William Peace

After a decade of increasingly severe neurological deficits, I was paralyzed in 1978 at the age of 18. Prior to the widespread development and use of antibiotics, people who had experienced a traumatic spinal cord injury (SCI) usually died. But by the time I was paralyzed, thanks to broad-based advances in medical care, men and women with SCI were not merely surviving, but thriving. All of a sudden, healthcare professionals were confronted with a population of paralyzed people such as myself who expected to live a long life post injury.

The job of “rehabilitating” a person fell to physiatrists and other rehabilitation professionals such as physical, occupational, and speech therapists. Even as a young man, I quickly learned that these professionals had no clue what to do. My generation of paralyzed people was essentially a pod of guinea pigs. On the forefront of the creation of modern-day rehabilitation, we all embraced experimentation. A Wild West mentality prevailed: no idea was too crazy, nothing dismissed. The focus was on getting paralyzed people ready for the real world.

At the time, I had few thoughts about the social structure of rehabilitation. A single emotion drove me and most of my peers: fear. What was I going to do with the rest of my life? I had just graduated from high school and all my friends were heading to college. I expected to do the same. I would like to say that my primary reason for going to college was to get a great education. Education was a priority, but as a newly paralyzed man, I had something far more basic in mind. No, not walking—my bulky Everest & Jennings wheelchair was more than enough for me. In fact, I considered that piece of junk a modern marvel. I had something more important in mind: I wanted to have sex. But did my dick still work? Could I still fuck?
Prior to leaving rehabilitation, I was a good patient. I worked hard to learn my “ADLs”—activities of daily living. I accepted without thought that I had to be able to do everything myself. Asking another person to help me was never a consideration—it was a sign of weakness, an anathema. I was brainwashed into an extreme sort of self-sufficiency and independence. Then, the week before I left rehabilitation, I asked the attending neurologist, “Can I have sex?” His reply unnerved me: “I don’t know.” These words reinforced something I could not articulate at the time: I had, in fact, learned virtually nothing from the health care professionals charged with teaching me how to really live with a SCI. The real lessons and practical information—and all of my SCI sexual education—had come from my paralyzed peers.

Part of that included an education about the “bad girls” of rehabilitation. Bad girls were broken up into two distinct and indeed opposite groups: one set formed the “dick police”; the other, the “head nurses.” The dick police had no redeeming value. Early mornings and late afternoons were when they roamed the hallways. When you hear the cart, I was told, hide. The cart was filled with catheters and was pushed by a nurse who was on the lowest rung of nursing seniority. These “bad girls” were young woman and inevitably pretty. Fresh out of nursing school, they had to spend their days teaching people like me how to get a catheter in and out. The first time I held a catheter with a very pretty bad girl deputized as a member of the dick police, I was shocked. You want me to shove that tube up and into my dick? You have got to be kidding me. This was bad enough but my “teacher” was barely older than me. She wanted to demonstrate the correct technique and I was supposed to replicate her efforts. The word humiliating does not begin to cover what I felt.

When the bad girl from the dick police wrapped her hand around the shaft of my penis, my descent into entropy seemed complete. I may have thought I was still the same person I was before I was paralyzed, but when the dick police came around, there was no doubt my life had taken on an Alice in Wonderland type of existence. Pretty young women were searching me out in a way I never dreamed possible. So, like those who had warned me, I learned to avoid the dick police.

But late at night, my roommates told me about the other group of bad girls—the ones I desperately wanted to meet. These bad girls were called “the head nurses.” Initially I thought this was an urban legend if not a bad practical joke. Yet I was told again and again that, at some point during my rehabilitation, a nurse I knew or had never seen would answer the call bell late at night and give me a blow job. There was no privacy in rehabilitation centers at the time. Rooms usually held four to six men. All that separated me from the other paralyzed guys was a flimsy curtain. We did not even have a television in the room. Just the physical set-up alone made the stories seem like impossible fantasy.

But sure enough, late one night I was awoken by the guttural sounds of deep moaning. I turned to see the silhouette of a young shapely woman giving my roommate a world-class blow job. I remember this night with crystal clarity because it was the first time since being paralyzed I got an erection. My dick was alive! Who needs a doctor when you have a head nurse?

A week or two later, I received my own visit. It started out badly. It was late at night and I had pissed all over myself and the bed. I hit the call button, upset. I thought I had had a handle on bladder management at that point. The nurse that came to help was one with whom I was very close. She changed my sheets and came back as I was washing myself. I was playing with myself without much luck. She explained I had to be a bit more vigorous and try non-traditional approaches.

