.
 32. Szasz and Laing receive only a footnote in E. Lunbeck's *The Psychiatric Persuasion: Knowledge, Gender, and Power in Modern America* (Princeton: Princeton University Press, 1994). After boiling down R.D. Laing's complex writings to the assertion that he considered schizophrenia 'a sane response to a mad society,' historian Edward Shorter remarks that 'incredibly, Laing became the chief investigator in the schizophrenia research unit at the Tavistock.' Gregory Bateson does not appear at all in either study. Admittedly, he was not a psychiatrist, but his theories and clinical practice were in constant dialogue with American psychiatry in the 1950s and 1960s. Shorter, *op.cit* (note 13), 276.
 33. *Ibid.*, 239.
 34. C.E. Rosenberg, 'Contested Boundaries: Psychiatry, Disease, and Diagnosis,' *Perspectives in Biology and Medicine* 49:3 (summer 2006): 407–24: 412.
 35. See P.W. Corrigan and A.C. Watson, 'At Issue: Stop the Stigma: Call Mental Illness a Brain Disease', *Schizophrenia Bulletin* 30:3 (2004), 477–79. In reference to ill treatment of those with severe mental illness, Corrigan and Watson maintain, 'the studies suggest that this harsher behavior may have been the result of seeing the person with mental illness as physically distinct—almost as a different species.' *Idem.*, 478.
 36. P. Williamson, *Mind, Brain, and Schizophrenia* (New York: Oxford University Press, 2006), 7.
 37. 'Schizophrenia Spectrum and Other Psychotic Disorders', American Psychiatric Association DSM-V Development, accessed 20 April, 2012, <http://www.dsm5.org/ProposedRevision/Pages/proposedrevision/Pages/SchizophreniaSpectrumandOtherPsychoticDisorders.aspx>.
 38. In another shift in diagnosis some researchers advocate abolishing the distinction between schizophrenia and other forms of psychosis, a move that retains the focus on organic causes and manifestations of disease but posits that the mechanisms of delusion are the same regardless of the disease. Ac-

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- ording to Gunvant K. Thaker, 'The hypothesis of an extensive overlap in the phenomenology and etiopathophysiology of psychosis occurring across different disorders is a fundamental challenge to the Kraepelinian conceptualization of major psychotic disorders. G.K. Thaker, 'Boundaries of the Psychosis Phenotype', *Schizophrenia Bulletin* 38:2 (Feb. 2012), 205–6: 205.
39. 'Schizophrenia Spectrum and Other Psychotic Disorders', *op. cit.* (note 37).
 40. C.A. Ross, *Schizophrenia: Innovations in Diagnosis and Treatment* (New York: Haworth Maltreatment and Trauma Press, 2004), 3.
 41. *Ibid.*, 23.
 42. L. Davis, *Bending Over Backwards: Disability, Dismodernism, and Other Difficult Positions* (New York: NYU Press, 2002), 7.
 43. For a fascinating discussion of the ways the interior of the human body historically became a the focus of research interest in the biological sciences, see E. Cohen, *A Body Worth Defending: Immunity, Biopolitics, and the Apotheosis of the Modern Body* (Durham, North Carolina: Duke University Press, 2009).
 44. T.G. Van Erp, et al., 'Verbal Recall and Recognition in Twins Discordant for Schizophrenia', *Psychiatry Research* 159 (2008), 271–280: check page.
 45. A. Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago: Univ. of Chicago Press, 1995), 12.
 46. T.D. Cannon *et. al.* 'Mapping Heritability and Molecular Genetic Associations with Cortical Features Using Probabilistic Brain Atlases: Methods and Applications to Schizophrenia" *Neuroinformatics* 4:1 (2006), 5.
 47. L. Davis, *op. cit.* (note 42), 19.
 48. For example, van Erp et al. work to to show that 'one implication for future research is that verbal declarative memory tasks that require active retrieval may be a useful endophenotypic measure that can be used in the search for schizophrenia susceptibility genes.' *Idem.*, check page.
 49. Ross, *op. cit.* (note 40), 131.
 50. P.J. Eakin, 'Introduction: Mapping the Ethics of Life Writing', in P.J. Eakin (ed.), *The Ethics of Life Writing* (Ithaca: Cornell University Press, 2004), 6.
 51. While these fields overlap in their concern with narrative and identity, there are also considerable tensions among their various approaches, especially given that medical humanities began in medical schools as a way to create more sensitive physicians and disability studies is grounded in disability activism and a social constructionist critique of medicine as an institution.

