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## A Unique Mental Health Conference That Supports People With DID

by Vivian Conan

The Healing Together conference compassionately unites people with Dissociative Identities, their loved ones, and the mental healthcare professionals who treat them.

Stationed safely behind my exhibit table at the annual Healing Together conference in Orlando, I observed the attendees milling about the hall. Their dress ran the gamut from business attire to resort wear, to outfits that seemed like Halloween costumes. Some were dressed as children, with ribbons, sparkles, young-style dresses, and fanciful headgear. Others looked like animals of one sort or another. A few pushed carts filled with stuffies or were with emotional service dogs. The weekend-long meeting, then in its 12th year, had just begun, and people were congregating at the snack and non-alcoholic beverage bar. Watching them greet one another enthusiastically, I surmised most were returnees. It was 2022, my first year at the conference, and I knew no one. The outfits disconcerted me most. I understood that they were an expression of dissociative identity disorder (DID), formerly called multiple personality disorder—the focus of the meeting—but I had never seen such an unabashed display, even in support groups.

## **Inside the DID Support Network**

The conference is sponsored by An Infinite Mind, a nonprofit that aims to increase awareness of and education about DID for three constituencies: people who have DID, their supporters (family and friends), and professionals (clinicians and researchers). The hope is that greater understanding of the condition will counter myths and stigma, enable people living with DID to navigate their lives and treatment more effectively, and broaden clinicians' skills and knowledge. Most medical conferences that offer Continuing Education Units (CEUs) invite presentations from professionals only. The board of An Infinite Mind invites them from all three cohorts, believing each can learn from the others. As someone living with DID—now 82, I was misdiagnosed as schizophrenic in my 20s and didn't learn I had DID until my 40s—I was there to give a talk about my experiences and to promote my memoir, Losing the Atmosphere.

Having spent decades trying to hide my neurodivergence—necessary for my dual careers as a librarian and an I.T. systems analyst—I was uncomfortable the entire weekend, though I went through all the proper motions: I spoke with people who stopped at my table, sold books, and gave my talk. In the weeks following the meeting, I tried to make sense of my reaction. In a way, I was like a dog acclimated to living with humans suddenly finding itself in a field of dogs. But where an actual dog would have joyously connected with its fellow creatures, I didn't dare mingle. Like the legendary sailors who tied themselves to the mast so they wouldn't succumb to Lorelai's song, I remained tethered to my exhibit table. Yet something about the meeting drew

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me back the following year. I was a little more relaxed then, but it wasn't until my third year, 2024, that I felt completely at ease, able to fully absorb the power of the conference. I would later learn that my timeframe was not uncommon.

A few hours before the 2024 doors officially opened, I entered the exhibit hall with my cart of books and handouts and began looking around for a table with my name on it.

"Hi, Vivian! Welcome!"

I turned. "Hi, Jaime!" I said to the founder of An Infinite Mind and the mastermind behind the Healing Together conference.

"Can I give you a hug?" she asked. My hesitation must have been obvious. "An elbow bump?"

We bumped.

She inquired about my train trip from New York, then said, "I know you don't like crowds, so I put you at the end, near the crafts corner."

"Thanks."

She remembered. I was pleased. My first two years were during the Covid pandemic, and I worried about getting sick.

A pre-school special education teacher, <u>Jaime Pollack</u> received several misdiagnoses, including schizophrenia, before she learned, in 2005, that she had DID. Her search for information about it led her to meet other people with the condition, and, in 2007, to start a peer-led support group. She soon realized they shared similar challenges, chief among them the lack of accurate information. There was an abundance of books and journal articles for clinicians and scientists but little for people who *had* DID—about what it felt like, how to manage day-to-day situations, how to find appropriate treatment. Believing she could be of more help filling this void, Jaime changed focus and started An Infinite Mind.

"This is our biggest conference ever," she said now, pride in her voice. "Would you believe we're 400 in person and 300 online? From 26 countries! There's even a group here from Australia!"

"Wow!"

"And people say DID is rare!"

As I made my way to my table, I felt an inner calm, despite being nervous about my talk the next day. I had come home.

My exhibit set up, I walked around to see what else was on display and to greet people I knew from previous years. There were a few other memoirs, various therapy practices from around the country, a short educational film about DID, workbooks to help you get in touch with your internal parts, DID-themed crafts, a DID writing program, artwork and jewelry created by people with DID, and more.

When the doors opened, the familiar Disney-like parade filled the hall, but now I saw it as a glorious celebration. At Healing Together, you didn't have to keep your inside selves hidden if you didn't want to. If your body was 60 but you felt 8, here you could be 8. If a part of you was nonhuman, perhaps an animal, here you could be that animal. And if you were conservatively dressed, as I was, that was OK, too.

