

Disability Gulag

by Harriet McBryde Johnson

"My father died when I was 2, and I lost my mother when I was 5." Throughout my childhood, that's what Grandmother says. She's a fine storyteller with rare gifts for gross delicacy and folksy pomposity, but she doesn't give the details, and we don't ask. To me, it's enough knowing that she's an orphan, like Heidi -- like Tarzan even! What else is worth knowing?

Eventually our cousins tell us. When Grandmother was 5, her mother didn't die. She was placed in an asylum. There she lived until Grandmother was in her 20's. There she died.

The news seems to answer some questions about Grandmother. Why does an independent thinker set such store on conventional behavior? Why did she marry a ridiculously steady Presbyterian?

I think it's fear. Fear that one day something will go wrong and she, too, will be taken from her family, snatched from the place she has made in the world, robbed of her carefully constructed self and locked up for life.

I know that fear. I share it.

Grandmother lost her mother in the early 1900's to what was considered progressive policy. To protect society from the insane, feebleminded and physically defective, states invested enormous public capital in institutions, often scattered in remote areas. Into this state-created disability gulag people disappeared, one by one.

Today, more than 1.7 million mothers and fathers, daughters and sons, are lost in America's disability gulag. Today's gulag characterizes isolation and control as care and protection, and the disappearances are often called voluntary placements. However, you don't vanish because that's what you want or need. You vanish because that's what the state offers. You make your choice from an array of one.

But now the gulag faces a challenge from people who know the fear firsthand.

It's 1978. Just out of college, I'm working for a local disability rights organization. I'm riding, and also in my small way powering, a new wave, a shift from care and protection to rights and equality for people with disabilities. Part of my job is to give technical assistance on the new Section 504 regulations, which ban disability discrimination where the federal dollar goes. This gig has me squirmy. I'm consulting with Coastal Center, a state institution housing people with developmental disabilities -- primarily cognitive impairments and some severe physical disabilities -- about 20 miles from my home in Charleston, S.C.

My paycheck won't support a lift-equipped van, so I go by car. I am transferred to my portable wheelchair and rolled into a room full of functionaries. How to establish an authoritative presence? I'm young and small and disabled and female. I seem to get away with the female part, but the rest is tough.

Still, once I get going I start to think I can talk circles around the very best functionaries. In no time, it's almost noon. We're breaking up.

The moment has come. "I have some old school friends in Cottage D-4," I say. "Could I possibly have lunch with them?"

There's some surprised hemming and hawing, but, yes, certainly, if I like. An administrative assistant is tasked to push me there.

The "cottage" is a big rectangle in cement blocks and brick veneer. One side houses boys -- adult "boys" -- and the other is for "girls."

My pusher leaves me in the central day room, parked against a wall. It seems both chaotic and lifeless. High on a wall, a TV blares, watched by no one. Ambulatory residents move across the floor with no apparent purpose. Along the walls, wheelchair people are lined up, obviously stuck where they're placed -- where we're placed, I should say, because I, too, am parked against a wall, unable to move -- like knickknacks on a shelf.

Six of these knickknacks are my old friends. Their eyes are happy to see me. Their bodies are beyond happy: wild, out of control. Cerebral palsy does that. I make myself grin.

My pal Thomas is a cool customer. He looks straight at me, then cuts a rueful look at the others spazzing out. I can't hear his soft voice over all the racket, but I know he's offering formal words of welcome.

Then we're moved en masse. Plates are put in front of us, with measured food in bite-size pieces. I'd like butter and salt, water instead of milk, but this isn't a restaurant. Thomas is parked beside me, and we chat about old times at our special cripp school. We talk politics, as we did as kids.

Some staff members sit and feed residents. Others come and go. They talk loudly to one another, and we tune them out. Then a woman's voice penetrates my skull, reaches my brain. "Is this the new girl from Whitten Center?"

She asks again, "Is this the new girl from Whitten Center?"

I'm aware that the state's oldest institution is trying to reduce crowding. I look around for the new girl from Whitten Center.

I realize that she means me.

I know it's irrational, but I want to scream. I can't, because they don't like screaming here, and in this panic I don't know what to do if I can't scream.

