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Funding social change since 1967

RESIST

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A Call to Resist Illegitimate Authority

May 1998

"Free our People"

ADAPT Demands Access to Justice

STEPHANIE THOMAS

American Disabled for Attendant Programs Today (ADAPT) of Texas has waged three simultaneous campaigns seeking justice for people with disabilities. ADAPT sponsored legislation known as MiCASA designed to allow attendant care services for disabled individuals who are currently "locked up" in institutions such as nursing homes. Secondly, for several years ADAPT has pressured Greyhound to comply with the Americans with Disabilities Act (ADA) by providing adequate lifts, ramps and services. Finally, ADAPT has begun a campaign to force Housing and Urban Development (HUD) to comply with ADA requirements by making public housing available for persons with disabilities.

MiCASA is My Right

ADAPT's activism for a national attendant services program has taken a decidedly legislative focus in the past year. Yet throughout the process, ADAPT has maintained its grassroots flare. In fact, direct action is sometimes the only way to address legislative [in]action.

What are we talking about? Well after targeting the (then) most powerful person in Congress for several actions, on the eve of the 1996 elections, House Speaker Newt Gingrich promised ADAPT he would introduce a national attendant services bill.

The bill would give people choices besides institutions and start to end the nursing homes' stranglehold on Medicaid long term care funding. At the same time Alexis Herman, representing the White House, flew in to meet with ADAPT and promised support from the Administration in addressing this problem.

By June of 1997 there had been many meetings, but ADAPT felt things had bogged down in a rut.

So we decided to apply our most effective

cure: we organized a two week "siege" of Washington, DC. Hundreds of ADAPT members came the first week and took on the White House, demanding attendant services instead of lip service. We then took the same message to Alexis Herman at her new job as Secretary of the Department of Labor and won a meeting with the President himself in September.

The second shift of hundreds of activists from across the nation arrived and continued the barrage: Gingrich was far from let off the hook. When his staff tried to placate us with faxed versions of a bill, we



ADAPT members march from the Rayburn House Office Building in Washington, DC, on November 1997 after winning a date for hearings on MiCASA. Photo courtesy of ADAPT

decided to wait him out in the Capitol Rotunda on the date they had promised to introduce legislation. As the day wore on ADAPT's troops ringed the room and security grew more and more tense, eventually closing the building. In a show of good faith, ADAPT finally sent a group to help craft the legislation. As they wrote late into the night, ADAPT continued its vigil in front of the Rayburn building. Around midnight the group emerged with MiCASA, the Medicaid Community Attendant Services Act, in hand.

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MiCASA, is a very simple concept. It would take the existing Medicaid entitlement programs for nursing homes and Intermediate Care Facilities for the Mentally Retarded (ICF-MRs) and make them more flexible and consumer-responsive: those eligible for a nursing home or ICF-MR could choose to have the dollars that currently fund these programs pay for services in such a facility—or could use these funds to pay for Qualified Community Based Attendant Services. The money would follow the individual.

The long term care system in this country is strongly biased toward institutions. Every state that receives Medicaid is required to fund nursing home services; there is no requirement for community-based services, though states can choose from a variety of optional programs and waivers. The vast majority of funds—roughly 80%—go to nursing homes and ICF-MRs, while 20% pays for *all* community-based services. It is no secret that the vast majority of people prefer exactly the opposite, namely, services in the community.

Demanding Action

When fall rolled around ADAPT was back at the Capitol to continue the fight. After six months of Congressional inactivity on MiCASA (introduced as HR 2020) ADAPT returned to the Rayburn building. This time we targeted the Chair of the Health and the Environment Subcommittee Michael Bilirakis, packing his office with interested members of the public. Hundreds and hundreds more ADAPT folk lined the halls of Congress, waiting for this Subcommittee to schedule a hearing. We were initially told that scheduling a hearing was “impossible.” However, after a few more hours of occupation, a staffer walked from hall to hall reading the commitment to hold the hearings in March as the crowds cheered!

