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Looking Outside the (Voice)Box

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Laura S. Brown, PhD, is a clinical and forensic psychologist in independent practice in Seattle, Washington. The bulk of her scholarly work has been in the fields of feminist therapy theory, trauma treatment, lesbian and gay issues, assessment and diagnosis, ethics and standards of care in psychotherapy, and cultural competence. She has authored or edited ten professional books, including the award-winning Subversive Dialogues: Theory in Feminist Therapy, as well as more than 140 other professional publications. She has also recently published her first book for general audiences, Your turn for care: Surviving the aging and death of the adults who harmed you. Laura has been featured in five psychotherapy training videos produced by the American Psychological Association. She was President of American Psychological Association Divisions 35 (Society for the Psychology of Women), 44 (Society for the Psychological Study of Lesbian, Gay and Bisexual Issues), and 56 (Trauma Psychology). Laura was also President of the Washington State Psychological Association. She is the founder and Director of the Fremont Community Therapy Project, a low-fee psychotherapy training clinic in Seattle. In the fall of 2000, she was the on-site psychologist for the reality show Survivor: The Australian Outback. In 1987, Laura lost her voice and was diagnosed with spasmodic dysphonia. In 1988, she found her voice again.

KEYWORDS *Dr. Laura Brown, feminist therapist, lesbian leaders, lesbians fighting disease and disability, lesbians and medical treatment, lesbians coping with illness, lesbian support systems, best medical practices, spasmodic dysphonia*

N.B. Laura Brown was interviewed for this chapter by Nanette Gartrell and Esther Rothblum.

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In 1987, I had just come back from the annual convention of the American Psychological Association in New York City. At that time, I was president of Division 44—the Society for the Psychological Study of LGBT Issues. I had attended a lot of sessions at which I had to speak very loudly, because our division was placed in a terrible hotel that, among other things, had poor acoustics. By the time I got home, I was hoarse and had a sore throat. I thought I had laryngitis from all that yelling.

But then the hoarseness did not go away. I began to have weird spasms where I would breathe in and my larynx would snap closed. At that point, I was still a well-trained daughter of Western medicine who trusted physicians because I grew up around them. My elementary school was in the bedroom community of Case Western Reserve University Medical School. Growing up, I knew lots of women who were doctors; my Girl Scout troop leader, for example, was a psychiatrist. I did not know that women in medicine were rare at that time because I knew quite a few women physicians.

I went to the otolaryngologist (ear, nose, and throat physician) about my hoarseness; he said, “This is psychosomatic.” He basically said that my symptoms were entirely psychological. With as much voice as I could muster, I said, “No it’s not. I’m a psychologist, I don’t somaticize.” It turns out that the condition I had, which was later diagnosed as spasmodic dysphonia, is a kind of neurological impairment. Up until then it had mostly been diagnosed in post-menopausal women, which I most definitely was not at that point. Because of sexist assumptions about women presenting with neurological phenomena, which were not easy to diagnose as such until current technology, such as electromyography (EMG) and magnetic resonance imaging (MRI), came around, my condition was presumed by most physicians to be a form of hysteria.

Once I got the formal diagnosis of spasmodic dysphonia, my friend Hannah Lerman, also a feminist psychologist, did an early Web search for me, looking for research on my condition. All the cites described it as psychological, which I refused to accept, thank goodness. I was more informed about psychological processes than the otolaryngologist was.

The otolaryngologist referred me to a speech pathologist who discovered that I had an unusual presentation. With spasmodic dysphonia you get either adductor symptoms with the vocal cords slammed shut and too tight, or abductor symptoms where the vocal cords are limp and do not vibrate sufficiently to allow sound to be created. What creates our voices is sound passing through the vocal cords as the vocal cords vibrate at various frequencies. So the normal voice therapy exercises that would help someone with either adductor or abductor symptoms were completely useless for me because I had both abductor and adductor symptoms.

It was very scary during the fall and early winter of 1987. My vocal cords would slam shut and then I could not breathe. I could not get air in or out. I would try to relax the vocal cords so I could breathe, but I had some

panicky moments. Eventually my speech pathologist connected me with the people who sell electronic larynxes—those little microphone devices that people use who have had their larynx removed. I was told this was about as good as it gets.

Iris Fodor and my other Feminist Therapy Institute friends really came through for me. I went to Mount Sinai Medical Center in New York City for a full-day evaluation at the Speech Disorders Clinic. Iris set up that appointment, and invited me to stay at her home during that process. The clinicians poked and prodded my larynx. They also did an EMG of my recurrent laryngeal nerve, which meant sticking needles into my throat. They had a hard time getting the needles in, because my cricothyroid cartilage is congenitally displaced upward. Ouch! I also had an x-ray with some kind of probe down my throat, and lots of other procedures.

