

Disability and desire: journey of a filmmaker

Shelly Barry



In 1996, at the age of 24, I found myself in hospital, with empty walls and broken dreams colouring my days. My partner at the time, Janine Clayton, and I were caught up in local taxi violence in Cape Town, South Africa, with members of rival taxi organisations firing at each other. The driver of the taxi we were in died, and my spine was severed by a bullet. My body told me long before doctors had the courage to admit it. I was paralysed from the chest down. During those endless afternoons with little else than my mind to entertain me, I contemplated the extent of my loss. Perhaps what struck me deepest at the time was my conviction that I would never be desired or loved again. I felt that my body had become damaged goods, my sexuality erased.

As time went by, I began to dismantle my perceptions by analysing their origins. I recognised that my mental picture of a person with a disability was that of someone in need of care, someone to be pitied, someone who certainly had no real claim to love or any kind of fulfilling life. The basis of my beliefs was largely informed by society's consensus on people with disabilities ... these were people who were mostly invisible, unless as beggars on the street or patients in hospital. The reflection of this invisibility was entrenched by the media.

My political consciousness grew within the disability rights movement. I began to acknowledge that it was society that had placed my body in a box with a label and stuck it away on a dusty shelf. I had a different body, yes. Not a damaged one. The process of reclaiming my body was an exceptionally powerful and liberating experience. I understood desire and sensuality from a completely different perspective. I realised that passion is something that everyone can access (it is not reserved for the young and the able-bodied), and it can suffuse through every aspect of our lives. I recognised the importance of self-love as opposed to requiring affirmation from others in order to love myself.

I felt pride. I even dared to feel beautiful. I cruised around on my wheels feeling that I had every right to be in the world, as much as anyone else did. And I began to live with a passion and fervour that fundamentally changed the course of my life.

My spiritual explorations into Eastern philosophy also came back to me with more force and power. I had always made a distinction between the body and the spirit, and this period gave that belief more clarity. For me, the body houses the spirit and is merely a vehicle. This does not mean that one does not honour the body – quite the opposite!

I truly believe in the power of a positive mind – something we can all access, and which begins with awareness of your thoughts. Our thoughts are energy, and energy manifests itself. It is amazing how much thought dictates outcome! Last year, I finally took the plunge and became a committed Buddhist.

After years in the disability rights movement, I returned to my dreams of becoming a filmmaker. I was fortunate enough to receive a scholarship to film school from the Ford Foundation. At 32, I became a full-time student again. In my first writing class at Temple University in Philadelphia, my professor told us, “Write about something because you HAVE to write about it. Write from your soul.” My first film birthed itself with this honesty. “Whole – A Trinity of Being”, a visual doc-poem of three short films, explores my spiritual journey of embracing and celebrating my body. The first segment, “Pin Pricks”, tells the tale of how the fabric of my life was torn apart and the revelations that took me beyond this loss: “I chose not to wear that garment of bitterness so easily fitted to the wounded body.”

The next segment deals with my second disability – my dependency on a tube that fits into a hole in my throat, allowing me to breathe and speak. In the film, I declare: “I celebrate this hole. The breath and speech it gives is my life force. So, I decorate it with jewellery, different handmade beads and trinkets because scars should also be crowned. Even if they’re not neat or pretty or hard to look at sometimes.”

For me, the power of this film came from the vulnerability involved in openly showing, on screen, the gaping wound in my throat. It had always been very difficult for me to look at it. By making a film about it, I hoped to encourage other women to feel beautiful, scars and all. Our scars are often imposed on us, yet we carry their shame. We are warriors because we have survived those scars, and live to tell their and our tales. I adorn my scar not to hide it, but to protect it and to celebrate it. This holds vital lessons for so-called able-bodied women as well – many have C-section scars, mastectomy scars and other injuries, but are taught to be ashamed of these and to hide them.

The last film of the trilogy is a sequence of images, snapshots of life in a wheelchair – not traditional snapshots, but those that dare to claim a strong



sense of sexuality and desire. One of the hardest scenes I did was a shot of my wheelchair next to me in the bath, cutting to a shot of my hands travelling over my body, in a gesture of masturbation. Doing this scene was not at all gratuitous. I made a political decision to present a picture of a disabled woman who has an active sexual relationship with herself. This was because the notion that women with disabilities might claim their sexuality or be sexually active is mostly absent, if not downright taboo, in all spheres of art, media and society in general. Black disabled women are the most invisible of all in this respect. Our cultures teach us to hide our sexuality, to not lay claim to our bodies, to wait demurely for a man to want us enough. Unless we begin to challenge those perceptions by inserting ourselves in this absence, this blank space, the status quo will continue.

In another scene, I depict my partner and myself in a loving embrace. This was difficult to do, because it meant exposing my personal life and relationships on screen, to an audience of strangers. Yet the necessity far outweighed the difficulty. I felt it was important to show that we should not only openly lay claim to loving ourselves, but claim the pleasure of being loved and loving others – in ways that are sensual, intimate and playful.

The film ends with a declaration of discovery: “I know about this dance of living. This dance is not with the feet. This dance is with the heart. And when I dance with the heart, music comes through me. Music is me. And then all that I am, is the dance.”

It has been two years since making that first film. To date, it has won four international film awards, much to my surprise! My work has continued to focus on re-envisaging a media that makes people with disabilities visible, not only as sexual beings, but as people in the fullness of human experience. I am juggling various stages of post-production on other films and hope to send them off into the world within the next few months. I am also working on the cinematic aesthetics of shooting films from a wheelchair. Unless we as people with disabilities, as women, as black people, as lesbians, become the makers of own images, our lives will constantly be depicted on the basis of assumptions that others hold about who we are, how we live, and how we love.



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