

CHAPTER ONE

SOCIAL WORK

It took a strange combination of events to wind up working in a homeless shelter for mentally-ill women. It was like falling down a rabbit hole and regaining consciousness in a parallel universe. Once you are awake to both worlds—mainstream, post 9-11, superpower America and marginalized, discredited and denied Americans—you can't choose not to know what you've experienced. I say that now, in 2006, but the Lowell Handler in Wonderland story first had to do with the rabbit hole, and I should give you a little background on that.

As the millennium was winding down, I was in my 40's, living in Manhattan and as up and on top as I'd ever been. After being recognized for my role in an Emmy-nominated film and then promoting my memoir, *Twitch and Shout: A Touretter's Tale*, I was enjoying the perks of minor celebrity. People in my East Village neighborhood who had practically crossed the street to ignore my jerking movements or hiccupping grunts (signature symptoms of Tourette syndrome) would now come up to me as I walked my dog and comment how they'd enjoyed an interview they'd seen me do on TV. I'd consulted on several other films with a Tourette angle and made good friends in the movie business. This blended into partying with the arts and culture crowd I'd met through my book tour and Tourette advocacy work. I gave readings at bookstores, bars,

and coffeehouses to large and friendly crowds. I'd arrived where I wanted to be. There was recognition and acceptance and a growing problem that didn't go with the picture.

The fact of the matter was that the income from *Twitch and Shout* was finite and dwindling. My photography sales and photojournalism commissions, erratic in the best of times, were almost non-existent after devoting two years to writing and promoting my book. In the midst of a glamorous social life, I had to take stock. I was divorced, unemployed, and needed to decide what to do next. I might have been a minor literary toast of the town, but the toast was getting stale.

I decided to be practical and, instead of gambling on freelance projects, to get a steady job. I'd left a job in social work to write *Twitch & Shout*, so that seemed like the logical place to look again. At first, there were numerous job leads, but the interviews did not go well. Prospective employers were inevitably put off by my Tourette symptoms, such as loud noises and kicking. I'd of course explain that it was a neurological disorder, usually well controlled by medication, but stressful situations (such as interviews) probably didn't show me at my best. One potential employer just kept staring at me as if I were an imbecile. She seemed appalled I would even present myself in her office, let alone apply for work there. This was at a nursing home, or long-term care facility.

Most of the jobs for which I applied were as caregiver at non-profit social service agencies. And most paid about \$20,000 yearly. That wasn't exactly a living wage in New York City, but I couldn't even get one of those jobs after my first book was published. It made me angry and even more determined to stop delaying reality with credit cards and

find someone to hire me. After several months with no offers, my resources were so depleted I wondered if I could make the rent.

So much for notoriety. The disconnect between what I'd felt of prosperity and recognition and what I was now facing—being broke and in debt—occurred before I knew it. I had barely tasted the fruits of success when I was thrust back into urban anonymity. It was winter at this point, and as strangers brushed by me on my cold walks to the newsstand, I realized no one cared who I was or what I had written, and certainly no one cared to have me interview for work at their place of business. Upon seeing a posting in *The New York Times* classifieds for a media and recreation specialist at a shelter for mentally-ill women, I decided to call. They gave me the address and I took the three subway transfers down to a neighborhood I'd never heard of.

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It was the “media specialist” that caught my attention in the ad. I'd been seeking some way of combining my teaching, photography and documentary writing skills with the constructive aspects of daily routine and work. In my travels with author/neurologist, Dr. Oliver Sacks, I used photography to chronicle and record how people perceive their reality. I'd also always been curious about mentally-ill people so starkly set apart from the mainstream. In the years before my diagnosis, I believed my Tourette symptoms were the result of some deep neurosis that the right kind of therapy would eventually cure. Yet I never thought of myself as crazy, not in the clinical sense of being mentally ill. Living in New York City, my idea of homelessness was the people I saw on the street, mostly men mumbling to themselves and smelling of alcohol. I was sure I didn't have anything

in common with them, but for some reason, I kept returning to the realm of mentally-ill people and some form of social work.