Then she rubbed my leg and pulled the skin on my inner groin, and sure enough I grew hard. I started to cry in relief. She wiped away my tears and then went down on me. She brought me to orgasm, and I was taken aback when I realized no ejaculate had emerged. She explained to me that this is common for paralyzed men and that it involves a retrograde ejaculation. She assured me it would not affect my fertility or my sex life in a major way. My son is living proof she was correct.

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That night forged a lifelong friendship with this woman, one that lasted until her death two years ago. Once in a blue moon, she or I made reference to that night, the night she reaffirmed my manhood and masculinity in a way I will forever appreciate.

Newly minted crippled men inform me that “head nurses” no longer exist. In fact, when I tell this story about two sorts of “bad girls” I encountered in rehabilitation circa 1978, most people do not believe me. I am accused of telling fish tales.

Obviously my experiences constitute a lost part of medical history—lost perhaps because people are too uncomfortable with it. The fact was that rehabilitation stays at the time were long and intense, physically and emotionally. The medical professionals that did the hard work were almost all young attractive women, not much older than myself; the patients were almost exclusively young men. The occupational and physical therapists and the nurses touched our bodies in intimate ways on a daily basis. They held us when we cried. To relieve the pressure we felt, much sexual innuendo and many sexually provocative jokes were exchanged. Drugs, prescribed and recreational, were shared and consumed. Sexual relations happened between patients and staff. Some married.

Truth be told, I could tell many stories that would be far more objectionable to most people than my “head nurse” experience. But what is etched in my mind some thirty-five years later is the compassion that woman showed me—the compassion so many of these women showed us young men. This woman was able to provide me a level of care and a connection that no longer exists. I should note that not all men received such a visit; this was not a standard part of nursing care. Married, older men, and those who did not work exceptionally hard to become independent never got a visit from a “head nurse.” Such visits were reserved for men such as myself. I was young, naïve, sexually inexperienced, polite, driven to succeed, and was in need of basic knowledge that was not forthcoming. Into this void the nurse injected a compassionate eroticism that made me a better man, one capable and prepared to function in a hostile post-SCI world. This was, after all, a time when there was no such thing as disability rights or disability studies. The ADA did not yet exist.

Part of me longs for the old days for newly crippled men. It’s true that rehabilitation thirty years ago was primitive. Many people who failed to progress or displayed too much anger or clinical depression were quietly sent to another facility. I now shudder and wonder what happened to these lost souls. But it was more typical to spend months in a rehabilitation facility where life-long friendships were forged. I knew a few quadriplegics that spent over a year at a rehabilitation facility. Today—forget extended rehabilitation experiences. Newly paralyzed people are shipped out within weeks and so are in my estimation set up to fail. Rehabilitation facilities are often quite nice and located in rural areas. But they now serve as short-term bubbles of social understanding. Worse yet, much time is wasted discussing a cure to SCI and less time is spent on practical matters for a post-injury life. Obviously a cure is an admirable hope, but a desire for cure is much less important than the sort of kindness a “bad girl” such as a “head nurse” can offer a paralyzed man who is wondering about the present and future of his sexuality.

I am not suggesting we return to our primitive past. Advances in rehabilitation and social progress have revolutionized the lives of many persons who suddenly find themselves paralyzed. But I will never forget the “bad girls” who gave me quite an educational experience—who gave me myself.

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“BAD GIRLS” from the World of Disability

Kristi Kirschner

Two decades ago, early in my career as a rehab doctor, I helped to found a reproductive health care center for women with disabilities.1 The smartest thing my colleagues and I did in creating that center was to engage a community board of about twenty women with a variety of physical disabilities to guide us. And what dynamos these women were! We had women of all ages, disabilities, socioeconomic classes, races, and ethnicities—some proudly self-identifying as disability activists and feminists, others not so sure. What was clear from these early meetings was that disabled women were coming into their own. They were tired of being treated as asexual, second-class patients, excluded from gynecological exams and mammograms by inaccessible clinics and hospitals. From the seeds of the feminist movement and the disability civil rights movement, and with the recent passage of the ADA in 1990, a new focus on the needs and rights of disabled women had begun to take root.

Most of what I learned about life with disability came not from medical training but from my engaging with these women, many of whom have also become dear friends. How I loved hearing their conversations. They talked about all the things women often talk about when they get together: relationships, dating, sexuality, birth control, the challenges of exercise, diet and managing their weight, their views on genetic counseling, pregnancy, abortion, parenting, and how to dress. Only it was different. Why did people assume that “crips” should date only other “crips”? What types of clothes worked best if one used a wheelchair or had a catheter? When should you talk to a potential partner about having a catheter, or that you could become dysreflexic during intercourse? Did a woman’s right to choose abortion trump concerns that selective abortion of a fetus with a disability (such as Down syndrome) is a form of genocide?

