

THIS BRAIN HAD A MOUTH

BY JAMES M. ODATO

Lucy Gwin
advocated and
fought for
disability rights.

*Gwin and her dog Millie
pose at a Rochester party in
the early 1980s.*

COURTESY OF CHRIS PULLEYN



In the early 1990s, a handyman constructed a crude wheelchair ramp out of old packing crates. It led to the front porch of the “Mouth House,” the Rochester address of Lucy Gwin, whose home had become a destination for a parade of visitors.

Gwin’s rented flat was the workplace for volunteer writers, many with mobility problems, and the nerve center of Gwin’s magazine, *Mouth*, for and about people with disabilities.

Gwin launched the magazine in July 1990, the same month that President George H. W. Bush signed the Americans with Disabilities Act (ADA). The ADA

mandated the elimination of discrimination against persons with mental and physical disabilities. In the landmark law’s infancy, *Mouth* became a leading voice for disability rights and disability pride.

Thirteen months before the magazine’s debut, Gwin was a 46-year-old writer and advertising professional with little knowledge of the disability movement or the people who had fought to create the ADA. Her years of work in the competitive advertising business in Chicago had been lucrative and successful. She had been promoted for her witty copy about cleaning products, fast food, and breakfast cereals for national brands. But it

Mouth became a leading voice for disability rights and disability pride.

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Lucy Gwin with Emas Bennett and Luis Roman from *Everybody Counts*, the Center for Independent Living serving northwestern Indiana.

TOM OLIN COLLECTION, MSS-294, WARD M. CANADAY CENTER FOR SPECIAL COLLECTIONS, THE UNIVERSITY OF TOLEDO LIBRARIES

Gwin became a leading voice for disability rights, speaking at conferences, covering rallies and demonstrations, and pushing the US Justice Department to prosecute violators of the ADA.

amounted to unrewarding, soul-sapping labor. She wrote to a friend about her plan to “stop lying for a living ... and make the one life I’ve got count for something.”

She had tried alternative lives. She had broken away from the conservative environs of her hometown, Indianapolis. She had moved to the Windy City, spending weekends in the country with hippie friends. Eventually, she quit the Chicago rat race, moved to Rochester with friends pursuing Zen Buddhist study, and, for a time, was a restaurateur. But even her Zen practice didn’t meet her needs. She wasn’t happy.

“I want a purpose in life,” Gwin said. She had closed her restaurant, sold off her possessions, and signed up for adventure in Louisiana. She became a deckhand on large boats serving the oil rigs in the Gulf Coast,

an experience that inspired her memoir, *Going Overboard*, which she hoped would propel a writing career. It didn’t pay the bills. By 1989, she was back in the North, three times married, and still looking for new outlets for her creativity and energy.

Violent Collision

On June 14, 1989, Gwin drove up Lake Avenue, a few blocks west of the Genesee River, with a lot on her mind. She’d been quarreling with her colleagues at the advertising firm she had joined to support herself. As she prepared to turn west, her new red Celica rammed into the front of a car heading south on Lake Avenue. The violent collision threw Gwin around the car. Her head struck several objects in the Toyota’s interior, including the metal post by the passenger window.

That afternoon, Lucy Gwin

joined tens of thousands of United States citizens with disabilities. She was confined to a hospital and then a rehab center for weeks, attempting to recover from serious head injuries. She exhibited difficulty concentrating, walking, and controlling her temper. The mishap also catapulted her to what her life’s work would become, her “mission” as a disability rights activist, protest organizer, and advocacy journalist.

Amid an incomplete recovery from brain trauma, Gwin published a magazine, *This Brain Has a Mouth*, later shortened to *Mouth*. It became a vivid reflection of Gwin. *Mouth* was filled with firsthand accounts of people living in isolation, receiving poor treatment, and having limited housing, working, and travel options. It echoed the angry, tough voice of a person who had no tolerance for greedy or incompetent operators of nursing homes, rehabilitation facilities, and other institutions housing persons with disabilities.

Mouth gave Gwin a platform to rail against the brain injury rehabilitation industry, particularly the corporation running a chain of rehab facilities, called New Medico. In letters to state and federal regulators and investigators, she called for inquiries into what she framed as the company’s corrupt practices. She had been transferred from a hospital to New Medico’s Cortland, New York, facility and for several weeks felt like a prisoner. She described her care and treatment as nearly non-existent and the facility as a sham to shake down insurers. “Admit

David Axelrod, M.D.
Commissioner

OFFICE OF HEALTH
SYSTEMS MANAGEMENT
Raymond Sweeney
Director
Norman S. Andzrejewski
Area Administrator

September 27, 1990

Lucy Gwin
61 Brighton Street
Rochester, NY 14607

Re: #S90-3-5-X
NEW MEDICO REHABILITATION AND
SKILLED NURSING FACILITY OF
CORTLAND

Dear Ms. Gwin:

On March 2, 1990, this office received notification of complaint regarding the New Medico Rehabilitation and Skilled Facility of Cortland. In your letter, you expressed a number of allegations regarding inadequate resident care in the areas of control (MHSA), physical therapy, rehabilitation, resident right of quality of life, etc.

