

1. Who's Harilyn?

I am a sixty-six-year-old woman with cerebral palsy. I was named after my maternal grandfather, Harry; when I turned out to be a girl rather than the boy everyone expected, my parents made up the name "Harilyn" in his honor. I could have done worse; everyone remembers my name. I was born and raised in New York City, and I still live there, in Greenwich Village. I am a college graduate with advanced training in social work and psychotherapy. But most of the work I have done over the past twenty-five years is as a disability rights activist. I advocate for and educate others on the needs, rights, and abilities of people with disabilities. I have a "significant other," Gene Brown, a smart, charming, loving man whom I have been with for more than twenty-five years. In addition to working and spending time with my partner, I like to paint and write. I also love crime shows on TV.

I want to tell you what it means to me to have a disability, cerebral palsy, and to describe my journey from "passing"—that is, pretending I wasn't disabled—to embracing my disability as an acceptable and (on a good day) even positive part of myself. Cerebral palsy (or CP) is a disability affecting body movements and coordination. Doctors have said I have a "mild" case of cerebral palsy, I suppose because I don't use assistive devices or need much help with daily tasks. Nonetheless, my CP affects the way I walk, move, hold my body, and speak. My walk is off-balance and, in my mind, ungraceful. Because I have a fair amount of involuntary movement in my arms and hands, pouring liquids, cutting on a straight line, and doing other tasks that require a lot of coordination and precision are extremely difficult for me to achieve. You wouldn't want me as your brain surgeon. However, I can write, paint, cook, and do most of what I need to do to get through the day. My speech is somewhat strained; it is usually comprehensible after people listen to me for a while. But when I'm tired or upset, my speech can sound quite garbled. When I speak, I often make weird facial gestures in an effort to get my words out, so my

disability is definitely visible and noticeable. Particularly when I was a kid, I faced a lot of staring and pointing and stupid questions like “What’s wrong with you?” which I hated. I still face stares and questions, but they usually bother me less, depending on my mood. Sometimes I stare back or say something provocative like “Nothing wrong with me. What’s *your* problem?” I like the idea of giving ignorant people a dose of their own medicine.

I grew up denying that I had cerebral palsy or any kind of disability. I did not want to be seen as different or, more to the point, defective. Of course, I knew I had differences—that I walked and talked differently. I just didn’t want to own up to them. I was afraid that if I said I had a disability, I’d be rejected and excluded; whereas, if I kept my mouth shut and pretended I was “normal,” no one would notice. It was a fantasy I held on to for a long time. I think the fact that I had CP rather than another type of disability made me even more eager to deny it. Cerebral palsy is not a very sexy disability; to me, it seemed downright disgusting.

My mother did volunteer work for an organization that helped children who were more significantly disabled as the result of CP than I was. They had not only greater physical limitations but also what I call “CP mannerisms”—shaking limbs, difficult-to-understand speech, weird facial expressions, drooling—that were more pronounced than mine. Looking at these children was like looking at myself in one of those distorted mirrors in a house of horrors. I was afraid that I was as ugly and repulsive as they seemed to me. Also, many of the children had what was then called mental retardation and is now called intellectual disabilities. I prided myself in being smart, and I was fearful that if I said I had CP, people would think I was a “retard.” (Actually, some kids at school called me that anyway.) The people with CP that I saw where my mother volunteered seemed like they couldn’t have much of a life. I assumed that no one would love them, so they’d never get married or have children, and that they would never be able to go to school or find a job. They seemed not quite human to my insecure mind. I couldn’t bear the thought of being like them. Not me. I was okay. I was “normal.”

My denial made me refuse to learn anything about CP. I didn’t want to know about CP because I didn’t want to have it. And I

didn't want to get to know anyone who had CP or any other disability. I wanted to be left alone and to be like everyone else.

I've come a long way since then. At this point in my life, most of the time I feel fine about having CP. I can't say I love it, but I don't hate it either. It's more a fact of my life that I live with comfortably and that, when the situation arises, I can speak about fairly openly without shame or apology. At times, particularly in recent years, I have come to view my disability as a positive source of identity and community. That's not to say that I don't occasionally encounter someone with CP—or even see myself in the mirror—and freak out. But those freak-outs don't happen nearly as often as they used to. I'll share with you some of what helped me move past my denial and self-hate.