In my twenties, I'd left college in a blaze of frustration and set out on an improvised journey down the Eastern seaboard. I ran out of money by the time I reached New Orleans, but that's where I found my first real welcome. Nobody seemed to have a problem with my noisy outbursts or jerking limbs; I made friends easily and was recommended by one of them to a job working with disadvantaged children. In the years following my sojourn in New Orleans, there were all kinds of jobs in no obvious progression. I was a dishwasher, waiter, cook, liquor store stock-boy, college photography teacher, photojournalist, spinner of yarns, and part-time research and traveling companion to Oliver Sacks. There was a turning point in the mid-90s. I was in the middle of a divorce and realized I needed to rethink a lot of things, including my approach to work.

A family friend worked for an organization in Manhattan that provided housing and counseling to mentally ill people. She suggested I interview for a new program they were opening on the Lower East Side. I thought a return to social work and the kind of satisfaction I'd experienced from that first job in New Orleans sounded like a good idea, but I didn't know what to expect. Would it be dangerous? Would I be qualified? Could I handle it?

At the interview with Community Access, I was introduced to Gordon Hough, who briefed me about the job opening at a flagship program on the Lower East Side. He showed me the Clubhouse for Community Access. Clubhouses are officially known as

psychosocial clubs, gathering places that could be therapeutic through positive reinforcement and interaction. The 1960s program on which they were modeled originated with Fountain House in New York City. The idea that people with mental illness could lead more productive lives was partially a result of the Civil Rights Movement, but also grew with the de-institutionalization of clients. The clubhouse served as a transition between discharge from a hospital or institution and return to the community. The clubhouse became such a standard component of social service that virtually every agency operated at least one.

Gordon ushered me to the Avenue C property and once inside a ramshackle series of rooms, he introduced me to the club's director, Lois, a commanding woman wearing dreadlocks who interviewed me along with Gordon and another staff member in a small office. We discussed my background working in camps with emotionally troubled children and in a group home with developmentally disabled adults, and Gordon explained why I might be right for the position of activities specialist. After the group quizzed me about my strengths and weaknesses, I asked them if there was ever any violence in this environment.

“It’s very rare,” Lois said

As if on cue, the door burst open, and a woman charged through it lunging across the desk, grabbing Lois by the throat and screaming, “I’m gonna kill you, bitch!”

Staff members quickly appeared and restrained the woman. The situation was defused, and we all breathed a sigh of relief... and then started laughing uncontrollably. Our mutual and immediate respect for the client’s comic timing was what made me accept the job on the spot. I think it was the combination of teamwork and black humor

that kept me there for the next two years. By the time I left, was quite confident I could return to social work at any time.

Arriving at the women's shelter in 1999, that confidence was shaken. What a difference location makes. In this part of New York, teamwork and humor weren't easy to spot. The neighborhood looked forgotten and abused, a hellish mix of industrial zone and residential slum. The vibe was that no one wanted to be here, and no one wanted you here either. I walked around trying to match up numbers to the address I'd been given. I observed rats, crack salesman, hookers, and homeless people on the sidewalk reeking of urine. Gray light flickered between crumbling buildings, and I came to what had been an old public school. This was it: the shelter.

Two women interviewed me. Both had a son at home with Tourette syndrome and obsessive-compulsive disorder (OCD), the same problems I have, and it was not by accident they asked me to meet with them. Both Bobbie and Linda knew me as the photographer and narrator of the PBS film *Twitch and Shout*, which they had seen on television three years earlier. I was skeptical how that could be relevant to their job opening, but I was game to find out. There was an arts grant involved, equipment and instruction would be covered; they wanted me to teach photography to the women in the shelter. They were proposing using photography in the program as both a craft and communication medium. My contract would be to teach the women in this place how to make photographs, and I accepted.

