

1 From the Kitty Room

Ourselves, our lives, our times, our truths, our culture. Do we collect it all piece by painful piece, or do we invent it? Does it matter? We've patched together our lives after years of disability, and now we're patching together our culture after decades of fragmentation. We're reinventing ourselves personally, and now we're doing it collectively.

—Barry Corbet, "Art and Life"

I BELIEVE I have finally made the circle. I fled from this little bedroom in my parents' home to live my own life when I was twenty-nine. I came back to this house in 1984, but it has taken me years to get to the point where I could feel comfortable coming back to this room.

Sometimes I think my whole life has been a journey to find out where my place is. For a long time, I didn't realize everyone is on such a journey. I thought other people, people who were not disabled, had it all figured out—that it was only I who didn't know where I fit in. Because I was different.

I learned when I was growing up that if you were a girl, you went to school, then college, and then you married, became a wife, and had a family. (I grew up before Betty Friedan wrote *The Feminine Mystique*.) When I became disabled, my journey, I was pretty sure, was not meant to take me in those directions. So I tried to find my place. What was I supposed to be? What kind of life was I supposed to have?

The role models I had were President Franklin D. Roosevelt, who had polio like I did and who was successful and was a hero for a whole nation; Elizabeth Barrett Browning, a romantic poet

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who was considered an invalid and was “rescued” by poet Robert Browning when he whisked her away from her oppressive father and began with her one of the most famous courtships in literature; and Tiny Tim from Charles Dickens’s *A Christmas Carol*, who was poor and humble and all-forgiving.

I knew from the beginning that if you were handicapped but had money, class, and stature, you could be like Roosevelt or Browning and have a good life. But if you were poor, you were Tiny Tim—or the little boy in elementary school I gave my sandwich to. He had wooden crutches and braces and worn-out brown high-top shoes. He was skinny and looked hungry. He was “crippled.” At that time, I was not. When I gave him part of my sandwich, Mom fussed at me for giving away my lunch. After I became handicapped, I was afraid I might end up like him.

I was lucky, because my parents could afford a handicapped child. I thought we were rich, but I did not have enough experience to be sure what rich was. We had a nice house in the south end of Louisville. Building was just beginning out here, and it was not a rich area, so land was inexpensive. My parents bought three-fourths of an acre on Kenwood Hill near Iroquois Park.

I think my family was pretty normal for the times. Both my parents were depression-era kids, even though the depression affected them in different ways. My mom came from a “good family,” although her father made some of his money from taverns. My dad’s family was poor. He worked during high school. He graduated third in his class, and he liked to point out that he was the youngest of the three top graduates. He worked through college and paid his own way. Since my dad’s family consisted of preachers or women who married preachers, his mom was not too keen on my maternal grandfather’s business. I never looked down on it. Because of Paw-Paw’s taverns and other property, my mom had a comfortable life—and was even a little stuck-up.

Maw-Maw, my maternal grandmother, told me stories about taking care of her first child (Mom) and cooking all morning in their apartment above the tavern. She would cook tongue for

sandwiches and a big pot of soup and then have to carry it all downstairs for the workers who came in for lunch. When I was a little girl, I was impressed that Paw-Paw never allowed unescorted woman in the tavern. I also bragged to my elementary school classmates that my grandfather could drink half a case of beer in a day. I didn't know that this was a pretty good indication of alcoholism.

My mom and dad met in college. Daddy was studying to be a chemist and Mom was studying to be a lawyer, which was what her dad wanted her to be. When she finally stood up for herself, she switched fields and became a teacher. She and Daddy got jobs after college, married, moved into an apartment, and began saving for a house. Typical for the pre-war 1940s.

When they bought land for the house, Mother and Daddy cleared it themselves, drew up the plans for the house, and designed many of the features inside. Mom used to talk about how she got a bad case of poison ivy from burning the rubbish they cleared; the poison ivy was in the smoke and got all over her. We always gasped when she told the story of Daddy falling through to the living room ceiling while trying to put insulation in the attic floor. He didn't get hurt. Their youth and pioneering spirit impressed me. As I look back, I realize that most of that pioneering was to save money. Still, it was impressive.