Yet this was a serious conference. My presentation would be one of more than 40 that weekend, a mixture of those based on lived experience and those based on science. A sampling:

- What One Therapist Wishes She Had Known Seven Years Ago about Treating Clients Who Live with DID
- One Body, Multiple Eating Disorders
- Healing from Toxic Shame
- So, You're in a Relationship with Someone Who Dissociates. What now?
- PTSD and DID: Physiological Adaptation in Response to Trauma.
- When Your Therapist Is Your Whole World (This was my talk, about becoming dependent on my therapist as a step toward healing, then eventually moving on, with my therapist still important but no longer my whole world.)

All three cohorts were welcome to attend any of the presentations. The only cohortspecific events were the optional lunchtime chat-and-chews. There were four groups:

- People living with dissociation and dissociative identities
- Supporters of people living with dissociation and dissociative identities

- Therapists with dissociation and dissociative identities
- Therapists who treat dissociation and dissociative identities

These get-togethers took place simultaneously, so if you identified as belonging to more than one group—there are professionals and supporters who dissociate—you had to choose.

When the first Healing Together conference, held in 2011, was in its planning stages, clinicians discouraged Jaime from going through with it. Bringing together many people with DID could create an unstable situation, they said. Jaime and the board of An Infinite Mind board didn't agree. Largely plurals themselves, they understood the issues and knew how to address them.

DID is usually caused by ongoing childhood trauma at the hands of someone the child knows well. The <u>trauma</u> can be physical, sexual, emotional, or spiritual. It can be neglect or unpredictable behavior on the part of a caregiver. (For me, it was a combination of physical and emotional trauma and my parents' unpredictable behavior.)

Some traumatized children wall off knowledge of the trauma and the feelings associated with it. The resulting lack of awareness allows them to live seemingly normal lives. The splitting is not intentional. It kicks in automatically, a kind of psychic immune system, shielding the child from emotions like pain, anger, terror, shame, and feeling betrayed that would otherwise overwhelm. The child's internal system may have multiple splits, with each walled-off part, or alter, playing a different role in protecting her. The parts may be of varying ages and sexes; some may be aware of the others, some may not.

This dissociation serves a purpose while the trauma is still ongoing. It becomes problematic when the child grows up, moves away, and is no longer being traumatized. Dividedness is not necessary for the adult's survival, but her alters, stuck in the past, don't know that. They are much like the Japanese holdout soldiers who hid in the jungle, ready to fight, long after World War II ended.

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The board of An Infinite Mind understood the dynamics of dissociation and switching, particularly the effect of triggers, which can "wake up" alters holding disturbing memories. This is similar to veterans with PTSD who hear a car backfire and react as if they are on the battlefield. The alter who surfaces in response to a trigger may not know what year it is or where they are. What the person with DID most needs when this happens is to become grounded. This means knowing that they are in the safe present, not the unsafe past.

Some ways to facilitate grounding are walking a labyrinth, doing crafts, journaling, and activating the five senses: taste, sight, touch, smell, and sound. The following notice appears on the first page of the 2024 Healing Together <u>agenda</u>:

Throughout the conference, you can visit our calming and grounding area when you need a break. There are art activities, a quiet space, sensory items, and a walking labyrinth.

## **Creating a Safe Space**

The conference is made into a safe space in other ways, too. The exhibit hall, presentation rooms, and grounding areas are accessible only to those who have registered. No random guest in the hotel complex can wander in. Each presenter is instructed to begin their talk by announcing that it's OK for attendees to walk out. Confidentiality is stressed. Most presentations are recorded; a few are not, because the presenters asked that they not be. The recordings are available for several weeks after the conference ends, so people can listen to sessions they did not get to attend or re-listen to others. Attendees are on their honor not to share the recordings with anyone who was not at the conference.

One effect of the safe-space bubble is that people with DID, whether dressed conservatively or conspicuously, get a taste of what it feels like to be neurotypical. We can converse in our native language. "We flew in yesterday" is DID-speak for "I flew in yesterday." We can mention "littles," and it is understood we are referring to the child parts inside us. We can talk about a particular alter having "body-time," and everyone knows it means that alter was "out," or "fronting," i.e., that was the alter interacting with the world at that moment.

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Like Brigadoon, the mythical Scottish village that comes to life one day every 100 years, Healing Together is a place where, for one weekend a year, people with DID get to be mainstream. It's the attendees who don't have DID who feel "other." More than a few people who stopped at my table felt the need to justify their presence by saying, "I don't have DID, but my daughter does...," or "I don't have DID, but I'm a therapist...," or "I don't have DID, but I'm buying the book for..."

