

## The Art of Disability: Some Ideas About Creativity, Health and Rehabilitation

### John F. McCreary Lecture

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Congratulations to you all and your leadership for honouring John F. McCreary's commitment to interdisciplinary approaches in health education and practice. You know that we, your clients and patients, like you, are in fact whole, multi-dimensional, interdisciplinary, human beings, we're more than the sum of our body parts or functions. To truly help us, you must work with us and with each other and every possible modality available to restore us to health and wholeness. Which I believe is exactly the function of creativity and the arts, and why I want to speak about it today.

I understand that this lecture is usually given by a physician or an academic. You have been creative in inviting the first "consumer" or "client" – though I have to say I find these words too market-oriented. We need to invent a replacement term, maybe "collaborator," to suggest that we be all on the same team.

So what are my qualifications for the job to speak for the client?

I'm a true veteran of the health-care system. And, as some of you know, my experiences with medical and rehabilitation therapists have run the gamut from horrific and harrowing to enormously helpful and heartening, with much more weight on the heartening end. (Though the horrific sometimes make the best stories!)

I waltzed through my first 46 years of life as a "non-disabled person." Then suddenly and dramatically I had a catastrophic stroke, due to a congenital malformation at the base of my brainstem. I experienced the range of disability from almost dying through quadriplegia, locked-in syndrome (I couldn't talk, though I was conscious), temporary psychosis, and the long journey of rehabilitation. I spent several months in a rehab institute, more as an out-patient, and experienced all the conventional therapies of PT, OT, speech and language, as well as every so-called alternative or complementary modality available in North America and beyond. Plus some which we invented.

More than a dozen years later, I continue to live with disabilities, both visible and invisible: mobility limitations (I walk short distances with two canes and drive an electric scooter), a paralyzed vocal cord, low energy, low tolerance for stress, and some cognitive difficulties related to organization and memory which are exacerbated? exasperated? by fatigue.

I was last in this room a few years ago to introduce the great neurologist, Oliver Sacks. A good friend had wisely given me one of his books, *The Man who Mistook his Wife for a Hat*, early in my first stroke. Sacks describes "cases" or characters with severe neurological disabilities who have extraordinary compensating characteristics, usually artistic. He sees how people creatively divert around obstacles. Sacks' insights gave me another set of lenses, early on in my stroke, to see disability not as scary, the worst tragedy that can happen, nor as pathetic, but as a potential gift, as the catalyst for experimentation and alternative means of expression, as a source of playfulness and humour.

I consider myself a bridge between the world of the not-yet-disabled – the world, probably, of the vast majority of you – though I believe disability is a continuum and everyone is disabled in some way if we scratch beneath the surface and especially if we acknowledge self-created disabilities – a bridge to the world of the disabled, a world I now inhabit.

When I was well enough, I needed to communicate the extraordinary experience I was living, I needed my stroke to be somehow useful, to not have been for nothing. I think this impulse to communicate is in no way unique to me but part of our nature as human beings. And it's key to my topic today about the art of disability...

As health professionals and students you see people during the acute and most vulnerable stage of our situation and rarely get the opportunity for long-term follow-up. Perhaps you don't even know people with disabilities actually living our lives. Maybe the process of living itself is ongoing rehabilitation? The line between rehabilitation and living is blurry. It's well defined at the acute stage of illness, when you see us and focus on the "re" in terms of restoring our physical functions, and we re-learn the things we learned naturally as children.

But there is a more fundamental definition of rehabilitation based on its Latin root "rehabitare," to re-inhabit or re-possess our Selves, our True Selves. This is bigger and more basic than re-learning to walk and talk. Looking back, I had lost my Self.

We don't have time to explore the philosophical depths of what our True Selves are about, so I am just going to tell you my own conclusions: that our true selves are creative, joyful and playful. And that these qualities are linked to Spirituality. I am therefore proposing a new model of rehabilitation based on creativity [to replace the medical model that most of us have transcended or at least expanded] that includes the creativity of both the therapist and the client.

Several years ago, a friend and fellow disability activist, Catherine Frazee, told me about a burgeoning disability arts and culture movement happening in various spots around the world. Individuals with disabilities, and mixed-abilities groups, are creating theatre, dance, comedy, and visual art out of their/our own experience. Put simply, the idea is this: It's our turn to tell the story. It's our turn to tell who we are, where we come from, what the journey is about. The telling is healing – rehabilitating – for us and for you.

