

The Cost of Transparency: Living with Schizoaffective Disorder

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Themes: Consciousness Mental Health

"We celebrate mental health awareness until someone actually needs mental health support."

In The Inclusion Illusion, I explored how tech companies perform diversity while quietly eliminating employees who actually need accommodations. What I didn't share was the personal cost of that analysis—how living openly with schizoaffective disorder has systematically excluded me from the very communities I helped foster.

Over the past few years, I've worked for at least twenty companies, cycling through positions as organizations discovered my mental health history and found creative ways to make me unwelcome

Search API company that championed neurodiversity—fired me within 24 hours of a manic episode triggered by a new medication. Each departure followed the same script: initial success, disclosure or visibility, growing discomfort, elimination.

. The pattern is consistent: initial enthusiasm for my technical contributions, followed by discomfort when my condition becomes visible, and finally the inevitable "restructuring" or "cultural fit" conversations that push me toward the exit.

I need to be clear about something. I'm not claiming innocence in every workplace conflict or community dispute. I've made mistakes, handled situations poorly, and there's been criticism of my behavior in some cases. The Requests 3 fundraising situation, in particular, was handled badly - I took on commitments I couldn't deliver and didn't communicate well about the problems. I've apologized for this, though I understand the damage was already done. Mental illness doesn't excuse harmful behavior, and I'm not asking it to.

But here's what I am saying: once you disclose a condition like schizoaffective disorder, every future conflict gets filtered through that lens. Criticism that might be delivered constructively to a neurotypical person becomes "see, we can't trust him, he's unstable." Normal workplace tensions become evidence of your fundamental unreliability rather than ordinary human fallibility.

The discrimination isn't being held accountable for actual mistakes. It's that those mistakes become proof of permanent unfitness rather than temporary setbacks to learn from and move past.

The Mental Health Care Paradox

The discrimination starts in healthcare itself. When I seek treatment for schizoaffective disorder, providers often approach me with a mixture of fear and condescension that would be immediately recognized as unacceptable if directed at any other patient population.

I've had therapists decline to continue working with me without clear explanations, leaving me to wonder whether my openness about my condition or my technical background created discomfort they couldn't navigate. I've had doctors become visibly afraid of me after witnessing me during an acute episode, their fear palpable in subsequent interactions. During inpatient treatment, I've been accused of not taking prescribed medication when I was compliant, as if the persistence of symptoms could only be explained by patient deception rather than the complex reality of treatment-resistant episodes.

The message is clear: people with schizoaffective disorder are expected to be passive victims of their condition, not active participants in their own care. When we demonstrate competence, insight, or agency, we become threatening rather than inspiring.

Professional Exclusion: The Algorithm of Discrimination

In professional settings, the discrimination operates like an algorithm optimized for elimination. Companies tout their mental health benefits and neurodiversity initiatives right up until they encounter someone whose mental health needs actual accommodation. Then the pattern-matching begins: mental health disclosure triggers risk assessment, risk assessment triggers exclusion, exclusion gets documented as "performance issues."

This connects directly to what I've explored in The Algorithm Eats Virtue—systems that claim to support mental health actually optimize for its invisibility. The same companies using AI to screen resumes for "cultural fit" are encoding discrimination against neurodivergence into their hiring algorithms.

I've been excluded from team meetings after disclosing my condition, with managers explaining they wanted to "reduce stress" for me

This "benevolent" exclusion is particularly insidious because it's framed as care while actually removing you from critical decision-making and visibility opportunities that affect career advancement.

. I've had colleagues avoid working with me after learning about my diagnosis, their discomfort palpable in every interaction. I've been passed over for promotions with vague explanations about "communication style" that clearly referenced my openness about mental health challenges

"Communication style," "cultural fit," and "leadership presence" have become euphemisms for disability discrimination in performance reviews, providing legal cover for eliminating employees with mental health conditions.

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The twenty-plus companies I've cycled through represent organizations that genuinely believe they're progressive and inclusive. They sponsor diversity conferences, implement mental health awareness training, and celebrate neurodiversity—until they encounter the reality of what supporting someone with a severe mental illness actually requires. It's discrimination by a thousand paper cuts, each individually deniable but collectively devastating.