I remember in particular their heated debates about two brave, high profile, and controversial women who blazed new paths by defying cultural stereotypes about the disabled female body. These two women weren’t “bad” in the simple sense of being disobedient or naughty—though there was a bit of that.

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They were confident, mischievous, sexy, and good-looking. These women challenged us to look at their naked, feminine and, yes, atypical bodies. They were unashamed, unloaked, with nothing to hide.

The first of these two women, Ellen Stohl, shocked feminists and disability activists alike by posing nude for Playboy in 1987. From the waist up, Stohl was indistinguishable from other “playmates.” From the waist down, she was atypical because she had paraplegia. The difference wasn’t immediately obvious to the casual observer. Indeed, as feminist disability studies scholar Rosemarie Garland-Thomson subsequently noted, Stohl could have “passed” as non-disabled, as the accompanying accoutrements of her disability (such as her wheelchair) were downplayed. But it was clear in the Playboy narrative, and several accompanying photos of a clothed Stohl using a wheelchair, that she was, indeed, a disabled woman.

The disabled body is intensely beautiful—memorable, unexpected, and lived in with great self-awareness. —Riva Lehrer

Prior to the motor vehicle crash which caused Stohl’s paraplegia (three years before her Playboy feature), Stohl had been a model and actress. She had been accustomed to the positive attention young attractive women receive. With the onset of her disability, though, she was thrust into a new reality—one involving covert social and cultural norms. On the inside she knew she was the same woman, albeit now with a physical difference. On the outside, she knew her sexuality and physical attractiveness had become suspect. Feeling invalidated, frustrated, and even angry she reached out to Hugh Hefner in a letter, writing:

The reason I choose Playboy for this endeavor is that sexuality is the hardest thing for disabled persons to hold onto. … Well, I believe it is time to show society the real story. Anyone can be sexy; it is a matter of how a person feels about himself or herself. …

The women of our community board aligned with Stohl’s sentiments, but not necessarily with her choices. They agreed that health care and society often viewed them as asexual, unattractive, and diminished. But was posing for Playboy really an act of empowerment, or was it co-option by a dominant male-cultural magazine that objectified women? Was it playing to a form of voyeurism? In the end, was it a really a step forward for disabled women, or was it a step backward? I simply loved the fact that we could be having this conversation, that these women could agree to disagree but ultimately desire the same options and access as other women.

The group also introduced me to Alison Lapper. Born in 1965 with phocomelia (absent arms, and foreshortened legs), institutionalized at birth by a rejecting mother who also refused to allow her adoption by a loving foster family, Lapper had to fight for every step of her independence and self-esteem. Though she was eventually fitted with prostheses, she rejected them and developed her own way of doing things, including cultivating a career as an artist in the media of photography, digital imaging, and painting. She often focused her work on the subjects of physical normality and beauty, playing with images of her own body, tapping into its iconic similarity to the iconic Venus de Milo. When, as a single woman, she found herself unexpectedly pregnant, Lapper rejoiced in the normality of her reproductive organs. Lapper even chose to pose nude for sculptor Marc Quinn in 1999, when she was eight-and-a-half months pregnant.

The resultant startling massive white marble sculpture (3.55 meters high), Alison Lapper Pregnant, occupied the fourth plinth in Trafalgar Square from September 2005 to October 2007 and stimulated much buzz. Quinn had been looking for a design that would bring needed feminism to the square, and his choice of Lapper for subject certainly raised the theme of gender and power while also opening questions about disability, power, sexuality, and motherhood. He noted that, while most public sculpture amounts to “triumphant male statuary” and almost never features people with disabilities, Trafalgar Square was one of the few public spaces where disability was represented, namely in the form of the statue of Lord Nelson with his apparent missing arm. In preparing his work for the Square, Quinn noted that:

Nelson’s Column is the epitome of a phallic male monument … In the past, heroes such as Nelson conquered the outside world. Now it seems to me they conquer their own circumstances and prejudices of others, and I believe that Alison’s portrait will symbolize this … From working with disabled sitters I realized how hidden different bodies are in public life and media. Her pregnancy also makes this monument to the possibilities of the future.