When I began the position, President Clinton had been impeached for lying about a blowjob. There was a war in Yugoslavia with tens of thousands of people being killed.

And at a homeless shelter for mentally-ill women in New York City, I was a social worker teaching photography. It wasn't the "party like it's 1999" I'd imagined.

That first week of commuting down to work, the word "shelter" felt like a cynical misnomer. The ominous-looking building was officially dubbed a "transitional living community," since women only lived there for a year or so. Barbed wire surrounded the complex. I tried to observe my surroundings fully but it didn't make me in any way connected to them. Directly opposite my building was a barren field littered with the trash and debris of city life, also framed in torn fencing. The next street over, children could be heard shooting hoops, the sounds of their play filling the air. This block, by contrast, was for grown ups. The dilapidated houses lining the street alternately functioned as crack houses and family homes. I would learn that the inhabitants of the block beyond the shelter were mostly the women's friends, johns, relatives, boyfriends, girlfriends, and those supported by this small industry and subculture. Among the down-and-out citizenry were young black men gathering metal scraps to sell to junk dealers; each morning, the coffee-and-sandwich wagon man served the staff and construction workers from the chicken-packaging factory going up in a nearby lot.

I stood outside the building still wondering what I'd gotten myself into. Two young black men drove by in a white Mercedes Benz and stopped to talk to some of the women leaving the building. A lame black cat hobbled across the street while the Mercedes idled. I wasn't sure what I'd expected, but I wasn't looking forward to getting to know the neighborhood. In my pocket was a tiny, folding 35-millimeter camera called a Minox. At first, no one knew I had it.

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Jamaica straddles a blaring stereo speaker, almost smothering it; her denim mini skirt hiked up to her hips. She gyrates with each undulation of the bass, hands clasping her crotch. People walking down the hallway are only mildly interested. It isn't an unusual event. All of the women on this floor of the shelter have a life-long history of psychiatric disturbance, something that prevents them from leading fully productive lives. They are women of all color, size and story.

There is Mary, who isn't crazy at all. Everyone she knew has died of AIDS, and she can no longer cope with life, especially living alone, so she took shelter in the family here. Tammy is a self-declared bull dyke, and her bitch, Sheila, is a darkly beautiful HIV positive woman who doesn't talk much. Sheila is cheating on Tammy with a woman from another floor. Rose is an elderly Jewish woman who resembles my grandmother. She is constantly kvetching about something, like the old lady next door gone severely wrong. "I need money Lowell," she'd say. "Please speak to that man about it. I can't talk to that man. He won't give me money." That man is Godfrey, her case manager. In many instances a non-profit organization would be asked to act as payee for clients who were unable to negotiate their finances.

Spring is in the air, and things are heating up with Jamaica, whose writhing has reached quite a pitch. I report this to my boss, Linda, who sighs and asks why I don't stop her. Because it's not in my job description, I want to say, and because I'm not sure I'm ready for how Jamaica will react. But I just throw up my hands.

"I think it calls for a woman's touch," I say.

The only other male on our staff is Godfrey, a tall black man who strikes me as an extremely diligent social worker. He is also an avid amateur basketball player. Godfrey

was raised near this neighborhood, and he has told me that, without the strong upbringing from his parents and his love of athletics, he could well have found himself on the other side of the shelter, one of the homeless or drug-addicted.

Linda, my supervisor, has a son with Tourette syndrome and obsessive-compulsive disorder. Bobbie, who runs the program, is Caucasian, a tall, imposing, Buddhist twelve-stepper who has OCD as well. Sarah, who shares my office, is in her mid-twenties and takes Prozac for depression. A common expression around here is the tag line of the television commercial for the Hair Club for Men, where the balding president swears by his product: "I'm not only the Hair Club President, I'm also a client."

Then there are the guards. Security guards are posted on each floor. To enter the building, one has to go through x-ray machines, metal detectors (not "mental" detectors, we joke) and past a barrage of guards armed with walkie-talkie radios that squawk unintelligible messages from unknown places.