There's a long history of artists with disabilities – Beethoven, Van Gogh, Lautrec, and Milton, to name just a few. This is not the place to explore whether or how disability enhances creativity – though without being essentialist, I believe it does. Living with a disability, whether from birth or acquired, is itself an art. People with disabilities don't have many role models or maps, every disability is unique, and we have to create our own paths. We have to confront society's idealized notions of perfection, and defy the stereotyped misconceptions about disability.

In my experience, we are resourceful, creative, often funny and brave. Our various disabilities push us to create new and interesting ways around obstacles, which can translate into innovative forms of speech, movement, sight and sound, stretching the boundaries of what we know as art. Artists with disabilities are taking risks that only we can take. In the process, we are transforming ourselves as individuals and as a political community, and dramatically transforming the wider public's notion of disability, as we push our limits, shatter stereotypes, and reveal our bond of shared humanity.

When I learned about this nascent disability arts movement, I committed myself to somehow make a festival and conference happen in Vancouver around the millennium. It would be the first such event in Canada, and would kickstart the development of disability art in Canada.

*(At this point in the lecture, a four minute videotape was played, featuring clips of a wheelchair acrobat, humourists, visual art by people de-institutionalized from residential facilities, and a wheelchair dance duet.)*

The dancer in the wheelchair is Geoff McMurchy. He's dancing with his sister Shannon, who has just received her MA in Dance from SFU. Geoff is Executive Director of our Society for Disability Arts and Culture, and Artistic Director of the KickstART! celebration.

I knew Geoff as a disability activist on staff with the BCCPD (British Columbia Coalition for People with Disabilities), and as a graphic designer on TRANSITION Magazine and other disability-related projects. I did *not* know that when he'd broken his neck in a diving accident at age 18, he was on his way to the NS College of Art and Design, nor that he had both sung and danced as a younger man. Our Society sponsored a one-day workshop with Candoco, a mixed-ability dance troupe from the UK, and Geoff, now 44 years old, danced for the first time since his accident. When I congratulated Shannon for her choreography, which moved me to tears, she shared that until this creation, despite their closeness, she had had difficulty relating to Geoff physically since he was in the wheelchair. We see their triumph in this tiny clip.

The video shows how disability art values our experience of living with disability. Disability art says "Piss on Pity," it refuses the victim role, it contradicts the distorted cultural stereotypes of us as passive, weak, needy – images of Tiny Tim or the idealized Super-Crip, images perpetuated in the media by well-meaning but non-disabled people who spread their own ignorance about and fear of disability.

Disability art substitutes authentic, dynamic, non-sentimental images; builds a sense of identity, pride, and solidarity, which complements our work in the disability movement for human rights. The pursuit of equality and inclusion is a cultural task as much as it is a political one. Legislation can change behaviour, but Art can change attitudes by touching our hearts and reminding us of our common human bonds.

Art and rehabilitation have a great deal in common: Both involve risk-taking, living with uncertainty; they ask us to be open-minded, to look for new pathways, to paint outside the lines. And yet to learn discipline, to persevere, to problem-solve, to synthesize and intuit.

What does all this fancy theory have to do with your daily lives treating patients and clients? I can suggest some answers with examples from my own story. The title of my book, *Slow Dance*, was both literal and metaphorical. Michael and I discovered only months after my stroke and long before I could take steps with a walker in the physio gym that we could literally dance together in our living room. The beat gave me cues for shifting my weight, bypassing from the rational part of the brain to the more intuitive .

My next step in the movement from exercise to dance was the addition of spirit: that's in the story of Emilie Conrad Da'Oud, a dancer in California who works with people who are paralyzed (among others) in what can best be described as movement from within. In a few short sessions with Emilie, I was reminded that my body was an integrated whole: my walking, my speech, my breathing, my sexuality, my intelligence and my emotions, which

had been fragmented and parceled out among many specialists – PT, OT, speech – were all interrelated. Surprise!