After this workup, they said the same thing, which was, “There’s nothing we can do.” Botox was not being used yet for spasmodic dysphonia; that treatment became available about two years later. There was an experimental procedure that some doctors were using: they were injecting Teflon into one vocal cord so that it would be paralyzed, and then the other cord would kind of bang against it. That resulted in the type of strangled voice that Diane Rehm has on National Public Radio. Diane Rehm has spasmodic dysphonia, and she’s been treated with Botox. That’s what I would have sounded like had Botox been around as a treatment in 1987. I am incredibly fortunate that it was not.

I was also referred to a neurologist about my recurrent laryngeal nerve. There I got my first brain MRI. I also had an electroencephalogram (EEG). They wanted to rule out multiple sclerosis, which they did, thank goodness.

At one point, the neurologist tried giving me Haldol, an older anti-psychotic medication. I began to experience extrapyramidal side effects, including involuntary movements and tremors. That was horrible. I immediately went off Haldol. That experience gave me empathy for everything clients have been saying for years about how miserable those drugs are. Next, the neurologist tried me on Xanax, since by then I was really anxious. All the Xanax did was make me sort of stupid and sleepy. I have no capacity to tolerate benzodiazepines or alcohol. Just the slightest bit of either knocks me completely out.

When I was told that there was nothing that the medical profession could do for me except give me an electronic larynx, I began to take advantage of the fact that Seattle is a city full of CAM (Complementary and Alternative Medicine) practitioners. My friend Dorsey Green’s first wife, Margaret Sorrel, is a famous cranio-sacral osteopath. Because my body continuously goes out of whack, I had seen her for treatments over the years. She referred me to a colleague of hers who had been classically trained in Chinese acupuncture, and he in turn referred me to a woman named Hoy Ping Yee Chan. Hoy Ping was the dean of Acupuncture in Seattle. She had acupuncture license

#1 in Washington State. She was trained as an MD and acupuncturist in the People's Republic of China before she came to the United States, but her English was never good enough to pass the Washington State medical exam. She was employed for years as a lab technician while working to develop the acupuncture license in Washington State. Her specialty was neurological disorders. So in late November of 1987, as all this medical diagnostic stuff was going on, I started seeing Hoy Ping. I was at that point pretty much a Western medicine person, with zero belief that Hoy Ping could help me, so there was no chance of any placebo effect if I experienced anything positive. I thought, "Okay, I don't believe in this, but nothing else is helping. What the hell, I'll try everything."

Margaret began working on me to get my neck aligned in order to provide the best passageway for the recurrent laryngeal nerve. Hoy Ping stuck needles in me and wrote prescriptions for me in Chinese. I took the prescriptions down to the International District to an herb shop to get them filled. At home, I boiled the herbs in a clay pot and drank the vile-tasting concoctions. I also started seeing a psychic healer. I was fairly desperate.

Because I am a therapist, my voice is my life. I am a teacher, and my voice is my instrument. At that time, I was in a relationship with someone who did not respond well. My then, now ex-partner's response to my getting sick was to get pretty pissed off. Frankly, I should have broken up with her then, but I was too terrified. She was very angry that I was ill and working less and that I was contemplating pulling out my disability policies and retiring. I was starting to think that I could not do therapy if I could not talk. Although I was doing therapy using the electronic larynx and I even gave a legal deposition with it, I knew I could not keep going like that. You certainly cannot teach with an electronic larynx. And I was not breathing well. I was just exhausted, not sleeping, and miserable, just as anyone would be who could not breathe well or speak, who had a partner who was unsympathetic.

All of a sudden in late December, early January, I started talking again. The acupuncture and osteopathy and everything else came together, and my voice came back! I had been getting acupuncture treatment for a couple of months, and each day I would open my mouth to try to talk. I kept trying, but no sounds came out. And then one day words came out, and sound! And my vocal cords began behaving normally again. That was about $3 \frac{1}{2}$ months after the original symptoms started.

That progress held for about 5 months, and then I began to relapse. I re-treated with Hoy Ping, and by the end of 1988, or early 1989, I had 99.5% of my old voice back. My singing voice has never completely returned to the level it had been. I used to be a singer with a lot of range. That range never entirely returned, although people who did not know my singing beforehand cannot tell because I still have an okay singing voice. But my brothers can tell because they sang with me before and after I lost my voice.

It's still the case that I get what are called "phonation breaks"—the vowels drop out—when I am really exhausted.

I was also chemically sensitive for a very long time. In retrospect, we realized that the worst symptoms of my spasmodic dysphonia began about a week after we tore the roof off our house. And the thing that activated the relapse was the neighbors tearing off their roof. I have done EMDR (Eye Movement Desensitization and Reprocessing) for chemical sensitivity, and therefore I am no longer sensitive to anything except exhaust fumes, which is completely miraculous. But for a long time, if I had a bad exposure to one of the things that were toxic to me, I would also get a little bit of phonation break occurring as well.