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- However these tensions are outside the scope of this book. See R. Garden, 'Disability and Narrative: New Directions for Medicine and the Medical Humanities', *Medical Humanities* 36:2 (2010 Dec), 70-4.
52. A. Broyard, *Intoxicated by My Illness: And Other Writings on Life and Death*, comp. and ed. Alexandra Broyard (New York: Clarkson N. Potter, 1992), 19.
53. A. Frank, *op. cit.* (note 45), 53.
54. *Ibid.*, 92.
55. A. Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition* (New York: Basic Books, 1988); C. Mattingly, *Healing Dramas, Clinical Plots: the Narrative Structure of Experience* (Cambridge: Cambridge University Press, 1998).
56. L. Zoloth and R. Charon, 'Like an Open Book: Reliability, Intersubjectivity, and Textuality in Bioethics,' in R. Charon and M. Montello (eds.), *Stories Matter: The Role of Narrative in Medical Ethics* (New York: Routledge, 2002), 21-36.
57. R. Garland-Thomson and M. Stoddard Holmes, 'Introduction', *Journal of Medical Humanities* 26.2-3 (2005), 73-77: 73.
58. M. Davidson, *Concerto for Left Hand: Disability and the Defamiliar Body* (Ann Arbor, MI: University of Michigan Press, 2008), 1.
59. L. Davis, *op. cit.* (note 42), 34.
60. K. Fries, *Staring Back: Disability Studies From the Inside Out* (New York: Plume, 1997); S. Black, J. Bartlett and M. Northen, *Beauty is a Verb: the New Poetry of Disability* (El Paso, TX: Cinco Puntos Press, 2011); M. Berube, *Life As We Know It: A Father, A Family, an Exceptional Child* (New York: Vintage, 1998); R.F. Murphy, *The Body Silent: the Different World of the Disabled* (New York: W.W. Norton, 2001); N. Mairs, *Waist-High in the World: A Life Among the Non-Disabled* (Boston: Beacon Press, 1996); E. Clare, *Exile and Pride: Disability, Queerness, and Liberation* (Cambridge, MA: South End Press, 1999); L. Davis, *op. cit.* (note 42); T. Couser, *Signifying Bodies: Disability in Contemporary Life Writing* (Ann Arbor, MI: University of Michigan Press, 2009).
61. Davis, *op. cit.* (note 42), 23.
62. See in particular B. Schneider, 'Constructing a "Schizophrenic" Identity', 129-37; L. Rodriguez del Barrio, 'Space, Temporality, and Subjectivity in a Narrative of Psychotic Experience', 139-47; and R. Ingram, 'Reports

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- from the Psych Wars', 237–45), in V. Raoul, et al. (eds.), *Unfitting Stories: Narrative Approaches to Disease, Disability, and Trauma* (Waterloo, Ontario, Canada: Wilfrid Laurier Univ. Press, 2007).
63. G.A. Hornstein, *Agnes's Jacket: A Psychologist's Search for the Meanings of Madness* (New York: Rodale, 2009), xix.
64. S. Romme et al. (eds.), *Living with Voices: Fifty Stories of Recovery* (Hertfordshire, UK: PCCS Books, 2009); M. Price, *Mad at School: Rhetorics of Mental Disability and Academic Life* (Ann Arbor, MI: University of Michigan Press, 2011).
65. For example, the Hearing Voices Network and Mindfreedom International.
66. A. Cavarero, *Relating Narratives: Storytelling and Selfhood* (London: Routledge, 1997), 34.
67. *Ibid.*, 36.
68. E. Grosz, 'Feminism and the Crisis of Reason', in *Space, Time, and Perversion: Essays on the Politics of Bodies* (New York: Routledge, 1995), 25–43, 38.
69. As Jonathan Culler states in an overview of narrative theory's understanding of stories and their tellers, 'every narrative has a narrator, whether or not he is explicitly identified'. J. Culler, 'Fabula and Sjuzhet in the Analysis of Narrative: Some American Discussions', in S. Onega and J.A. Garcia Landa (eds.), *Narratology* (New York: Longman, 1996), 94.
70. R. Ingram, *op. cit.* (note 62), 242.
71. M. Davidson, *op. cit.* (note 58), xvi.