I judged all homes by this house. The first time I went to a friend's house to play, I was shocked that their house was so small. I remember thinking it would be unpleasant to live there. But I never thought we were rich because we had a big house. In fact, I often felt we were kind of poor, because the basement was unfinished and the upstairs had an unfinished attic and a tiny bedroom my sister, Ann, and I shared. If our bedroom was any indicator, I was sure, we were poor.

The room barely held two beds and two kids' tiny desks and chairs, although we did have a big walk-in closet (before they were trendy). We also had a metal furnace grate on the floor. On cold winter days I would stand on it until I felt its crisscross marks

being branded on the bottoms of my socked feet. I wouldn't get off even when my feet began to hurt badly, because I knew that soon, too soon, the furnace would go off and my billowing white cotton slip would slowly collapse around my legs and I'd be cold. I never understood how it could get that cold that fast.

In 1954, when I was nine years old, I got polio at Girl Scout camp. It was an epidemic at that time. When I became sick, the camp nurse called Mom. Mom thought it was just homesickness (and I was homesick too!) so she said, "Let's just wait a day or two." The next morning when the camp nurse came to check on me I was sitting with my arms propped behind me. The pose was a classic symptom of polio. She was distraught that she had not discovered me sooner.

After a six months' hospital stay, I was able to come home. I could not walk anymore, so I couldn't go back to the room upstairs I shared with my sister. I moved into the room beside the kitchen. It had been a nursery, then Daddy's den, and was now occupied by my four-year-old brother, M.C.

When it was a den, the piano was there, and Daddy's desk with his pipes and pipe rack, and his glass ashtray with the rubber tire around it from some convention. One wall was covered with *Esquire* magazine cartoons—Mom edged them with black tape so they look framed. The room also had three corner windows. When my brother was born, it became a nursery again.

When I saw my brother for the first time he was in his crib crying. I was able to quiet him, and I felt maternal. When he was two, I had to pick him up and remove him from the presence of a "no-no" and he was mad and kicked me in the shins. I decided then that I did not want children.

Some might think it was kind of weird sharing a room with your little brother, but it was good for me—it meant I didn't have to be alone. We grew close because we lived in the same room for a couple of years and we depended on each other. At different times in my life, I have depended on him too much. I think we all have.

After I had polio, I spent a lot of time being rehabilitated at the Roosevelt Institute at Warm Springs, Georgia; it was the “in” place for people who had polio. I did not realize until years later that most kids around Louisville went to the city’s Kosair Crippled Children’s Hospital for rehabilitation. I’m not sure why I got to go to Warm Springs, but friends tell me we must have been rich because only rich people could afford to go there. I was sure we were not rich, because Daddy always talked about how expensive it was to travel, and I know we had financial help from the March of Dimes.

When I remember the times I was unafraid and unalone as a child, I find those times were at Warm Springs. Until then, my mother had kept pointing out to me that I was different from most handicapped kids, so I hadn’t associated with them. It is a paradox that an institution can be liberating, but for me Warm Springs was. Life was accessible to me there. There I learned about life with a disability and how to get along in the world—life lessons.

Home was different. There were lots of activities Mom had to stop participating in, because even though I was nine and small for my age, a handicapped child—any age, any size—is a burden. Sometimes Mom liked to use me as an excuse: “Well, you see, I have this handicapped child at home so, no, I cannot bake cakes for the school festival.”

When I was ten years old, my sister, Ann, told me that the reason Mom drank so much was because she had to take care of me. I was too much work for her, my sister said. I shouldn’t ask for so much. My sister was twelve. What did she know? But that experience, plus my mother’s “weak stomach” and her distaste for all bodily functions taught me early on not to ask for too much from her. I tried to make life easier for others. My aunts complimented me on the fact that I never complained, never felt sorry for myself; I was praised for having adjusted to my handicap. And so I learned that people like you better when you make few demands on them.

What my child's mind could not realize was that my mother's inability to care for me had more to do with her disability (alcoholism) than with mine. I did not leave the room for months because it was more convenient for her if I didn't. I remember noting in my diary that I had spent thirty days in my room. In my bed, actually. I knew that was significant, although I did not know I had become "bedridden." It was just easier on my mom if I did not get in my wheelchair.