My friends, amused, grimace and writhe. Please don't start laughing, I want to say. Don't go all spazzy!

"Is this the new girl from Whitten Center?"

Thomas answers. "She's our friend. She's from outside." He has come to my defense!

The loudmouthed staff members don't hear. "Who is this girl?"

"She's from outside."

"Did you say from outside?"

Thomas coughs. "Look at her hair."

The aide studies the shiny braid that falls to my knees. She remarks on my pretty dress and my real gold bangle bracelet. Obviously from outside. Speaking to me now, she asks simple questions. I manage to explain how I know these people, where I live, what I do. The staff members are amazed that someone with such high care needs went to college, has a job, lives outside. All agree that I'm high-functioning, mentally.

Time to go home, but first I have to use the bathroom. Why did I sip that coffee in the conference room? Oh, well. At least this place has beds and bedpans and aides who handle them regularly. I ask for help.

Aides scurry about to improvise a screen. "I'm sorry there's no privacy; we're just not set up for visitors to use bedpans."

What about residents? Is privacy only for visitors with gold bracelets?

I can't ask; I'm begging a favor. In front of my friends, I can't demand special treatment. If they routinely show their nakedness and what falls into their bedpans, then I will, too. Despite my degree and job and long hair, I'm still one of them. I'm a crip. A bedpan crip. And for a bedpan crip in this place, private urination is not something we have a right to expect. I say it's O.K.

It's a two-person job the way they do it. My way is quicker and easier, but they get their instructions from their bosses, not from the people they help. They try to hide me with sheets.

That evening, I tell my family the funny story about how I was mistaken for the new girl from Whitten Center and how Thomas and my long hair saved me from life in prison. I don't tell them it wasn't funny when it happened. I don't tell how the fear felt.

It comes from a different experience, but I'm convinced that my fear is the same fear Grandmother knew. Because of a neuromuscular disease, I have never walked, dressed, bathed or done much of anything on my own. Therefore, I am categorized as needing special treatment and care.

To Grandmother, that meant extra concern, special pleasure when things went well, tangible help at times. Most summers, she kept me at her house for a week or so with my cousin Mary Neil. The widow of a prosperous small-town pharmacy owner, Grandmother let us roam the town with whichever teenager she had hired to help. Anyone could do the job, because I explained everything step by step; Mary Neil learned the drill, too. Free of hands-on duties, Grandmother entertained herself and us with her inexhaustible store of memorized poetry, quoted inappropriately. Squeezing into an old-fashioned girdle, she would say, "What strange Providence hath shaped our ends?" or Oh, that this too too solid flesh would melt." Coping with my special needs wasn't all that onerous. To the larger world, my needs had serious implication. I couldn't go to school or to camp with my brothers and sister. I was exiled to "special" places. As my peer group entered adolescence, the gulag swallowed about half of my classmates. Four went in 1969. They "graduated" into an institution after a ceremony with caps and gowns and tears. Others, including Thomas, just didn't come back after summer vacation. My friends' parents, asking the state for help, were persuaded to place them where they would get the specialized care they supposedly needed. In fact, until they disappeared, my friends got their care from people with no formal training. The main difference between them and me was economic. My family could afford hired help. Thus insulated, they didn't go to the state, and the state didn't tell them it puts people like me away.

I knew my family wasn't like F.D.R's or Helen Keller's; they didn't have the means to set me up for life. I was more like one of my girlfriends, who had lived with nice parents in a nice house with a nice hired lady to take her to the park to meet me and my lady - until something went wrong and she disappeared into Coastal Center. Whenever my parents scrambled to pay for something unexpected, a part of me saw my freedom hanging in the balance. I learned early that privilege doesn't always last.

The non-disabled world sees powerlessness as the natural product of dependence and dependence as the natural product of our needs. However, for

non-disabled people, needs are met routinely without restricting your freedom. In the gulag, you have no power. The gulag swallows your money, separates you from your friends, makes you fearful, robs you of your capacity to say - or even know - what you want.