The odd thing is that most of the guards are Nigerian women, striking and Amazon-like, but who seem to share a stigmatized view of mental illness. One of the beauties is clearly mentally-ill herself. She often dances and hallucinates in our hallway to music no one else hears. The staff speculates whether she is in the right place on the wrong side.

Most of the security guards are nice enough. They pose no real threat and serve no real purpose. It is decoration... an illusion of order and civility. But it is rumored that male and female guards are receiving sexual favors from the residents in return for special treatment, such as entry into the building at night past the ten o'clock curfew.

The truth is that the price of a blowjob on this street is only five dollars plus a vile of crack, available to anyone so inclined.

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It took quite a while for the women to accept the presence of a white middle-class man with a camera. Many felt they could not trust someone from the staff when they were actively using drugs and turning tricks. Some were worried that I would turn them in, meaning possible jail time instead of a bed at the shelter. Numerous women were veterans of the criminal justice system and had no wish to return.

I needed to gain their trust to be able to teach, and it wasn't about how to operate a camera. I wanted them to make photographs of their world, but I would also have to gain acceptance before I could take the photographs I wanted of them. My job involved more than teaching photography—I was to take them on outings away from the shelter; to help distract them from their problems as much as to help them cope with them; to use the activity of picture-taking for fun. I couldn't know at the time how much we shared with each other while photographing, but the collection we made represents a visual dialogue. Stigma and illness don't figure in the pictures.

In my other, parallel existence, there wasn't much good news on the horizon. The scandal with President Clinton had at last run its course, but the war in the Balkans was becoming uglier with each new revelation. I would watch television reports about the rest of the world when I returned home from the shelter and find myself both alarmed and numb. The news played like so much static, just at the edge of everyday awareness or interest or attention. I was at the front of another kind of war in New York City, a war of

poverty, mental illness, and desperation. They say hope is eternal, that there is no such thing as false hope. Is it possible to be hopeless?

The exterminator had a maintenance contract with the shelter. Every few months he would spray a poison liquid in each crevasse, but it was hard to deter cockroaches that had been there for generations. The exterminator, with his friendly demeanor and jump suit uniform, hadn't been able to do anything about the rat turds in the water fountain or the mice in the office.

We tried not to let our personal lives affect our work, but one particular day I was in a black mood, and it showed. On my subway trip to work a passenger who didn't like my Tourette syndrome harassed me. I had been waiting on the platform, not conscious of my twitching or noises until I noticed a man staring at me from a subway car with open doors. When our eyes met, he yelled, "You must be a fucking retard!"

"Yes," I replied, not raising my voice, "And you must be a very smart man."

Thankfully, the doors closed just as I spoke, but I could see him screaming through the glass, his breath pouring into wet steam on the inside of the train window, his fists pounding against the doors as the subway roared away. It was as if he was outraged that a lower life form would dare to speak back to him.

I was still feeling shaken when Lisa, one of the residents, came into my office for advice on a problem. I didn't want her thinking I was irritable because of her, so I told her about the incident. She patted me on the shoulder.

"Well, you know what they say," she said.

I didn't, and I was almost afraid to ask.

“Mother made 'em, Mother named 'em, Mother fuck 'em. Don't let no one diss you because you've got Tourette, Lowell.”

In that moment, Lisa helped me more than I had hoped to help her. While my condition may not be a mental illness, I had been stigmatized in much the same way as she had been. Sharing that, we became allies in this undeclared war. I knew I was not without hope if we could have that rapport, an essential understanding of each other.

Jamaica would still get off to music, her legs appreciatively wrapped around the bass notes from the speaker. I now knew how to reach over her for the radio and turn down the volume.

But she's on to something: The pounding vibrations are like a chorus of heartbeats in rhythm with each other. Occasionally, there is dancing, unexpected and expressive, to tunes the rest of us forget we know.