As expected, the sculpture provoked much public debate about beauty and difference and was again in the public eye at the 2012 summer Paralympics when a giant replica (43 feet high) was displayed in the opening ceremony.

This then brings me to the last of the three “bad” girls I want to profile in this piece: the artist Riva Lehrer. Riva and I met about ten years ago through a disability arts festival planning committee in Chicago. She was then in the midst of creating her Circle Stories—collaborative portraits of disabled artists in which the artist is portrayed in a setting of their choosing (either real or fantastical). Riva’s sense of exquisite detail, brilliant use of color, and explorations of themes of atypical beauty permeate each of her works. She has written:

The disabled body is intensely beautiful—memorable, unexpected, and lived in with great self-awareness. These are not bodies that are taken for granted or left unexplored. This beauty has often stayed unseen despite the constant, invasive public stare. Disability is complex; it demands images that combine hard facts with unexpected gifts.
I remember when I first saw Riva's painting of a nude full figure standing against the startling cerulean backdrop. The figure initially appears young, twenties perhaps, her red hair pulled back into a jaunty ponytail grazing her left shoulder blade, her bangs casually brushed to the side. We see her mostly from behind, her body with a quarter-turn toward the right, her arms raised and externally rotated behind her neck. As with a Mary Cassatt painting, one can easily imagine the subject captured unaware, perhaps in the midst of performing her morning toilette.

Upon further study, the eye is drawn to the exquisite details—the woman's large sinuous, hands, the collapsing scaffolding of her chest wall. Her low back is lordotic, pelvis tilted with her left hip rising higher than right. Her pink flesh is firm, her upper arms muscular, her buttocks pert and slightly rounded.

And then we see it—a ghostly mammalian skeleton hovering in the background. The spine of the skeleton is massively elongated, its right posterior acetabulum merging with the woman's left hip, drawing the eye to her gray-scaleischial tuberosities, femurs, and sacrum. The animal's long shadowy skull is tilted back looking toward the woman. Her sensual nakedness feels invaded by the radiographically-exposed anatomical details.

The portrait's initially puzzling title, Cauda Equina ("Horse's Tail"), becomes jarringly clear. The woman has spina bifida. The anatomical difference in her neural tube (at a point where the filamentous tail of the spinal cord is in fact known in medicine as the "cauda equina") gives rise to her small stature, her curved spine, her thin limbs.

Unashamed by her physical difference, the woman's carriage is proud, sensual, defiant even. How delightful to learn that the woman is none other than the artist, Riva Lehrer. I was mesmerized by the portrait at the time I purchased it years ago, and still am.

I asked Riva to engage with me in a conversation about her work, and the evolution of her work over the years as she has explored themes of beauty and disability by painting bodies. What follows are lightly edited excerpts from that conversation:

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**KLK:** When I showed my colleague and guest editor of this issue of *Arrium*, Alice Dreger, your *Cauda Equina* self-portrait, she immediately saw a connection with the work of seventeenth-century German-born Dutch anatomist, Bernhard Seigfried Albinus. Are you familiar with his *Clara Rhinoceros* piece? I’m wondering whether he consciously influenced your approach to own piece?

**RL:** Yes, I know that series of engravings quite well. I teach anatomy at the School of the Art Institute, and drawing for medical students at Northwestern. I’ve used Albinus engravings in class off and on for years, and find the incongruous pairing pretty darn amusing. That said, I’m not consciously aware of being influenced by that image in particular. Every portrait I make is a layering of ideas and desires. Part of this one came from thinking about imaginary anatomies, such as those that might belong to centaurs and mermaids. It seemed to me that I became both animal and mythic from the waist down because of the mutation in my spinal column. The cauda equina was a perfect way to meld myself toward a bestiary.

**KLK:** Some of your portraits are naked, some not. How do you choose how much of the body to show?

**RL:** I rarely ask others to pose nude for me, because of the toxic history of medical imagery around the disabled body. (And, for that matter, the problematic history of the female nude.) When a viewer sees a naked, variant body, I believe that his or her tendency is to reduce that person to a specimen, that is, to become unseeing of nuance and attributes that would give you a deeper, more complex entrée into that person’s life. Disabled people (if they are visibly disabled) often live with constant observation and painful judgment. I never want to replicate that in either the making of, or final product of, a portrait.

When I have portrayed someone nude, it’s almost always because it fits with what we’re trying to say about who this is. Sexuality within disability is an intricate and essential subject, and I always welcome the places we can go when a collaborator wants to explore that in their portrait. I NEVER try to persuade a person to pose unclothed unless it arises naturally and importantly during our process.