The day I visited Coastal Center, I was beginning an interesting career and should have felt that the world was all before me. Instead, worries nagged me. What if there isn't enough money? What if family can't take care of me? Back then, my best hope was to die young. My disability would progress until I needed a ventilator. Then, near the end of my life, I figured, I'd slide into my slot in the gulag.

All it takes to teach me how wrong I have been is about 45 seconds in the company of a man named Ed Roberts.

It's 1979. He's speaking in Arlington, VA.

In the small world of disability rights, he is a star with a famous story. He is paralyzed from the neck down as a result of childhood polio. In his youth, he was denied services by California's Department of Rehabilitation for being too disabled to work. A decade and a half later, he became head of the department. In between, he fought his way into the University of California at Berkeley and, with other severely disabled activists, helped set in motion the disability rights movement, which is now challenging the gulag's right to exist. It is pushing for a shift away from public financing for institutionalization and to public financing for personal assistance, controlled by us. The government should pay for the help we need, and it should not force us to give up our freedom as the quid pro quo. Never was a big star more frail. Physically, his power chair overwhelms him. And there's more. He gets each breath from a machine; his speech follows the rhythms of the ventilator whoosh. With each whoosh, he is changing my worldview.

It's not what he has done. Not what he is saying. Not who he is. It's his presence. Whoosh. His bad-boy delight in truth-telling. Whoosh. His hellcat gusto for proving the world wrong. Whoosh.

He is decrepit and tough and amazingly funny. He is a big state agency head unlike any the world has ever seen. In less than a minute, Ed shows me that I have been wrong about people with vents, just as the non-disabled world has been wrong about me. Whoosh.

A life like his can turn a life like mine upside down. Whoosh. And lives like ours can turn the world upside down -- or maybe set it right side up. Whoosh.

It's 1984. I'm living in Columbia, S.C., 100 miles from my family, taking advantage of new possibilities. Until the Section 504 regulations, disability

discrimination by universities was routine and unapologetic. Now, at the University of South Carolina law school, I am one of six wheelchair users. Five of us use power chairs; without someone's help, we can't get out of bed. As schoolmates strut in power suits, we whir around with book bags hanging from our push handles and make bottlenecks at the elevators. I think of us as a counterculture that challenges the get-ahead Me Decade. Most people, when they think about us, operate under the delusion that we're inspirations.

Between classes, I catch up with Dave, a classmate who is quadriplegic as a result of spinal cord injury. There's a good movie at the student union tonight. Let's go. O.K., and a burger before. Fine. A plan.

Nearly. First we repair to adjoining pay phones to reschedule our afternoons. Each of us grabs a passing student to dial. Busy signal. Try this number. No answer. Try that first number again. Hey, can you do 4 instead of 5? Then another call. No answer. Try this one.

My student dialer has to run. Another takes his place.

Hey, I'm going out. Can we do 10 instead of 9? Do you know where so-and-so is? Hi. Can you unpack my books at 3?

Between us, it takes about a dozen calls.

"Dave," I say, "this is some crazy way to live, ain't it?"

He gives his diffident C-student shrug. "Yeah. When I was injured, I didn't want to live this way. They said I'd adjust, but I wanted to die. Well, you know, the guy I was then, he got what he wanted. He died. I'm a different guy now."

It's a complicated life, to schedule in advance each bathroom trip, each bath, each bedtime, each laying out of our food and big law books, each getting in and out of our chairs. But it can be done. We're doing it. We can do what we want. No need to get anyone's permission. No need to have it documented in any nursing plan or logged onto any chart. No one can tell us no.

We can meet for a burger and a movie if we want.

Every so often, there are efforts to try something different for young disabled people. When Dave and I were in law school, the university got one dormitory licensed as a care facility. Medically, I qualified for placement there, and the promise of around-the-clock aides sounded appealing when I had never lived away from home. Financially, I was too rich for Medicaid and way too poor for the self-pay rate. Dave had Medicaid, but his life had already taught him the value of freedom. The students in the on-campus nursing home helped me learn the same lesson. Even with a good staff and decent conditions, they were robbed of

basic choices. The staff members were controlled by the facility, not by the students who lived there.