Open Source Ostracism

The Python community's response to my mental health advocacy has been particularly painful. This is a community I helped build, one that benefits from tools I created, yet it has systematically excluded me as I've become more open about living with schizoaffective disorder

Requests alone has over 20 million downloads daily and powers much of the modern web, yet the community that benefits from this contribution has made it clear that mental health disclosure makes you too uncomfortable to include in leadership or speaking opportunities.

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To be clear: I've made mistakes in the Python community. Some of my behavior during episodes has been difficult for collaborators. But there's a difference between accountability for actual mistakes and systematic exclusion based on mental health disclosure.

I've watched as former collaborators distance themselves, conference invitations dry up, and contributions get scrutinized with a level of suspicion not applied to other developers. The community celebrates the abstract idea of mental health awareness while making it clear that actual mental health disclosure makes you a liability.

The message from open source leadership is unmistakable: you can advocate for mental health in general terms, but if you make your own struggles visible, you become too uncomfortable to include. The very transparency that helped normalize mental health discussions in tech has made me persona non grata in spaces I helped foster.

Personal Relationship Casualties

Perhaps most devastating is how mental health disclosure affects personal relationships. Friends, romantic partners, and social connections often initially express support for mental health awareness, right up until they encounter the reality of schizoaffective disorder.

I've lost friendships when people learned my diagnosis, with former friends suddenly finding excuses to avoid contact. I've had romantic relationships end when partners realized that dating someone with schizoaffective disorder meant occasional difficult conversations about symptoms, medication, and hospitalization risks. I've been excluded from social gatherings where my presence might make others "uncomfortable."

But there are exceptions that prove the rule—people like Sarah, whose response to learning about my condition was to educate herself, offer genuine support, and treat me as a complete person rather than a diagnosis. As she puts it:

"Your condition really can't be learned about. It's so abstract it must be experienced."

This wisdom—recognizing the limits of external understanding while still offering genuine support—represents how people should respond to mental health disclosure. These relationships are rare enough to be remarkable, which itself illustrates the problem.

The isolation is profound. The very condition that most requires social support becomes the barrier to accessing it.

The Stakes: Life and Death Statistics

The discrimination I'm documenting isn't just uncomfortable—it has life-and-death consequences for people with schizoaffective disorder. It's a perfect example of when values eat their young: the mental health awareness that tech proudly champions becomes a weapon against those who actually need support.

Life Expectancy: People with schizoaffective disorder die 15-20 years younger than the general population. A 2017 meta-analysis in World Psychiatry found mortality rates 2-3 times higher than the general population

Walker et al. (2015) documented median years of potential life lost at 14.5 years for schizophrenia spectrum disorders. The leading causes: suicide (40% higher risk), cardiovascular disease, and accidents—many linked to social isolation and inadequate healthcare.

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Employment Discrimination: Only 10-20% of people with schizoaffective disorder maintain competitive employment, despite many being capable of working with proper accommodation

Marwaha & Johnson (2004) found employment rates between 10-20% for schizophrenia spectrum disorders in Europe. The primary barrier isn't capability but employer discrimination and lack of accommodation.

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Homelessness Crisis: People with schizoaffective disorder are 10-20 times more likely to experience homelessness. In major cities, 20-40% of homeless individuals have psychotic disorders

Folsom et al. (2005) found 40% prevalence of psychotic disorders among homeless in San Diego. The pathway: job loss \rightarrow housing loss \rightarrow treatment disruption \rightarrow chronic homelessness.

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These aren't abstract statistics. They represent the human cost of systematic exclusion. When healthcare discriminates, when employers eliminate us, when communities ostracize us, people with schizoaffective disorder literally die younger and more often become homeless.

The Fear Behind the Discrimination

What drives this systematic exclusion is fear. Fear of the unknown, fear of mental illness, and particularly fear of schizoaffective disorder's association with psychosis. People can intellectually support mental health awareness while being viscerally uncomfortable with conditions that challenge their assumptions about consciousness, reality, and social functioning.

Schizoaffective disorder carries stigma that depression and anxiety don't. People can relate to feeling sad or worried; they cannot relate to experiencing reality differently. The moment someone learns you've had psychotic episodes, you become fundamentally Other in their perception. No longer fully human, no longer fully trustworthy, no longer safe to include.

This fear is reinforced by media portrayals, social stereotypes, and the medical model's emphasis on pathology over person. People see the diagnosis before they see the individual, the condition before the contributions.