When I was in my late twenties, after a lifetime of avoidance of other people with CP or any other disability, I decided it was time to start meeting others who were disabled. My motivation was self-serving. I had decided to become a psychotherapist and thought that I might be able to build up my own business as a therapist, or what is called in the trade a “private psychotherapy practice,” by working with people with disabilities. In hindsight, it was an absurd plan. I was so conflicted about my own disability that it was ridiculous to think I could help others with disabilities, especially if they were coming to therapy to resolve disability issues. Also, disabled people seeking psychotherapy wouldn't necessarily want a disabled therapist. For a host of reasons, including their own hang-ups about disability, they might simply prefer a nondisabled, “normal” therapist. But I was naïve and didn't know how impractical my plan was, so I just went full speed ahead.

I was lucky in the sense that I began exploring my disability identity in the late 1970s, when the disability rights movement was gaining strength. People with disabilities, influenced by the civil rights movement and the women's movement, realized that they, too, faced discrimination and began organizing for equal rights. At that time, disability rights groups were forming in New York City and in most major cities throughout the country. These groups seemed like the perfect place for me to meet people with disabilities and “drum up business” for my psychotherapy practice. I began attending meetings of one of the earliest and most

successful disability rights groups in New York City, Disabled in Action, and was amazed to find people there who had disabilities *and* were smart, attractive, and fun to be with. I became close friends with several people with disabilities, including a few with CP, who, unlike me, talked openly about being disabled. When I began to follow their example and share my feelings about my disability, I was initially frightened but also greatly relieved. I didn't have to pretend I was nondisabled any more. And, for the first time, I was not the only one in the group with a disability. My new friends understood firsthand my disability experiences and didn't judge or abandon me.

In the midst of my meeting these new friends with disabilities, something important happened in my career that helped me, or maybe I should say forced me, to embrace my identity as a person with a disability still further. As I mentioned, I had decided to become a psychotherapist, and after obtaining a master's degree in social work, I had enrolled in a psychotherapy institute to get more training. When I had been at that institute for about a year, I was asked to leave on the grounds that some of the key staff thought that a person with my disability could not be a good psychotherapist. The administrators were convinced that my CP mannerisms would distress my psychotherapy clients, causing them to flee—or at least to ask for another, more “normal” therapist.

I was horrified by the staff's decision to expel me. I had never before faced such obvious discrimination. I knew it was wrong for others to use my disability to deny me opportunities. It was like denying someone a job because he was African American or because she was a woman. That was discrimination based on prejudice, and prejudice was not right, especially in this country, which was supposed to provide equal opportunity for all. By way of the experience of being asked to leave the institute, I came to understand more fully than ever before that many of the problems I was facing in my life—the rejection, the staring, the isolation—were caused not by my disability, my CP, but by prejudice against my disability. And I had to recognize that I, too, was prejudiced—I held many of the same negative stereotypes about my disability as the staff at the institute and the world at large. That was why I had to deny my disability—because, at that time, I thought that

to claim it would mean that I had accepted those stereotypes as *the* truth about me. Of course, the stereotypes were wrong, but until I was thrown out of the institute, I never questioned them.

Recognizing my own prejudice was a real revelation. While I wasn't suddenly able to claim my disability with pride, I was able to understand that my reluctance to acknowledge having a disability was not the fault of my disability itself but rather the fault of my attitude toward it. So the question was this: How do I change my attitude?

After I left the institute, I took several steps that helped. First, I looked for other therapists with disabilities to learn what their experiences had been. Many of the more than forty that I tracked down told me that they, too, had faced discrimination in both their training and their careers as psychotherapists. After sharing our experiences, we decided to raise awareness of disability discrimination in our area of work. We formed a group of psychotherapists with disabilities, organized a conference on disability discrimination in the psychotherapy profession, and wrote a paper about the conference that was published in a major mental health journal. In addition, with support from the other disabled therapists, I decided to sue the institute that had expelled me, charging them with disability discrimination. Even though I did not win the lawsuit, because disability rights laws at that time were not as strong as they are today, the very process of filing the lawsuit was empowering. I felt like I was taking action rather than allowing myself to be a passive victim of discrimination. All of these acts caused me to become very public about the fact that I had a disability. I could no longer hide in the closet or deny that I had CP—nor did I want to. I was out there—and I had a community that provided support and solidarity.