People living with DID have many hurdles to navigate. One is the diagnosis itself. A fair number of clinicians, believing the condition is rarer than it is, don't recognize it when they see it—outside of this meeting, **people with DID** do not generally "dress up." Someone with DID spends an average of seven years in the mental health system before receiving the correct diagnosis. (For me, it was 30 years.) In fact, DID affects between 1-1.5% of the population. For comparison, **schizophrenia** affects 0.25-0.64%, and **autism** 2.8%.

Another hurdle is finding a therapist. DID is about creating internal silos. Therapy involves breaking down the silo walls so information and feelings, however painful, can be shared among alters. Not many therapists are experienced in doing this difficult and lengthy work. (The search for a therapist with DID expertise took me six years, bringing me into my 50s.)

Still another hurdle is stigma, in large part generated by sensational media portrayals of DID. Among many examples are the 2003 mystery/thriller *Identity* and the 2016 horror/thriller *Split*. A physician I once consulted for digestive problems changed from

cordial to fearful when he found out I had DID. First, he asked me to wait outside while he made a phone call. Then his receptionist said I could go home, and the doctor would mail me his recommendations. I subsequently sent him an article about DID I had written for *New York Magazine*, along with a note explaining that people with DID were no more apt to commit violent crimes than anyone in the general population. He apologized by mail, saying my article taught him a lot, but I chose not to see him again.

At Healing Together, people with DID, regardless of how we are dressed, have ordinary conversations, attend meetings, and participate in Q&A sessions as if we are just regular people, which we are. By the end of the weekend, it struck me that I hardly noticed the outfits anymore. And if I closed my eyes when I was talking to someone, I wouldn't have known whether they were a person with DID, a supporter, or a professional, unless they chose to tell me, or unless they used plural pronouns while referring to themselves.

Though I could have used the grounding area during my first two years, I was too overwhelmed by the conference to seek it out. But in 2024, when my pre-talk nervousness escalated, I made my way to the crafts table. I didn't know what I was going to draw until I saw a flower appear on the paper that was the hallmark of six-year-old Emily, one of my alters. Feeling calmer, I made another and posted both above my table.

I wasn't happy with my talk. My pacing was off, and I had to skip the middle and jump to the end to stay within the time frame. Ordinarily, I would have found it hard to hold my head up afterward, yet I continued to be buoyed by the conference and enjoy interacting with the attendees. It wasn't until the train ride back to New York, with 24 hours of rolling landscape as a buffer between Healing Together and the "real" world, that I understood why.

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I consider myself mostly healed—I have reached the stage of "functional multiplicity," where my DID does not interfere with my having a full and satisfying life in the non-multiple world—but I had never before experienced an environment where I didn't feel at *all* different from other people. It was also an environment where, despite my talk, I felt I mattered. Several times during the weekend, people told me they heard me speak in prior years, or had read my book, or had given a copy to their therapist. A feeling common in people with DID is that we are inherently less than, or not as worthy as, "regular" people. In me, that feeling is often buried so deep I am not aware of it. But for the entire weekend, I felt easy in my body in a way I hadn't known was possible, as if a burden I didn't know I was carrying had been lifted. Gazing at the trees whizzing by my window, I realized the burden was shame.

Healing Together is a space where those of us with DID can think of ourselves as having dissociative identities. Full stop. The word "disorder" has no place in the description, being inappropriate for the remarkably creative way our psyches shielded us from the effects of trauma. It is a serious meeting with a generous sprinkling of light moments. My favorite from 2024: When introducing the keynote speaker, Jaime asked attendees to raise their hands if they had dissociative identities. Many hands went up. "So, there's actually a lot more people in this room than are in this room," she said to laughter and applause.

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I look forward to hearing her introduce the 2025 keynote.

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My table in the exhibit hall of the Healing Together conference



The two flowers I drew at the crafts table.

Editor's Note: An excerpt from Vivian Conan's *Losing the Atmosphere* can be found on Psychotherapy.net.



**Vivian Conan** is a writer, librarian, and IT business analyst who lives in Manhattan. Her work has appeared in *The New York Times*, *New York*, *Lilith* (award-winning essay), *Narratively*, *Cleaver*, and *Dorothy Parker's Ashes*. She received a 2007 fellowship in Nonfiction Literature from the New York Foundation for the Arts and a 2019 Simon Rockower Award from the American Jewish Press Association. Her memoir about healing from mental illness is *Losing the Atmosphere*. The audiobook was a finalist for the 2021 Independent Press Award and the 2021 Independent Audiobook Awards. Learn more at **VivianConan.com**.