ADAPT made a “house call” to the Congressional Budget Office (CBO) to cure another MiCASA problem. The CBO had sloppily painted MiCASA with a doom-day overtone. In protest, wave after wave of ADAPT folks rolled in the building and up the banks of elevators to the spacious offices of the faceless government bureaucrats. Several of us rolled right into the Director’s office as she sat at her desk. CBO officials were quite taken aback, but after

an hour or so of wading through wheelchairs and listening to the effect of their slipshod work on real people’s real lives, they agreed to take another look at the issue.

Less dramatic but very important has been the dramatic growth of the MiCASA supporters, national, state and local groups



ADAPT lined the walls of the Rayburn Office Building waiting for Health and Environment Subcommittee to commit to a hearing date for MiCASA.

from around the country which have pledged their support for MiCASA. From August of 1997 to March of 1998 the list has grown from roughly 80 organizations to almost 400. Periodic national activities allow these groups to coordinate their efforts in support of MiCASA. Perhaps the most successful of these was the Valentine’s Day action. Supporters from across the nation sent valentines to Congresspeople, telling them that home is where the heart is and calling on them to give folks the choice to live at home. Groups closest to DC made visits and delivered giant valentines in person.

The MiCASA supporters also helped to give the March hearing a grassroots flavor. More than 300 observers turned out, along with written testimony from those who knew first hand the impact of forced institutionalization on their lives. The written testimony became part of the Congressional Record of the hearing.

ADAPT does not plan to stop here. We

are now calling for Field Hearing for HR 2020, so that members of the Committee can hear from the literally millions of people across the nation who will be affected by the lack of choice in long term care during their lifetimes. We will be in Memphis in May to announce the 10 worst states for attendant services and we will continue to press until real choice in long term care is a reality.

Riding the Dog at Greyhound

Greyhound claims that they do not need to put lifts on their buses, that they serve people with disabilities “just fine” without them. In addition, they claim they are complying with the ADA. However, the results of a “test” by ADAPT activists show that, over seven years after the ADA was enacted, the level of service Greyhound offers can only be described as disgraceful. (See box on page three for test results.)

Though the industry has long used cost as a reason not to provide access to buses, the Department of Transportation found that inter-city passenger trips cost about 38 cents per passenger. For comparison

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purposes, the average per passenger ticket price is \$33.

On Friday, March 20, 1998, Department of Transportation Secretary Rodney Slater proposed regulations which would require all newly purchased over-the-road buses (OTRBs) to be accessible by 2012. "The Americans with Disabilities Act envisioned transportation which is accessible for all citizens," said Secretary Slater. "Under this proposal, the words 'now boarding' will truly mean, 'Now boarding everyone.'" Slater pointed out that OTRBs are an important link to our national transportation system. This is especially true for those with low incomes or living in rural areas, many of whom are people with disabilities.

There's No Place Like Home

Attendant care has been a consistent demand from people with disabilities. So has accessible housing. The majority of people with disabilities fall into the low-income category, with many receiving only a small disability income. For those who need public housing, the choices are limited, or non-existent. Although Housing and Urban Development (HUD) has been required to make accessible units, they have not followed through.

ADAPT pressured HUD officials in Austin, Texas to comply with the ADA and won. The bottom line of Austin ADAPT's major housing victory: it was pretty damn easy. Organizing for accessible housing may take a while, but other local groups can win pretty damn easily, too. Here's how:

1) Demand a list of all the housing projects of any kind that a city/county/state has done using any HUD funds, since 1988. Ask which HUD funding program(s) was used for each project. If you are having problems, use the freedom of information act or do a mini-action in their office. A group of folks occupying the office will usually grease the process.

2) Then just drive/roll by these places and see if there is any sign of access work having been done. Look for the obvious signs of inaccessibility: a step at each apartment door, no handicapped parking spaces, "regular" doorknobs and peepholes, etc. You don't need to go into people's homes with a tape measure or anything like that.

3) If they aren't making places accessible file a complaint with HUD. Just send them a letter listing the problems you saw,

"For us this is not a matter of developing policy, it is a struggle for our lives and the lives of our friends and colleagues."

**—Mike Auberger, ADAPT Member
testifying before the
Congressional Subcommittee**

the addresses, and names of the complexes. The Austin complaint took over a year, so you might want to do step 4 too.