This office initiated an unannounced investigation on 1990. Our survey team consisted of nine surveyors with expertise in areas of nursing, social work, therapies, environmental health survey continued through March 15, 1990.

During our review, forty-three (43) active medical records were reviewed. The facility was also toured and discussions were held with residents and staff. We also held a session in which we solicited the views of visitors and the general public.

Based upon our survey, this facility was deemed to meet minimum compliance standards for the Medicare and Medicaid program. This facility was also issued a list of negative findings, which included areas of quality of life, physical environment and infection control. We will ensure that appropriate corrective action is taken.

Thank you for bringing your concerns to our attention. If you have any questions, please contact Raymond B. Sergott, Compliance Coordinator, at (315) 426-7666.

Sincerely,

Lawrence T. Spöner
Lawrence T. Spöner
Long Term Care Program Director

LTS:rjf
1364F

them when there are beds to fill, discharge them when their insurance money runs out," she said in a speech called "Whose rehab is it?" for a meeting sponsored by the JMA Foundation and the National Brain Injury Research Foundation. She felt she was being held hostage and had no agency over her care. After persuading a friend to get her out, she returned to Rochester to begin her anti-New Medico crusade.

Before long, the FBI began probing New Medico and Congress convened hearings to look into the brain injury rehab industry. Gwin fed information to the FBI and supplied testimony to Congress. She and a few others began a suit against New Medico, and the company dismantled its brain trauma facilities, eventually selling them off.

Leading Voice

Gwin became a leading voice for disability rights, speaking at conferences, covering rallies and demonstrations, and pushing the US Justice Department to prosecute violators of the ADA. She built her subscription base to about 5,000. The magazine was distributed among independent living centers and other places where persons with disabilities gathered.

She branched into covering issues of concern for all people with disabilities, not just the brain-injured on whom she first focused her attention. In the pages of her magazine, she reported about the civil disobedience spreading across the nation. She stood with these demonstrators—people in

wheelchairs, blind persons, and others with disabilities—who marched or surrounded buses, office buildings, or statehouses to call for laws and policies that gave them more freedom, such as Medicaid funding that allowed them to live and receive services in their own homes rather than in institutions.

Mouth House

At a time before the internet and email, *Mouth* got the word out about upcoming demonstrations. At these "actions," organized by the group American Disabled for Attendant Programs Today (ADAPT), people locked their wheelchairs to structures or blocked entrances to pressure lawmakers, often getting arrested in the process. Gwin not only covered the events, she participated.

As her apartment in Rochester became a destination for activists and leaders in the movement, it

became known as the Mouth House. The second-floor flat was like a command headquarters in a war. There, amid stacks of books, piles of paper, and thick cigarette smoke, Gwin and a staff she recruited assembled the bimonthly magazine and planned new ways to battle the enemies of their cause.

The issues were filled with sharp attacks on anyone considered a foe, whether a politician or a celebrity. *Mouth* blasted Jerry Lewis and his telethons to raise money for the Muscular Dystrophy Association for portraying wheelchair users as people to be pitied. She castigated Tommy Olmstead, the head of the Georgia Department

Your invitation to crash the gate at Jerry's place

FROM BILL BOLT

Here it comes again, Jerry Day. It is only right that it be on Labor Day, since watching the Telethon is like 26 hours in labor. I want to see you all in front of the Sahara Hotel at about the time the Telethon begins. Let's make it a be-in at sunset—maybe a little later to avoid being cooked by the desert sun. It's like daylight on the strip all night. If you are there the cameras will be there. I'm convinced we will get network and CNN coverage, so the more action the better. Who am I to say that? I'm not just a writer with a pretty face. I've been in jail ten times and arrested twenty. I planned (and had to fight the Bay Area Establishment) to carry out the civil disobedience that shut down the San Francisco cable cars. That got plenty of press coverage.

Let's not do this Las Vegas action like a paternalistic thing where I or someone else arranges everything. Let's just show up. On your own, book a flight as far in advance as possible to get the discount rate. Come in a little ahead so the flights aren't booked or too expensive. Maybe stay a day later to enjoy yourself at cheap after-Labor-Day rates. Reserve your own rooms close to the Sahara (or in the Sahara). You can get all your info from local travel agencies for nothing. Just let them book you in when you've made your choices.

Rooms will cost more during the two days of the holiday, but no more than ADAPT paid recently for rooms near Washington, D.C. And in most hotels the price is the same no matter how many you put in a room. In Vegas they figure this way: the more people, the more gamblers. Right before and right after the two-day Labor Day holiday, room prices tumble to preposterously low rates.