When I was about eleven, a social worker came to visit to discuss a March of Dimes event. As she sat with me and my mom in my room, she remarked on our house ("How beautiful!") and said she could tell just by talking to me that my parents were educated—that showed in how articulate I was. She told me I was very lucky to have parents who cared. Many kids she visited were poor and dirty; their moms couldn't take care of them.

I was educated in this room from fifth grade through high school except for one class when I was a junior. The schools called the program Home Instruction for the Homebound. I called it "home tutoring," because that sounded prestigious. It was an inadequate education. How much can you learn in two hours, one day a week? I missed most of the typical experiences of adolescence because I was in this room instead of in school—although from all I've heard about adolescence, I'm glad I missed them!

Finally, my senior year, I got to go to school all day (actually four hours a day, because that's all the credits I needed).

By this time Daddy had hired a maid to help Mom; her name was Chris. She was black. She started coming to the house two days a week, then three days a week; then, when I got to go back to regular school, she came every weekday. Five days a week she helped me get bathed, dressed, up in my wheelchair, and out of the house. She became my second mom, although I didn't realize that until years later.

On my first day at high school the girls' counselor introduced me to Ruth, the only other visibly handicapped student in my

class. The counselor thought we would be fast friends. Ruth had a big family, was from the country, and was poor. She had had polio too, but she could walk. Only one leg was affected; she limped. The cause of our disability was the only thing we had in common—yet we did become friends.

Ruth and I were pretty much accepted by our classmates. Ruth was smart, hardworking, and involved with school activities and church. I was accepted probably because I wasn't there long enough for people to get to know me well enough to find fault with me. I was learning, though, that part of being handicapped is being different. And being different in high school is hard. You know you are different—and you know you cannot do much about it. You cannot cure it. You cannot change it. The only solace is knowing it is not your fault.

But the proms were difficult. I went to the junior-senior prom when I was a junior, because the juniors gave the dance for the seniors. Since I was working at the reception table, it looked okay not to have a date. Ruth worked at the reception table, too. Maw-Maw made my dress; it was blue taffeta with spaghetti straps and white eyelet lace over the skirt. She also made a lace jacket to cover my shoulders. I got my hair done the day before and tried to sleep on it without messing it up. I was not successful.

Daddy drove me to the prom and Ruth's brother drove her. It was in a big, posh hotel downtown, and during the prom, Daddy went to dinner with one of his good-looking bachelor friends. When they came to pick Ruth and me up, Daddy's handsome friend asked Ruth to dance, which made her night!

I did not go to my senior prom because I did not have a date. Two junior girls asked me a week before the prom if I would like to help them at the reception table. I told them I was busy that night. I wasn't.

High school was a defining place for me. I was different not only because I was handicapped but also because I had not been to

formal school for five years. During those years of home instruction—even though I never got more than halfway through any textbook—I still made all As and Bs.

When I got to “real” school, I was eager to find out how I measured up to normal kids. You know how important it is for college, stature, and ego to be in the top ten? In a class of 110, I was number 11. I wanted to feel sad that I had gotten so close and missed, until I realized the rankings were based on grades, and my grades did not accurately reflect my educational achievements. My education had not been the same as my classmates’.

I was smart enough to go to college. I lived at home, in this room, and Chris drove me back and forth. Mom finally admitted she could not do it. Well, she did not actually admit it, but she did say she could be doing other things with the time. Like resting.

I went to college in the late Sixties—that era of liberation. Thank God I didn’t go to our local university! I would have been lost on the huge campus, let alone among the masses of people, the large, old buildings, the steps! Instead I went to a small, accessible Baptist college. It opened in 1962 and closed in 1969. Long enough for me to come out of my back room and grow and spread my wings and begin to become my own person—at last.

During my third year in college, I wrote for the school newspaper, was vice president of the art club and president of the literary club (politics got me there), and a part of the group that had the first dance held on campus. The downside to these extracurricular events was that I had to depend on my dad for transportation. It was kind of humiliating to be one of two people in my college whose fathers drove us to ball games and lit club meetings and such. Of course, for me, it was understandable—I was a cripple. The other girl who shared this humiliation was a missionary’s daughter; she was not allowed to go anywhere on her own.