Emilie says that movement is not something we do but something we are; that I too – even crippled as I was – was a dancer. That encounter was the turning point in my rehabilitation! I re-claimed my old lost Self, took control of my rehabilitation, and held onto this notion of myself as a dancer as I tried to integrate the aesthetic and spiritual pleasure of movement with the more traditional therapies and alternative explorations that followed. My progress literally leaped.

Another art key to my rehabilitation was the film *Mile Zero*. I spent my days in the rehab institute making potholders and doing puzzles, activities that could have been fun but were glumly serious in this context. Then I spent weekend furloughs working with my filmmaking colleagues to edit and finish the documentary film I had begun before my stroke, a hopeful film about how four teen-agers set out on a cross-Canada tour to stop nuclear war.

Putting the film together, like a puzzle, I was struggling to revive my intellectual self, reclaim my professional skills, and re-engage with the larger world outside myself. I was chastised when I returned to the rehab institute too tired from this endeavor to make potholders and recite word lists. My otherwise excellent therapists were possibly too caught up in the pressures of their own jobs and programs to see the rehabilitation happening when I was not on their turf, to appreciate the relationship between creativity and rehabilitation, not to mention the positive message of the film that anything is possible (also the theme of KickstART!) This example of filmmaking is admittedly rather specialized but has general implications about work, purpose, engagement, and collaboration.

A final example: *Slow Dance* ends with a journal called *The Dancer Inside Me*, written at Independence 92. This was an international disability conference in Vancouver four and a half years after my stroke, where I made the powerful discovery of fellowship and solidarity with my peers: "*This was our world,*" I wrote. "*We were a people, a nation, a tribe: with our own culture, history, heroes, our own languages, our own irreverent, rude humour, our own poets and artists.*"

The climax of the conference for me was a performance by three Brazilian dancers. I was swept up with the unself-conscious joy of their movement.

*"They danced, powerfully, sensuously. We all have a primal instinct and desire to communicate, even when many of our abilities are taken away from us. Maybe when the clutter of life is gone, we're free to discover its essence."*

Later that night was the closing party of the conference, the Brazilian women were dancing, and I shyly asked if I could dance with them myself. I put my canes aside. I was leaning on Rosangela, the non-disabled dancer, with every part of my body. She was giving me cues, whispering in my ear in her sultry Latin voice: "*Relax your head, lend me your arms, lean on me, trust my body, my legs will be your legs.*"

I let go and trusted. We moved fast and wild. I heard myself screaming with joy. I had no idea what it looked like – nor did I care. The dancer inside me was out.

But was she? Where did she go? What happened in the years between these epiphanies with Emilie, the Brazilian dancers, and now? Why were these hints so fleeting and tentative? I can speculate: It's scary for anyone to admit our own power, scary in our culture to use the word artist, with its connotations of elitism, or God-given talent – or not. Scary in particular for a person with disabilities, a blatant contradiction to the messages of weakness, imperfection, and revulsion which we internalize and sometimes fulfill. To give permission to the artist within your disabled body is an outrageous act of defiance.

As I've become involved with disability arts, I've felt a satisfying symmetry with the rest of my life, like coming full circle. I discovered in making the film *Not a Love Story* that sexist pornography is about the fragmentation of our female selves, our body parts, the separation and compartmentalization of our physical bodies from our hearts and our souls, a denial of our human spirit. The result is that it makes us hate our women's bodies. Funnily, I found the same thing to be true about disability: medicine and rehabilitation (like pornography) treat our bodies without the larger context of our whole being – our emotional, social, and spiritual selves, and we are seen in distorted stereotypes which makes us hate our disabled bodies. Both pornography and disability see us as broken and silence us.

It is the function of creativity/art to integrate and celebrate. It involves and engages our whole selves. Disability art by example challenges non-disabled people to use all your creativity as well.

Please don't treat our bodies without the larger context of our whole being, our emotional, psychological, spiritual and creative selves. Creativity overlaps with all that we are; it is not something "out there." I was surprised to realize that rehabilitation – not filmmaking – was the most creative act of my life. (The only comparable project is parenting.)

When you can see the dancer in the wheelchair, you see the whole person in that chair. And you see the dancer in yourself.

I urge you to see, and to dance together.

Here's how our fellow Canadian Leonard Cohen puts it in *The Future*:

Ring the bells that still can ring  
Forget your perfect offering  
There is a crack in everything  
That's how the light gets in.

Thank you.