Hey, why not stay in the Sahara itself. I know it's sorta rewarding evil, but you can bring a nice suit if they won't let you into your own room before, during, or after the demonstration.

You might wear pins from Jerry's Orphans (\$2



Last Labor Day Bill Bolt scouted the territory. Now he invites you to this year's action.

each from Cris Matthews, 754 W. Belden, Apt 3, Chicago IL 60614), the ones with a cartoon of Jerry inside a circular "No" symbol. It's free speech, isn't it? You're not disturbing anyone, are you? You might even mill around the flight of stairs and the escalator which are the only ways to get into the Telethon. Those escalators and stairs are right next to each other and rise from the left rear of the gambling casino as you enter the casino from Las Vegas Boulevard.

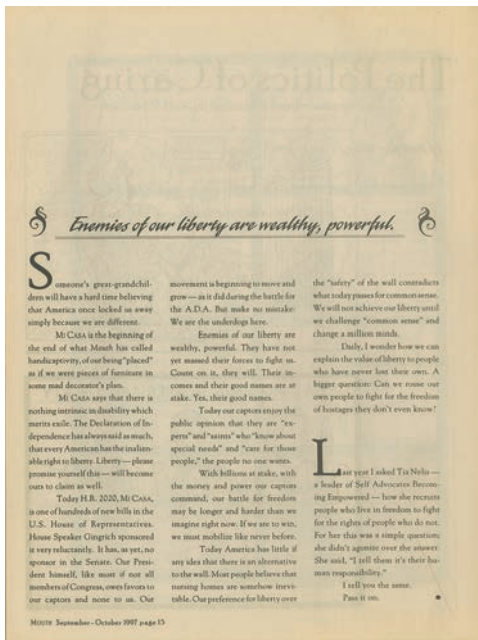
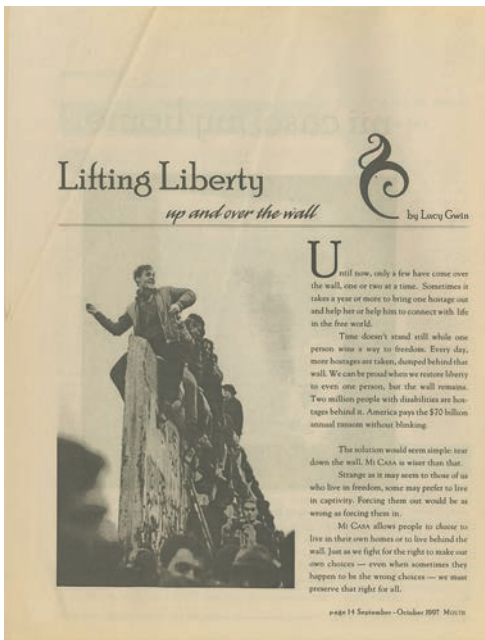
Let me repeat: the only way to attend the Telethon is up an escalator or up some stairs. The telethon is wheelchair inaccessible. It has been wheelchair inaccessible for as long as it has been at the Sahara. If that doesn't make you mad—even if you have some sort of sick infatuation with Jerry—I do not know what will make you mad. Think of it. They have been raising all of this money, supposedly for us, and we can't even get into their lousy fundraiser.

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Left: Gwin called for inquiries into what she framed as corrupt practices at rehab facilities run by New Medico.

Right: Mouth was critical of Jerry Lewis and his telethons to raise money for the Muscular Dystrophy Association.

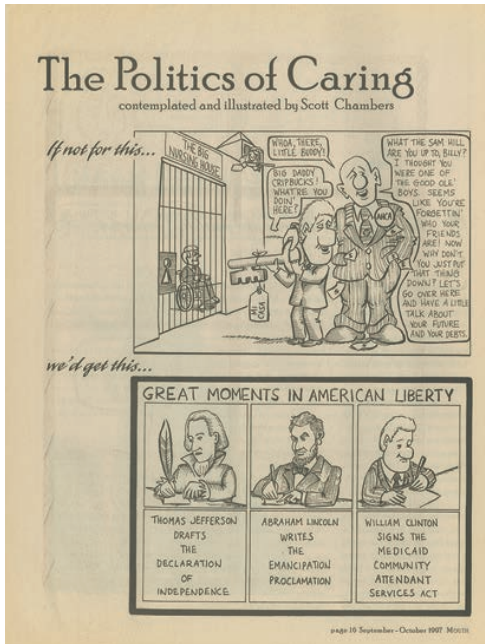
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The magazine was packed with powerful photographs by longtime staff photographer Tom Olin and with funny, pointed cartoons by such artists as Scott H. Chambers, who made the slights endured by disabled people the subjects of graphic statements.