The Impossible Choice

I face an impossible choice: remain silent about my condition and pass as neurotypical, or live authentically and face systematic exclusion. Neither option is sustainable.

Silence means constantly monitoring my behavior for signs that might reveal my condition, avoiding discussions of mental health that might trigger suspicion, and living with the constant anxiety that discovery will lead to rejection. It means being unable to advocate for accommodations I need, being forced to suffer in isolation, and perpetuating the very stigma that makes others afraid to seek help.

Transparency means facing the discrimination I've documented—professional exclusion, social isolation, and the constant emotional labor of educating people about a condition they'd rather not understand

The emotional labor is exhausting: constantly explaining that psychosis doesn't make you dangerous, that medication doesn't make you less competent, that accommodation needs don't make you unreliable. You become a one-person education campaign while trying to do your actual job.

. It means accepting that my openness will cost me opportunities, relationships, and belonging in communities I helped create.

But transparency also means modeling that people with schizoaffective disorder can be productive, insightful, and valuable community members. It means challenging the assumptions that drive discrimination. It means refusing to disappear into the shame that society expects from people with severe mental illness.

What Needs to Change

The pattern of discrimination I've experienced isn't unique—it's systematic. People with schizoaffective disorder face exclusion across all sectors of society, from healthcare to employment to personal relationships. The problem isn't individual prejudice but structural stigma that makes our very existence uncomfortable for others.

Real inclusion means:

- Healthcare providers who approach patients with schizoaffective disorder as partners in care rather than subjects to be managed. It means recognizing that insight into one's condition is a strength, not a manipulation, and that people with lived experience often understand their needs better than external observers.
- Professional environments that provide actual accommodation rather than performative awareness. This means flexible work arrangements during symptom management, understanding that medication changes affect performance temporarily, and recognizing that mental health disclosure should be met with support rather than suspicion.
- **Communities** that welcome the full spectrum of neurodiversity, including conditions that make people uncomfortable. The Python community, and tech culture generally, must move beyond celebrating abstract diversity toward actually including people whose neurodifference challenges social norms.
- Personal relationships based on understanding rather than fear. This
 requires education about schizoaffective disorder, recognition that
 mental illness doesn't define personality or worth, and commitment to
 inclusion even when it requires emotional labor.

Moving Forward

I'm done apologizing for living openly with schizoaffective disorder. The discrimination I've faced isn't my fault—it's a reflection of society's failure to move beyond tokenistic awareness toward genuine inclusion.

My condition doesn't make me less competent, less valuable, or less worthy of belonging. The tools I've created serve millions of developers; the insights I've shared have helped normalize mental health discussions in tech; the transparency I've modeled has encouraged others to seek help rather than suffer in silence

I regularly receive messages from developers who say my openness about mental health gave them permission to seek treatment, disclose their own conditions, or simply feel less alone. The personal cost of transparency has created collective benefit for others facing similar struggles.

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The twenty companies that couldn't handle my openness about schizoaffective disorder represent their failure, not mine. The professional opportunities lost to stigma reflect society's limitations, not my worth. The relationships that couldn't survive mental health disclosure weren't relationships worth preserving.

I will continue living authentically, advocating openly, and refusing to disappear into the shame that society expects from people with severe mental illness. The cost of transparency has been high, but the cost of silence—both personal and societal—is higher.

People with schizoaffective disorder deserve better than systematic exclusion dressed up as concern. We deserve healthcare that treats us as partners, workplaces that provide actual accommodation, communities that welcome our contributions, and relationships based on understanding rather than fear.

Until that changes, I'll keep paying the cost of transparency—because the alternative is accepting a world where people like me are expected to remain invisible, untreated, and alone.

That's a cost too high to bear.

If you're living with schizoaffective disorder and facing discrimination, you're not alone. The patterns I've described are systematic, not personal failures. Your worth isn't determined by others' comfort with your condition.

The follow-up essay The Async Contributor Model: A Practical Approach to Mental Health Accommodation explores a concrete framework for workplace inclusion that emerged from the discussion of this essay. This connects to Digital Chakras: Our Scattered Online Selves which examines how we fragment different aspects of identity across platforms, making authentic mental health disclosure particularly challenging in digital spaces.

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