I relied mainly on resources available to any student. Because of Section 504, I had access to student housing, transportation and cafeteria service. A small grant from a disability agency, a student loan, work study, summer earnings and a Strom Thurmond Scholarship, of all things, covered the usual costs of law school, plus three and a half hours of help per day from student workers I selected. Sometimes I kicked in a bit extra on the rent to get an especially helpful roommate. It's true that I depended on the kindness of strangers and friends and sometimes wondered how I would hold it together. But always there was some lucky break.

Sometimes the break was a check from Grandmother with a note, "Be prepared a strict account to give." Or, "Squander in riotous living." Either way, she showed that she still rejoiced in my success and also worried about me.

By this time, she also worried about her own place on the edge of the gulag. As age brought disabilities, she got my cousin Mary Neil to move in. Grandmother had enough money to see her through, but not if it had to purchase lots of long-term care. The state's only solution was to make her poor and then foot the big bill for lockup in a nursing home.

The nursing home is the gulag's face for people like Dave, me and Grandmother. That is where the imperatives of Medicaid financing drive us, sometimes facilitated by hospital discharge planners, "continuum of care" contracts or social-service workers whose job is to "protect vulnerable adults." Pushed by other financing mechanisms, people with cognitive disabilities land in "state schools," and the psychiatrically uncured and chronic are Ping-Ponged in and out of hospitals or mired in board-and-care homes. For all these groups, the disability rights critique identified a common structure that needlessly steals away liberty as the price of care.

In 1984, the general thinking couldn't go beyond nicer, smaller, "homier" institutions. With my experience as a high-maintenance, low-budget crip surviving outside the gulag, I offered myself in local meetings, hearings and informal discussions as an independent living poster girl. I explained that certain states, like New York, Massachusetts, Colorado and California, offer in-home services.

But, people said, South Carolina is a conservative state.

I talked up the need for comprehensive civil rights legislation. Extend Section 504's principles to all levels of government and the private sector.

It'll never happen, people said. The civil rights era has passed.

We got civil rights legislation -- the Americans With Disabilities Act -- in 1990. It's a fluke, people said. It won't be enforced.

In 1995, the United States Court of Appeals for the Third Circuit ruled that the A.D.A. bans segregation. Needless isolation of people with disabilities in institutions is segregation. That's a liberal circuit, people said. The Supreme Court will reverse.

In 1999, the Supreme Court, in *Olmstead v. L.C.*, affirmed that needless institutional confinement violates the A.D.A. Fine, but it's just words on paper, people said. The financing still drives us into institutions.

That's very true. But the movement has been treating *Olmstead* rights as if they're real, using the court's legitimacy to demand a wide variety of programs, like in-home care, on-call and backup help, phone monitoring, non-institutional housing options, independent-living-skills training and assistive technology. We're also going after red tape, legal restrictions and the mind-set that says that if you need help, you need professional supervision.

It's the spring of 2002. I'm testifying before a subcommittee of the South Carolina State Senate. Beside me is my friend Kermit.

Kermit calls me his big sister in disability. In fact, he's downright massive and a generation older than I am, but I'm his senior because he became a quad two years after I was born into disability.

The black battery box on his chair sports two stickers. The shocking pink one is from *Mouth*, a radical disability magazine. It says, "Too sexy for a nursing home." "It's true, you know," Kermit often explains. "I did seven years inside. In so long, I felt weird when someone took me out, like I didn't belong. But I was too sexy to stay. I took up with one of the aides and married my way to freedom." That marriage ended years ago, and Kermit no longer has family help, but he will never go back. His other sticker, plain white, says, "Yes 977." He had them printed today. They're about the bill we're here for.

Senate Bill 977 would amend state law to exclude "self-directed attendant services" from the legal definition of nursing. Current law presumes that all hands-on physical care, for pay, is the practice of nursing and must be provided by or supervised by licensed personnel. The nursing profession has jurisdiction over our bodies and decides when to delegate authority. Those who handle us are supposed to get their instructions from a written nursing plan, not from us.