of Human Resources, after two women sued him so they could obtain services for their disorders in the community and not in institutions. Their suit went all the way to the Supreme Court. She demonized Dr. Jack Kevorkian for assisting people in ending their lives, which Gwin saw as a way to rid the world of people with disabilities. *Mouth*, which Gwin dubbed "the voice of disability nation," also featured leaders in the disability rights movement, including Ed Roberts, a founder of the independent living movement aimed at giving people with disabilities equal access to community living; federal policymakers such as Evan J. Kemp Jr., former head of the Equal Employment Opportunities Commission; and Justin Dart Jr., who had fought to create the ADA. Dart, considered the father of the landmark act, praised Gwin and called her magazine "the world's leading public media voice" for democracy. Gwin planned each edition around themes, such as unfair educational and employment opportunities, but always tied them to civil rights. And the coverage included criticisms of indifferent caregivers and providers. She brought up issues on the minds of her readers, including loneliness and sexuality. Her covers featured Black people, lesbian lovers, and children with deformities. She advanced "disability pride" and tried to topple society's notion of "normal." *Mouth* articles were often written by non-journalists. For example, a young girl named Eleanor wrote about discovering

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that a bath wouldn't wash away her Down syndrome.

The magazine was packed with powerful photographs by longtime staff photographer Tom Olin and with funny, pointed cartoons by such artists as Scott H. Chambers, who made the slights endured by disabled people the subjects of graphic statements. Gwin used her advertising background to balance graphics and text to hook readers and deliver news on matters that were receiving little or light coverage in mainstream journalism.

Gwin moved the Mouth House twice, first to Topeka, Kansas, to be in a community with a strong center for independent living and to partner with its leader. Her final move took her to Washington, Pennsylvania, where she hoped to find a still better arrangement with a center and its hard-driving founder.

Always challenged to keep her anger in check, Gwin won and lost friends along the way. But she left a trail of admirers, among them Dart, who listed her as one of the influencers who helped fuel his activism.

Dart and Kemp, who had flanked Bush outside the White House when the president signed the ADA into law, joined Gwin in Washington, DC, when she organized a major demonstration outside the Supreme Court on January 8, 1997.

The court heard arguments that day in favor of the constitutional right to physician-assisted suicide. Gwin organized activists to voice their opposition in the cold air of the nation's capital in a vigil, chanting "we want to live." She partnered with

the organization Not Dead Yet to design its signature logo. She printed a special issue of *Mouth* in attempts to bolster attendance and included a mailer for people to fill out and return to her home, the Mouth House in Rochester, urging them to become "heroes" whom she defined as people who are "awakening communities—soon the whole nation—to the fact that people with disabilities are full human beings, that we are leaders, that our lives are valuable too."

The magazine lasted for eighteen years. Its 102 issues documented the disability rights movement during the ADA period and formed the legacy of a woman whose disability helped her find her calling. *Mouth* ceased publication in 2008 as Gwin struggled with her health. The final issue includes a photo of Eleanor, the student with Down syndrome who had written in an earlier issue, in a graduation robe holding up her mortarboard, smiling. Gwin died in 2014 at age seventy-one after years of deteriorating respiratory function.

To this day, the magazine shows up here and there, such as at organizations serving persons with disabilities. "I still have every copy of *Mouth* in my office," says Teresa Torres, executive director of Everybody Counts in Merrillville, Indiana, "to remind myself what this movement is all about." ■



For classroom activities related to this article, see our Educator Guide at <https://considerthesourcenry.org/magazine-educator-guides>

THE ARCHIVES CONNECTION

This Brain Had a Mouth, Lucy Gwin and the Voice of Disability Nation by James M. Odatu was published by the University of Massachusetts Press in October 2021.

The papers of Lucy Gwin, available at the University of Massachusetts at Amherst Libraries Special Collections & University Archives, served as the backbone of this work. The archives contain letters, partial works of fiction, proposed memoir manuscripts, song lyrics, poetry, journals, and notes by Gwin, as well as every issue of *Mouth* magazine. The author obtained important augmentation—access to back issues of Rochester newspapers, alternative presses, and books on the disability movement—from libraries in New York, including microfilm and digital files at the Rochester Public Library, Union College, and the University at Albany. Also, documents supporting the research, such as business records and civil filings, came from the Monroe County County Clerk's Office. An investigatory file on the New Medico probe at a repository of the Federal Bureau of Investigation in Virginia, which included New York-related material about New Medico, provided significant support and offered leads to sources.

The New York State Archives has recently awarded a Documentary Heritage Program grant to the College of Staten Island/CUNY for a project that will bring together multiple local stakeholders interested in understanding, preserving, and making accessible the overlapping histories of disability-specific movements and advocacy organizations that emerged after World War II and into the 1980s.



For more about the history of people with disabilities in New York State, see "...to Speak of Myself to Others" by Sheila Edmunds, Winter 2003.