I should say something about that process. I’ve developed a collaborative method that begins with a long series of interviews. I ask my portrait subjects about the effect that their bodies have had on their lives, and vice versa. My subjects are given quite a bit of control of the visual narrative. Their opinions and ideas are crucial to the final image. These are not commissions. I usually choose subjects because of the work they do, and out of a fascination with how they inhabit their bodies.

The majority of my subjects are disabled, though not all of them are visibly different. An increasing number are not disabled at all. It surprises people to learn that some of the most fraught egos I’ve worked with have belonged to non-disabled people. Perhaps this is because those with variant bodies are forced to try to reach levels of peace with their appearance. The experience of being looked at is a familiar daily struggle. For some, being observed in the studio is a way to engage that struggle directly and fruitfully.

Most of the nudes I’ve done have actually been self-portraits, as with *Cauda Equina*. Self-portraiture lets me explore ideas that might be too painful for others. I can work with my own body in extreme ways that might be too scary for someone else, and I don’t have to worry about hurting another human being. I know what I can tolerate. Still, I’m trying to push that line with my newest collaborative works. I’ve been asking those who work with me to go to edgier places than ever before.

Another important part of the process is that I work in thematic series. This allows me to explore the similarities and variances between individuals, and between disabled and able-bodied lives. I ask a central question and see how it plays out in divergent ways. This series approach has included *Totems and Familiars*, which looked at personal symbols as sources of strength; *Mirror Shards*, which places collaborators in animal costumes to consider loss and metamorphosis; and
If Body and Ghost Parade, which both document the invisible bodies (those which we used to have, wanted to have, or expect to have) that haunt our experience of embodiment.

KLK: Your subjects are almost always staring directly at the viewer. Tell me about that.

RL: That comes from two sources. One, I want to begin from a position of power. I want the person I’m drawing or painting to not be a passive subject, but fully, actively engaged in the act of looking at me while I look at her or him. Looking away immediately puts someone in a much more objectified state. When I agree to be stared at while staring, it makes things significantly more equal than a one-way exchange. I do on occasion have my subject look elsewhere, if we’re going for an intentional feeling of privacy or distance.

I make portraits so that I can let people exist in the world in a way they generally can’t do for themselves. Often this has had a transformative effect. I want this to be a mutual transformation. I’ve been changed through portrait relationships every bit as much as anyone who has sat for me—or more. Having subjects look at me, at the viewer, and at themselves in the mirror of a portrait is to begin that change.

KLK: I imagine your paintings are somewhat like your children. I’m sure it’s hard to pick a favorite, but do you have one or two that would rise to the top of your list? Why?

RL: Oh, boy. I don’t really like looking at my work after I do it. It takes about ten years before I stop seeing the problems, mistakes, and failures. I only have one of my works hung in my house, which is Zora: How I Understand. It’s a portrait of my dog that I completed just before she died. My portraits of Zora tend to be the pieces I want to look at most and that I regret having sold. Other works represent major transitions or milestones, as with Corner (Terra Incognita), the first full nude self-portrait I ever did. I think of it as the wall I had to break through before I could do my real work.

KLK: Where do you hope to go next with your work?

RL: I’m working on the Ghost Parade series now. I’m asking people about the bodies they thought they’d have as children; bodies that they wanted to have; bodies they lost due to physical history (illness, surgery, weight change, gender change, pregnancy, etc.); and their fantasy bodies (not in the “I want to look like Audrey Hepburn” sense, but asking whether they’d ever wanted wings, or horns, or tiger stripes).

I feel that we’re haunted by invisible bodies, and that they disrupt our ability to live in the ones we have. I’m depicting these ghost selves using medical imagery and devices. Right now I’m doing a portrait of a South African curator, using maps and acupuncture meridians to explore issues of racial dislocation.

I’m also writing a book about being a member of a transitional generation, the first one to live with significant disabilities that the previous generation did not, for the most part, survive. We lack elders or precursors. Everything had to be invented as we grew up. It’s also about my family, about art, and sex, and my haunted elementary school. The title is Golem Girl Gets Lucky.

For more on Riva Lehrer’s extraordinary work, see her website: rivalehrerart.com.

1 At the time, I was on staff at the Rehabilitation Institute of Chicago; the program was originally known as the RIC Health Resource Center for Women with Disabilities and later as the RIC Women with Disabilities Center. The program closed in 2010. For a description of the program see www.hhs.gov/od/summit/whitepaper.doc.


6 Quinn, quoted in ibid.

7 See http://bodiesofworkchicago.org.