In the middle of all of this I was trying to imagine my presidential address for Division 44, which I was scheduled to give in August of 1988 at the American Psychological Association convention. As I was sitting in my house, still voice-free, trying to figure out what I was going to say, the talk came to me as an inspiration: "New Voices, New Visions: Towards a Lesbian/Gay Paradigm for Psychology," focusing on how I lost my voice and found it again.

In terms of support, my friends came through magnificently. I tried to resign from Bonnie Stickland's Task Force on Women and Depression, but she refused. She said, "If you can write, be there. Just come." But my then, now ex-partner was angry because I was not available to help her with what was going on for her. My parents and I have been estranged for 43 years and remain mostly estranged; our family of origin did not deal well with my having my own voice. Ironically now that they are aging and dying I am involved in their care. But they never knew that I had lost my voice; they had no idea what was going on. They had moved to Israel and this was in the days before cell phones or the Internet. I think I eventually contacted my aunt and uncle in Cleveland who are sort of my quasi-parents, but really the support came from my friends in the world of feminist psychology who were maternal toward me in the best possible ways. Some of them are lesbians but the majority are not. My support network has always been defined by the parameter of feminist more than the parameter of lesbian. Hannah Lerman is one of my very first mentors in the field from the days when I was in graduate school, and Iris Fodor not too long after that. Lynne Bravo Rosewater and Lenore Walker were really there for me. These women had more of a maternal relationship with me; they are 10 to 15 years older than I am. If Adrienne Smith had not herself been ill—she was diagnosed with the cancer that eventually killed her around this time—she would likely also have been part of my team.

My therapy clients could not miss what was going on because I was sounding like Darth Vader with the electronic larynx. It was diagnostic how people responded. Two people fired me because they believed that I was unable to give them my full and complete attention. One person who was

supposed to be finishing therapy tried not to leave therapy because he wanted to stay and take care of me. He was reenacting his childhood trauma of taking care of his mother who was dying of cancer the whole time he was growing up. I told him he could not do that. Other clients grieved the sound of my voice. It turns out that many were fairly attached to how I sounded. Some worried that I would disappear, reasonably so, because I was maybe a month away from calling it quits when my voice started to return. I kept saying, "I am taking care of myself and I know this is hard." I made clients talk about what it meant for them to have a therapist who suddenly became a person with a very audible and unavoidable disability. I used that experience for deep empathy, because I learned something about utter helplessness and powerlessness that as a privileged upper-middle-class Euro-American I had not experienced often. As is true for all of my horrible experiences in life, it was an extraordinarily valuable one for me as a clinician.

The fact that I was out as a lesbian may have thrown a few doctors who crossed my path. There was not anywhere I was not out. People would say, "What's your relationship status?" And I would say, "I'm partnered to a woman." I think being *Doctor Brown* helped a lot when interacting with the medical profession. Quite frankly, the privilege and power and authority that comes with being "doctor somebody" is not to be underrated. I was really glad I introduced myself as "Dr. Brown" to medical providers and not as "Laura." I still refer to myself as "Dr. Brown" in healthcare settings, particularly now that I am seeing more and more physicians who are younger than I am.

Hoy Ping did not care what I was. She was the most amazingly engaged practitioner. She exemplified what healthcare should be like. All she wanted was to be an ally in my healing process. I gave her permission to write up my case for an academic acupuncture journal. Eventually she had to retire, because she had breast cancer and the chemotherapy really exhausted her. I went to another acupuncturist two years ago when a new dystonia, in my foot, started up. This acupuncturist asked if I had had acupuncture before, and I told her that I had seen Hoy Ping, and what for. She said, "You're Hoy Ping's famous case!" In the acupuncture world, my case is well known, because Hoy Ping is well known, and I had a very successful outcome.

Central to my healing was my willingness to connect and to network. Also, my ability to have relationships with the people who assisted me. I do not think I would have been able to make it through that period of time without that support network. Living in a place where even in 1987 there was a well-developed, expert community of CAM practitioners was very helpful. If acupuncture had not worked, I would have gone to see a homeopath, because we have a naturopathic medical school here. One of the naturopathic tracks is homeopathy, and there are some nationally known homeopaths teaching here. I would have tried everything until I

found something that helped, because I was unwilling to believe that there was no solution.

The most salient part of this experience for me had to do with my willingness to go outside of all my boxes. As I said in my “New Voices, New Visions” talk, our generation of lesbians had no map to the territory of a good life. The only images of ourselves anywhere were these horrible ones. So we were used to thinking outside of the boxes. To be a mentally healthy adult lesbian in the 1970s and 1980s, you had to be willing to say, “Excuse me, where is that written? I don’t agree.” I think that my capacity to embrace every possible avenue toward getting better, and my unwillingness to accept what I was told, had a great deal to do with the politics and the worldview that I brought to my interaction with every healthcare provider. My being a lesbian and feminist had a great deal to do with my recovery.