I even lived in a dorm during my sophomore year, with the help of two dorm mates and with Chris coming to my dorm two days a week. And with Daddy, of course, paying the bills. I could do almost anything as long as I had help.

After college I tried for a couple of years to get a job teaching. Not one public or private school in the area would hire me—a teacher in a wheelchair. For several more years I tried to get other jobs, but no luck. I was in my late twenties, living at home with my mom and dad. My sister and brother had long since grown up and moved out. I was still here, unemployed and miserable.

I lived in this room and looked out the window at night and realized that, even though I was very lucky, I had missed a lot. I used my wheelchair only when I went out. The rest of the time, I was in bed. Not asleep, not incapacitated or sick. Just—in bed. Staying there just made everything easier.

A red sticker with a big black “I” pasted on our front door let firefighters know that inside, there was a handicapped person, an “invalid.” I knew intellectually it did not label me “not valid,” but some days I felt that way.

I lived in this room and looked out the window at night and prayed and cried and wished things would be better. I wished Mom would stop drinking or Daddy would be home more—except Mom drank more when he was home.

Sometimes when she fell and no one was here but me, I wished she would not get up. Or sometimes I wished Daddy would die and Mom would not have any reason to drink anymore and she would be able to take care of me and she would like me better.

A harsh truth began to emerge: Most of the negative elements in my life were caused by my parents’ problems. I had to get out of this room, out of this house. If this is all I will ever have, I don’t want to be here, I thought. I considered killing myself.

A college friend, a social worker, suggested I go to a family counselor. This was not a foreign idea to me. I minored in psychology and I had gone to counseling in college. Now, with the counselor’s help, I discovered it was possible for me to live elsewhere with a companion, as I came to call my personal care attendant. And for ten years I lived away. I lived in some neat places around Louisville: in the historic Cherokee Triangle area;

on a horse farm in Prospect, Kentucky; at a landscape nursery in Lyndon, Kentucky

Even when I moved out of my parents' house into my own apartment and got a motorized wheelchair, I stayed in bed a lot, for I had learned that some people can be more productive, more functional, in bed. These bedrooms, though, were very different from the one I stayed in at my parents' house. In every rented apartment, in every house, I claimed the biggest room for my bedroom.

Mother and Daddy separated a couple of years after I moved out, and soon Mom decided this house was much too large for her. She moved to an apartment. And I moved back home. Daddy coordinated the move so closely that one mover moved Mom out of Kenwood into an apartment and moved Michael and me out of the country and into Kenwood all in one day. Daddy said it was cheaper since it was considered one job.

I moved back to this house—but not to this room. I took Mom's old bedroom. The next thing I did was make my old bedroom into a dining room. The house already had a perfectly beautiful dining room: chandelier, bay windows, built-in china cabinet, chair rail on one side. The dining room is the room in a home you use the least; usually, it is reserved for eating and people and gaiety. I made this bedroom my dining room because I knew I would not have to spend much time here.

Still, I knew I had to deal with my sad memories of this room. Sometimes I sat in my newly christened dining room where my bed used to sit and examined my feelings to see if the room felt or looked the same. The view out the corner windows was the same, but the trees were larger and the woods out back seemed steeper than I remembered. (Perhaps the rumor about Kenwood Hill's moving is true! Houses on the hill show cracks in the walls as evidence of its shift.)

I recognized the black circular stain on the floor where the thirty-pound weight sat when it was not hanging from a rope along the ceiling with me on the other end, my head in a sling.

The aim had been to straighten my back. I was supposed to hang there for twenty minutes twice a day. How many days, months, years I don't remember—but from the looks of me, it was not enough.

When I first came back to this room, I felt the old oppression and loneliness. It has taken time, and growing, for me to be able to put those feelings where they belong. I balance them against the knowledge that I was pretty lucky. Still, I was a back-room person.

