Schizophrenia: A Journey through Higher Education

By Diane Zeeuw

From an early age, my son Alex exhibited small signs of neurological disorder: odd hand gestures, an awkward gait, extreme sensitivity to physical sensation or touch. Alex struggled during the K–12 years with minor conceptual deficits, odd social disconnections, and a strange kind of physical dislocation in space. As a child, Alex was first diagnosed with attention deficit, and then later with autistic spectrum disorder. But life progressed and, as we expect all young people to do, Alex eventually made friends, graduated from high school, began attending a respected private college, held down a job, and moved into his own house. But, things were never quite right. Unbeknownst to us, Alex was slipping piecemeal into a secret place. Picture the onset of the symptoms of schizophrenia as a kind of mental equivalent to the fluorescent snow of an off-channel cathode ray tube, the suggestive whispering hiss of constant visual and audial white noise, muffling and veiling the world in ghostly semblances. In this nightmarish realm, one’s fears may be unwittingly broadcast via thought insertion, physical objects often manifest anthropomorphic qualities, boundaries become permeable, and malevolent beings battle for dominance.

Professor Diane Zeeuw possesses over twenty years of experience teaching graduate courses on aesthetics, ethics, critical theory, and visual culture at Kendall College of Art and Design of Ferris State University. Her research has been presented at numerous national and international conferences including the Mediations Biennale, Poznan, Poland, and the Conference on the Image, Freie Universität, Berlin.
Today, schizophrenia controls my son’s life: every decision we make must be weighed against carefully monitored symptoms, medications, and daily routines. However, the initial onset was insidious, only measurable in hindsight by an accumulation of small incidents over time.

Advocates of critical disability theory have been somewhat successful in broadening ideas of what might constitute a disability. However, we are only now as a society beginning to grapple with the complex and problematic notions of psychiatric and neurological disabilities. Some disabilities of cognition are clearly established as having a genetic or biological etiology or etiological component (e.g., autism, schizophrenia).

Other mental conditions are classified as “disorders,” or “maladaptive” behaviors, further fueling confusion regarding individual accountability and volition.

Those coping with a mental illness also face an added stigma: despite all of the evidence to the contrary, our society tends to associate, and even conflate, mental illness with violence. For example, a survey conducted by the Harvard Health Medical School in 2011 found that “60 percent of the general public […] thought that people with schizophrenia were likely to act violently toward someone else, while 32 percent thought that people with major depression were likely to do so.”

This widespread perception is exacerbated by sensationalized coverage of a few, albeit tragic, cases. Nonetheless, the NIMH reports that:

Mental Illness contributes very little to the overall rate of violence in the community. Most people with SMI (severe mental illness) are not violent, and most violent acts are not committed by people with SMI. In fact, people with SMI are actually at higher risk of being victims of violence than perpetrators (emphasis added). Teplin et al. found that those with SMI are 11 times more likely to be victims of violent crime than the general population.

Given the widespread association between mental illness and violence, however, is it really all that difficult for us to grasp why someone coping with this condition might elect to remain invisible?
MY SON, THE STUDENT

“Alex” is not a pseudonym. My son requested his real name be used within this paper. He is not ashamed of having schizophrenia. Schizophrenia is not the sum of his worth; rather it is a condition that befell him in life. Alex, in some respects, is both the same person he was before becoming ill (loving and kind), and also radically changed. I have witnessed first-hand his shrinking world and increasingly opaque future. Small everyday decisions have become difficult for him to navigate. To hear his own thoughts over a competing internal third-person dialogue, he must read out loud, like a monk chanting evening prayers. He has good days and very bad days. But he also creatively constructs hybridized computers from bits and pieces, and immerses himself in books on algebra, geometry, and calculus. While he may never hold a job, or raise a family, or even be able to live fully independently, he still has a deep and abiding love of learning.

As educators, in the few cases where we have taken notice of students like Alex, our focus historically has been negative and exclusionary. We have spent far more time and effort discussing ways to protect ourselves from this population than in ways to engage them as students and citizens.

CITIZENSHIP AND EDUCATION

So, what does it mean to enjoy our citizenship? How does citizenship relate to our place within the broader community? Researchers Devlin and Pothier offer us a substantive notion of what it means to hold citizenship, defining it as, “the capacity to participate fully in all the institutions of society—not just those that fit the conventional definitions of the political, but also the social and cultural.”

There is yet another obstacle dampening our conversation surrounding this topic. Pothier and Devlin note the many uncomfortable (and pejorative) terms used in our attempts to categorize or even discuss disability. They ruminate upon some of the definitions offered by the *Oxford English Dictionary*, including “want of ability, […] inability, incapacity, impotence and ‘disable’ as, among other things, ‘to pronounce incapable; hence to disparage, depreciate, detract from, belittle.’” Even when we would like to be able to speak about this subject with, at the very least, neutral terms, the very category disallows this. It’s difficult for us to adjust our notions regarding the capabilities of those coping with psychiatric or neurological conditions, without inadvertently equating such persons with deficits. Many disability researchers and advocates have suggested that we shift our framework from viewing limitation as internal to the subject, to viewing limitation as an aspect of the environment. This shift in focus has the advantage of making us all responsible as a society, rather than presuming that this is someone else’s individual problem. This view also provides a site for positive action. Rather than think of the educational institution as providing accommodations, we can re-conceive of our mission as providing an inclusive and welcoming environment to all students.