Now that I identified as disabled, I became involved in fighting for the rights of people with disabilities as part of my work life. For example, I started a program for adolescent girls with disabilities, providing them with the opportunity to meet adult women with disabilities who served as mentors and role models. I wrote and spoke extensively about issues of disability. Yet I continued to grapple with mixed feelings about my disability. I had grown up thinking that disabled people were defective, abnormal, even

freaks, and although I now knew better, at least intellectually, it was hard for me to shake those old notions. For example, I was often surprised when I unexpectedly caught a glimpse of myself in a store window or in a mirror and saw that I had those CP mannerisms. Despite my disability activism, somewhere in my head I still saw myself as nondisabled. Also, I continued to feel uneasy when I encountered some people with CP. They, too, served as mirrors, challenging that image of myself as “normal.”

Such grappling continued for years—decades, in fact—and I’m not entirely comfortable with my disabled body even today. But other experiences, besides disability activism, helped me progress in the process of truly embracing myself as a woman with CP. First, I fell in love. Or more to the point, a few men whom I wanted fell in love with me—not all at once, mind you, but at different points in my life. During my adolescence and young adulthood, I had never dated. I simply assumed that no man would want me, given my disability. I finally began dating in my late twenties, a time of my life when I was feeling successful in my work, had my own apartment, and felt it was time to get out of my cocoon and at least “try” to date. So I joined some social clubs, wrote some personal ads in newspapers, and hoped for the best. I was still terrified, and naïve—I didn’t even know how to kiss or neck, much less have sex—but I was determined to put myself out there. I discovered that dating was not as impossible as I had thought. Sure, lots of men were turned off by my disability, but not all men were. And, best of all, a few were interested and actually turned on. To become romantically involved with men who found me attractive, desirable, and sexy with my body, disability and all, was very healing. Their appreciation of my body just the way it was helped me appreciate and see it through their eyes.

In a related but less dramatic way, the appreciation of my disabled body by some of my women friends also helped me develop a more positive body image. For example, when I complained about my clumsy, unfeminine walk to one of my closest friends, who had a disability herself, she said, “I love to see your ‘crooked’ walk, because when I see it, it means you are coming to visit.” To my friends, my disability, including my CP mannerisms, were just part of the person they liked very much; their more positive

associations with respect to my mannerisms helped me challenge my more negative associations.

Another factor that helped me challenge my negative feelings about my disabled body was my own psychotherapy. I was not only a psychotherapist but also, for many years, a patient in psychotherapy. One of the most helpful things that my therapist did was to encourage me to be curious about my negative feelings toward my body. At one point in my treatment, he suggested that instead of my sitting in a chair facing him, I lie on a couch, which is typical in a deeper form of psychotherapy. When you are lying down, you can't see the therapist's reactions to what you are saying, so you can become more involved in your own thoughts and feelings. I was reluctant to lie on the therapist's couch because I have a harder time controlling my bodily movements when I'm reclining. When I explained my hesitation to my therapist, he asked why I cared if I shook more. At first, I thought that was a ridiculous question. Surely most people would be self-conscious if they had involuntary movements that they couldn't control. But I was wrong. He explained that while my involuntary movements were indeed a fact about my body, I could have many different kinds of feelings about that fact. For example, I could hate the movements and feel ashamed, love them and feel proud, or not have strong feelings one way or the other. That there were many ways that I could feel about my body was a revelation that gave me hope. I realized that while I couldn't change the facts about my disability, perhaps I could change the feelings. Of course, I knew that already from my experiences with activism, romance, and friendships, which had all shifted my feelings about my disability. But my therapist's simple formulation—facts versus feelings about facts—and his curiosity about why I felt negative rather than some other way gave me a greater understanding and sense of control over my feelings. Perhaps I didn't have to rely solely on the disability community, on friends, on lovers, or even on therapists to nudge my feelings along. Maybe I could take a more active stance on my own.

In the past few years, I have been trying to figure out how to further shift my attitude toward my disability in a positive direction. For example, I've used my interest in making art, specifically

painting. I took up painting in my forties—I was a late bloomer—because I felt a strong desire to express myself nonverbally. Words often felt too confining and controlled. I was eager to let loose.

As an experiment, I took a few painting classes, and I loved them. I found that my shaky hands were not necessarily a liability; at times they were an asset, enabling me to feel free and spontaneous. At first I didn't give much thought to what I wanted to paint, but over time my work has become increasing autobiographical, depicting my disabled body and my life as a disabled woman.