Several years later, after Daddy retired to his cottage at Lake Cumberland and Mom was in a nursing home, we tried to persuade her to come live here. We made this little room into a bedroom again, repainted it, carpeted it. But she would not leave the nursing home, maybe because she wanted the big bedroom or because this used to be her house. Or maybe because the nursing home felt like home to her. But, because she did not need this room, it became my office.

Actually, I avoid calling it an office, because "office" means "work," and I don't want to think of what I do in here as work. I call it the Kitty Room, because it was supposed to be my mother's room and her college friends called her Kitty.

I could have chosen another room as my office, but I chose this one to reclaim my memories and my history and to learn from what I had experienced. And to write about it. In 1982, in an article for *The Disability Rag* magazine, I wrote: "Unlike most minority groups, we do not have our own culture and traditions." I was wrong. But at the time, I thought of one's culture as one's background, one's mom and dad, one's grandparents. I saw culture as being where one came from. My ancestors were French, German, and English. My home, Louisville, has the Ohio River circling around, Churchill Downs, bourbon whisky, Olmstead parks—and these, too, are part of my background. I am proud of my heritage, my history, those things that formed us as a family, as part of an ethnic group. When I wrote that piece in *The Rag*, I did not see disability as related to my culture.

Since the majority of us with disabilities come from nondisabled parents, we think we cannot connect to disability culture. Psychologist Carol Gill once said that people with disabilities are “cultural foster children.” My parents taught me everything I needed to know about where I came from and where I was projected to go. But they had little experience with disability. The lessons I learned from my mom about disability were not accurate.

It’s hard for us with disabilities to know who we are. Because others in our family have not had the experiences we’re now having, we are, for the most part, alone. Not wanting to be alone, I believe, made me look for family at Warm Springs. I wanted to belong to Roosevelt’s Warm Springs family, but I was born too late. Still, I found a part of it.

Like everyone, I was hungry for a hero. I found my hero at Warm Springs: Franklin D. Roosevelt. Some of my friends think I am obsessed with Warm Springs, but it is a big part of my childhood and adolescence. I have learned a great deal about disability in America from Roosevelt and stories about him. It is a part of who I am; it is a part of my heritage, a part of my culture.

It was the belief that one must look to the past for lessons that sent me searching through my personal history. If I am to write the stories, I have to come back to the memories of this old bedroom. I have to come back to the pain and the isolation. I have to try and touch those memories, those events that made me who I am.

I’ve always thought that my experiences in life have been both diverse and universal. I know what oppression is, even though I come from a social class where there should be no oppression. I know what poverty is, and yet I come from an economic class where there should be no poverty.

From my experience, to grow up with a disability in America is to live with unconventionality, confinement, and oppression. We have to acknowledge that part of our culture has been

oppressive—physically, economically, educationally, institutionally—an oppression often not acknowledged but real nevertheless.

It is sad that part of our past was painful, but it is a tragedy if we do not learn from it. That is why disability folks are coming together and getting involved. That is why we are chronicling and reclaiming our history, why we are teaching disability history, and why we are starting to write about it from our perspective. We are building a disability family, celebrating our culture.

“Skeptics notwithstanding, disability culture is incandescent and spreading,” says Carol Gill. “I’m still betting on it to warm this tired world.”¹

This time by design, I am here in the room where I spent much of my childhood. This is not a big room. It’s smaller still if it is your whole world. For too many years, it was my whole world. But I’ve come back partly because I expect the memories I find here to give me the energy to help define and celebrate our disability culture. The Kitty Room is a warm room now, a safe room and a safe place to remember.

Probably because I have spent so much time in here recently, I am comfortable. I enjoy it even when I remember the hard times. Sometimes the rituals of growing, the trials of moving from child to adolescent to “grown up,” are not as important as the things we learn from those experiences. One grows because of them. Today, I feel I have the experience and the credentials and, finally, the credibility to do whatever I set out to do.

I am enthusiastic about being in the Kitty Room. I am encouraged by its accessibility; I feel quite capable now to take on any project. I have come back because this is *my* room.

1. Mary Johnson, “Emotion and Pride: The Search for a Disability Culture,” *The Disability Rag*, January/February, 1987, 1.