To effect this change, we need to be cognizant of the assumptions that underlay our policies and adjust our language accordingly. On the one hand, as a society and as an institution, we clearly aspire to be inclusive; on the other, we rely upon narrow definitions of normalcy to formulate funding, assessment, and outcomes models. We are most certainly in conflict with our own ethical standards and stated objectives, even hypocritical in our denial of how such models may, and most likely will, affect our admission standards, funding at the institutional and programmatic levels, and the “tracking” (even red-lining?) of students. Why is it that we cannot find language and tools that will help us with our funding and assessment issues without falling into the divisive metrics of normalcy?

Devlin and Pothier note that “full citizenship” includes, at some level, the notion of a “capacity for productivity.” They go on to ask, “What is productivity? What are the criteria? Who gets to make the assessment? And most importantly, why should productivity (regardless of how we
define it) be a legitimate criterion? Embedded in the discourse of productivity is an unavoidable cost-benefit analysis. It doesn’t take a political scientist to see that our current performance-based funding models favor a corporate standard of productivity, de-emphasizing other important outcomes of quality education such as social membership, social awareness, innovation, imagination, and individual growth.

If we really desire to be an inclusive society, we will need to adjust our notions of what it means to be productive. If a person may never be able to hold a job, should this also prevent him or her from engaging in higher educational opportunities? Is this a “waste” of taxpayer dollars? What does it mean to “waste” money? What does this say about how we actually value others, irrespective of our official mission statements to the contrary? Those coping from schizophrenia in particular will most likely suffer additional bias. With an ever shrinking funding base, what program, department, or institution will want to risk missing performance benchmarks by admitting this population? Furthermore, while it is indeed the case that this disorder involves key deficits, this should never be equated with an inability to engage in complex student learning or the potential for a meaningful life.

Rather than merely adjusting our values, perhaps we need to reexamine our basic presuppositions regarding what constitutes education. We have fallen into the habit of late of discussing education in the terms of outcomes and productivity—without ever really questioning what it is we are ultimately saying about what constitutes (as Plato would have said) a good society. Many researchers (e.g., Piaget, Vygotsky, Engestrom) have suggested we shift our conceptualization of education from thinking in terms of product or performance outcomes to conceiving of it as an activity. Given this model, students and teachers may be thought of as engaging in the activity of learning together. Learning is thus to be understood as open-ended, provisional, culturally embedded, hermeneutically dialectical, and ongoing. Furthermore, I would argue that from an ethical rather than a financial standpoint, full access to education, irrespective of each individual’s potential capacity to contribute to the future economy, should be intrinsic to our notion of citizenship.

**RECONCILIATION?**

I offer four suggestions as possible avenues for action. First, I have always been open about my son’s schizophrenia, allowing such information to filter into classroom seminar discussions regarding ethics, identity, and personhood. As educators, we must be willing to openly and in an informed manner, discuss the many fears, myths, and misconceptions historically shrouding this topic. Second, we must critically reassess our self-comforting institutional discourse of accommodation. Third, we need to expand institutional and professional notions of success, and be more cognizant of the message our graduation-rate benchmarks send to our student population. Finally, it is absolutely critical that we expand our discourse on issues of diversity. As educators, it is imperative that we stop retreating into more easily negotiated definitions limited by sexual orientation, socio-economics, ethnicity or race.

To open a conversation addressing this issue, we might start by asking, “As educators, what do we think we know about schizophrenia?” Have we simply lumped all mental illness into one homogenous category so large as to be effectively meaningless? (This, of course, is something we would not dream of doing when considering race or ethnicity.) Or perhaps we have dismissed the subject altogether telling ourselves that this is really the school counselor’s area of expertise. To even begin to understand the parameters Alex and others sharing this illness must negotiate, it would be helpful if educators had at least a basic working knowledge of the effects of even well-managed schizophrenia, including an awareness of sensory gating issues, the intense sedating and body-transforming effects of potent antipsychotic medications, the necessity of adhering to strict routines for maintaining stability, ongoing
“Indexing Schizophrenia #2,” mixed media, by Diane Zorou.
problems coping with breakthrough symptoms, and were accepting of the odd, insuppressible, compulsive body tics commonly manifested in those suffering from this illness.11

To end this article, I’ll ask, “To whom are the current funding and assessment models accountable, and more importantly, who does not count? How can we foster an educational milieu where all students feel safe and welcomed?” My son Alex is still waiting to be fully included in an environment where his illness does not constitute a taboo subject, a world where he is accepted, not feared nor ridiculed so he may partake of learning on his terms, and for the pure joy of it.68

ENDNOTES

2. Substance Abuse and Mental Health Services Administration. Building Bridges. Mental Health on Campus: Student Mental Health Leaders and College Administrators, Counselors, and Faculty in Dialogue, p. 11.
6. Insel, Diagnosis—Schizophrenia and Schizoaffective Disorder.
8. Ibid., p. 4.
9. Ibid., p. 18
10. Martin Ryder School of Education, Activity Theory. See also Lakoff and Johnson, Philosophy in the Flesh, The Embodied Mind and its Challenge to Western Thought.

WORKS CITED