The law hasn't been enforced against self-pay crips like Kermit and me, but federal law requires Medicaid and Medicare to abide by the state nursing law. That means that their beneficiaries must accept whatever comes from a licensed

agency. Agencies typically can't cover Christmas morning, late nights out or many bathroom trips spread out over the day. Because the easiest place to get nursing is in a nursing facility, this law becomes another path into the gulag.

Kermit and I know what works. Through informal networks, we find people to do what we need. Because we are the ones doing the delegating, we are free. Kermit used his freedom for a civil service career; today he uses \$20,000 per year of his retirement savings to pay for that freedom, about half of South Carolina's Medicaid nursing home rate. With family backup, I get by with the irregular income of a solo law practice, stashing money in good years to cover bad ones. Our bill would legalize the way we live. It would also remove a legal barrier so that we can agitate for South Carolina Medicaid to finance self-directed services and make real choices possible.

The subcommittee is bothered about safety. The administrator for the Board of Nursing argues that complications like pressure sores and infections can be fatal. Nursing supervision is needed, she says, to recognize the danger signs.

I wish Kermit were testifying. He has been self-directing very complicated stuff, and he endures, more than 40 years after his accident. He also has a great physical persona. His stillness communicates rock-solid strength. His whiteness - a result of avoiding Columbia's killing sun -- is not so much pale as gleaming. But he doesn't like public speaking. He is happiest finding people in nursing homes with dreams of freedom, helping them make the break. It's underground railroad work, and I'm ashamed to say it's not for me. I still panic when I go into those places. Let me talk to the functionaries.

So I explain our reality to the senators. We learn to recognize our danger signs. We care about our own safety. We can decide when to consult a professional, as non-disabled people do.

And, incidentally -- bad things have been known to happen even when a nursing plan is in place.

Inevitably, the senators look for a middle ground. What if we allow self-direction for "routine" procedures like bathing and dressing, but retain nursing control over "non-routine" procedures like vent care and catheters?

Kermit's craggy face falls. They're talking about fixing the law for me, but not for him -- or for Ed Roberts, who lived on a ventilator, or future me.

I have been advised to sidestep the gory stuff, but here we go. "Senator, if you need a urinary catheter inserted every time you need to go, say three to six times per day, that becomes a routine procedure -- for you."

I sit so low, I can see, under their table, all of the senators crossing their legs. I have their attention.

They question me about procedures involving tubes, needles, rubber-gloved fingers, orifices natural and man-made. I won't flinch. Never mind that Grandmother would consider all of this indelicate. "We know how to do them. And all these procedures are commonly done by unpaid family members. That's entirely legal, and the nurses don't mind. The nursing law isn't about safety and professional qualifications. It's about who can get paid."

One senator is a fundamentalist-Christian Republican, the kind who says that the anti-sodomy laws should be strengthened and enforced. "Ms. Johnson, you've explained why this bill won't put people at greater risk, but I don't understand why you care enough to travel from Charleston to push for it.

"Two reasons, Senator. One is, changing the law will free up resources to meet needs that aren't being met now. With this change, we can push third-party payers like Medicaid to fund more options, make the money go further. Home care in the aggregate costs less than locking people up.

"The other is simpler. I want the legal right to say who comes in my bedroom and who sees me naked -- same as you do, Senator!"

Redness rises from the senator's tie and washes up his face. Once we have him blushing, the others fall in line. The favorable vote is unanimous.

We roll outside. My teal minivan is parked near Kermit's "Freedom Van" -- a white vehicle with controls he can operate with his limp fingers in metal splints.

Kermit stops. "You done good, girlie."

No one but Kermit gets to call me girlie. I sometimes call him Mount Rushmore.

Our bill became law on July 1, 2002, in time for Independence Day. Self-pay people won the right to control our bodies, but getting public financiers to allow the same flexibility is a continuing struggle.

Ultimately, saving ourselves from the gulag will take more than redefinition. It also takes money for in-home services. But in a sense, we're spending the money now -- \$20,000 to \$100,000 per person per year, depending on the state - - for institutional lockup, the most expensive and least efficient service alternative.