In some paintings I have focused on the parts of my body that looked most different from the norm. For example, I have limited use of my right hand, and my fingers not only have a great deal of involuntary movement but also turn up, so they look like a bunch of small bananas. I've always been self-conscious about this hand because it looks weird. I have made several big paintings of this hand that capture the odd shape of my fingers. The very process of painting my hand has changed my attitude toward it. First, I have fallen in love with some of the colors and textures that I've used to create the hand on paper. The image has been transformed from an oddity to a colorful, beautiful form—a piece of art. Second, the large size of the image creates a sense of power; my weak little hand, which in daily life seems unable to do much, in the picture becomes a symbol of strength. Finally, that hand, with its odd twists and turns, is recognizably, undeniably mine—it's me, like a self-portrait. There's something endearing and appealing about seeing it up on the easel or wall. As a result of these paintings of my hand, I've come to like my real right hand better—my feelings have shifted.

I've also made collages that consist of cut-up photographs of my face, specifically my mouth. When I talk, the muscles around my mouth get tight and can create facial expressions that are quite scary. I have captured some of those frightening expressions in photos and have deliberately included them in the collages, along with other, more flattering facial photos. Placed in collages, those scary images become less scary and more interesting. They become part of abstract patterns of light and dark and shape that make me want to look rather than turn away. So when I see my “scary”

expressions in the mirror, I remember the collages and I can see the movements of my mouth in another, more positive way.

Writing is another way I work on my feelings about my CP. I have written about those parts of myself that I dislike the most. Describing these parts in great detail has become a form of knowing and claiming them. Yet I often struggle to find words that are free of judgment. For example, in describing my walk, I find myself using negative words such as *awkward*, *off-balance*, *crooked*, and *ungraceful*. My mixed feelings about my body influence my choice of words. I cannot come up with descriptions that are less biased. I am hopeful that if or when my feelings shift to a more neutral or positive stance, my words will shift in the same direction.

In addition to writing descriptions about my bodily features, I've written about how I deal with feeling like a freak (I consider a religious ritual called an exorcism to evict the freakish feelings), how I handle being stared at (I stare back while harboring murderous fantasies), and what the advantages are of having a wandering right hand (it can be very useful in sexual activities). Essentially I've been trying to write about as many aspects of my disability experience as I can think of, both good and bad, in part so I can stop having secrets from myself about my disability and so I can develop a more balanced view of what having a disability, specifically CP, has meant in my life.

Having a disability has helped shape some important parts of my identity that I value—like being open to differences of all kinds in other people (I'm often more open to others' differences than to my own), like being a fighter for social justice (any type of prejudice or discrimination infuriates me), and like having a knack for creative problem solving (you have to become creative when you can't do things in the usual ways).

I have not yet fully owned my disability, but I'm in a better place than I was even last year, and definitely better than five years ago. I have more work to do on the road to self-discovery and self-acceptance, and I will probably come across some tools that I haven't yet tried or even thought of—like belly dancing or flying a plane. I need to keep discovering new ways to be out there in the world as myself, with myself, with no need to cover up or pretend.

I'm betting on the fact that ultimately, being exactly who I am, a woman with CP, will give me the best shot at having the kind of life I want. Definitely it will give me the most energy for creating a good life. Covering up my disability identity has zapped a lot of energy that could be used for more important endeavors, like painting or falling in love.

So that's my story, my journey in a nutshell. Having come to a place where I not only accept but at times appreciate and celebrate my disability status, I'd like to offer support and a bit of advice to young people who may be struggling with the fact that they have a disability and who may be hoping beyond hope that it will go away or that no one will notice. I'd like them to consider the possibility that they can stop hiding and pretending, that they can claim disability and be all right. There's no magic pill to get them to that all-right place—if there were, I'd gladly give it to them (and take one myself). But there is a path, their path, to get there. Maybe my journey will help them. Even if nothing I did makes any sense to them and they have to forge their own direction, I want them to take heart. They should trust themselves to find their way—and call on some of their older sisters and brothers with disabilities to help them. Most important, they should know that there are some great moments of self-discovery and freedom ahead of them.

Daring to claim disability or any part of yourself that you have been taught to disavow can be an amazing adventure, as you are about to see.