For decades, our movement has been pushing federal legislation, currently known as MiCassa, the Medicaid Community Assistance Services and Supports Act, to correct the institutional bias in public financing, especially Medicaid, the

gulag's big engine. We ask, Why does Medicaid law require every state to finance the gulag but make in-home services optional? Why must states ask Washington for a special "waiver" for comprehensive in-home services? Why not make lockup the exception? "Our homes, not nursing homes." It's a powerful rallying cry within the movement. In the larger world, it's mostly unheard, poorly understood. We are still conceptualized as bundles of needs occupying institutional beds, a drain upon society.

We know better. Integrated into communities, we ride the city bus or our own cars instead of medical transportation. We enjoy friends instead of recreational therapy. We get our food from supermarkets instead of dietitians. We go to work instead of to day programs. Our needs become less "special" and more like the ordinary needs that are routinely met in society. In freedom, we can do our bit to meet the needs of others. We might prove too valuable to be put away.

While the movement has been collectively trying to change the world, individuals continue to live and die.

My law-school friend Dave fell into the gulag in the end. A series of events -- a career setback, some acute medical problems, perhaps creeping disappointment -- made him sign into a nursing home. He vanished without telling his friends he was going and died within the year. My little brother Kermit remains free and is using his freedom well.

Ed Roberts died in 1995, free, keyed up about digital organizing among other things. For one, he was planning to get back to Hawaii to swim with whales: a shark sighting had thwarted his previous attempt. He did manage to float with dolphins in Florida. His respirator fell into the ocean, but he always traveled with two.

Most of my friends from Coastal Center are now placed in small group homes. Although they have bedrooms with doors they can close, they work in "special" programs, and they still can't select their own assistants or decide where they live or with whom. After more than 30 years in the system, they probably can't imagine living any other way, but in a way they never had a choice. "Placed" remains the operative word.

Thomas lives in his own apartment and works as a courier in a hospital. Through a waiver program, South Carolina Medicaid pays an agency to get him in and out of bed each day. To cover frequent no-shows, he paid an on-call aide out of pocket for a while, but he couldn't afford to continue. He would like to use Medicaid funds to pay his own people, but state rules haven't yet been changed to allow that. He has taken advantage of programs that have slowly evolved and says he hopes to stay free long enough to have genuine control of his life.

Grandmother died in 1985 and avoided the gulag, thanks to Mary Neil. She inherited the house and lives with her family in the rural community where our family would otherwise be extinct.

When Grandmother died, I thought she might leave me some money -- for riotous living or a strict account to give. She didn't, but I wasn't disappointed. She left me the silver spoons that belonged to her mother. Sometimes I wonder if my great-grandmother missed her spoons when she was locked up. More often I wonder how Grandmother felt when she held her lost mother's spoons and turned them over in her mouth and let her tongue mold itself to their shape.

I use those spoons daily. Their flat handles are easy to grasp. Their deep bowls hold as much yogurt as I can swallow. For me, that smooth silver represents the treasure of living free. Riding in the van I bought, in a hand-me-down power chair I got from Kermit, I hold my freedom precious. I can no longer braid my own hair, but I remain free to keep it long, and I do. My gold bracelet was mangled in a fall a while back, but I still wear it for good luck. I still need all the luck I can get.

I have prospered and know a world I once could not imagine. I sometimes dare to dream that the gulag will be gone in a generation or two. But meanwhile, the lost languish in the gulag. Those who die there are replaced by new arrivals. Powerful interests, both capital and labor, profit from our confinement and fight to keep things as they are. At this writing, MiCassa is stalled in committee. Again. Institutional financing remains nondiscretionary under Medicaid.

It is still possible -- indeed, probable -- that before I die I will become separated from my silver spoons and my gold bracelet and I'll have to get my hair cut for the convenience of the people who staff whatever facility I am placed in.

Even now, I live on the edge of the disability gulag.

Harriet McBryde Johnson has been a lawyer in Charleston SC since 1985 and has been active in the disability rights movement for about 30 years. She frequently writes and speaks on a variety of issues and her memoir in stories (Too Late to Die Young: Nearly True Tales from a Life) will be published by Henry Holt and Company of NY in April 2005. She is former staffer, former client (self-identified), and a current Board member of Protection & Advocacy for People with Disabilities in South Carolina.