4) Take over the city CDBG office and/or local HUD office. Have a set of demands about setting aside some of their community development funds to make people's inaccessible apartments and homes accessible. HUD has sent out information nationally about an architectural barriers removal program, so give them a hard time if they act like they never heard of the concept.

5) You can do a lawsuit too. It will take a long time, as will the complaint (but we

need to build up a pile of complaints at HUD because they say they don't get many complaints.)

Activists in ADAPT continue to put on the pressure for justice for people with disabilities. Free our people!

Stephanie Thomas is co-director of ADAPT of Texas. ADAPT received a grant from Resist in 1998. For more information, contact ADAPT, 1319 Lamar Square Drive #101, Austin, TX 78704; www.adapt.org. To order a HUD complaint packet, send \$2 to ADAPT.

Greyhound Fails Activists' Test of ADA Compliance

Last September ADAPT members made 41 trips on Greyhound Lines to test the level of service and compliance with the Americans with Disabilities Act. Of those who rode:

- * 36% had to get help from non-employees when Greyhound employees would not or did not know how to assist
- * 25% were dropped or otherwise hurt being "helped" on and off the bus
- * 18% sustained damage to their wheelchairs
- * 22% of the riders were asked to reschedule their trip for the convenience of Greyhound, rather than when they needed/wanted to travel
- * 58% whose buses stopped at rest stops were not given help to get off at the rest stops (Restrooms on the bus are not accessible)

At Greyhound stations, testers found inaccessible entrances, restrooms, toilet stalls, phones, water fountains.

Nearly 60% of all testers were treated rudely by Greyhound personnel. They hear, "People like you should not ride the bus," and "we don't know how to handle your kind of people." One tester, who was deaf, could never get an answer from the Greyhound ADA-TTY assistance line.

"These tests are the mere tip of the iceberg," said ADAPT. They "represent a widespread failure by Greyhound to meet either the spirit or the letter of the law."

Nearly one-third of those involved in the test were simply refused rides by Greyhound—the company either refused to honor tickets already purchased or said flatly that they'd be unable to accommodate the tester, or told the tester to reschedule another time to ride.

More than one Greyhound station who did take riders in wheelchairs called "911" for assistance in getting the rider on or off the bus.

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“On A Roll” for Disability Rights

Pushing Civil Rights Into Mainstream Media

GREG SMITH

For most of our history, people with disabilities have perceived our conditions as personal problems that we have dealt with individually. The concept of equal rights for people with disabilities is relatively new. The awareness of disability, not as a diagnosis of medical condition, but as a lifestyle and as a culture is growing rapidly. People with disabilities are beginning to see themselves as a natural part of the beautiful diversity that is human life. This new self-perception is exponentially increasing the number of participants in the disability rights movement.

By replacing the barrier of shame with the addition of pride, people with disabilities are making an empowering connection. This new self-definition is one of three major forces that are impacting a bright future for our movement. The other two forces—the explosion of informational resources and the rapidly increasing labor shortage—give the disability rights movement an opportunity for progress in the new millennium. But there is one key ingredient to social change that the disability rights movement must acquire to expedite progress: access to the mainstream media.

Media and Change

Activists in the struggle for civil rights for African Americans taught an important lesson about the power of media. For example, by utilizing the medium of television to document the events of the March on Selma, organizers made the racist actions too close and real for society to ignore. Through the relatively new medium of television, which was at its zenith of popularity, civil rights organizers propelled their activism on to a new level of public awareness. Today, the relatively new mass medium of the Internet can enable the disability rights movement to ride an informational wave of its own.

The Internet and its thousands of web sites dedicated to resources and information for people with disabilities provide vital knowledge. Also for disabled activists, E-mail lists have become the disability



A girl shows her pride during a Disability Pride March in Boston, Massachusetts in 1997. Photo by Ellen Shub

newswire service. One message on the right list ensures that news and action alerts get spread throughout the Internet community in minutes. Every legislative consideration flashes across the screens of thousands of disability rights leaders on a daily basis.

This ease of communication has led to some very effective activism. In July 1997, American Disabled for Attendant Programs Today (ADAPT) utilized their e-mail list to organize the most successful concurrent nationwide action in its history against Greyhound Bus terminals. Since then, ADAPT has continued to utilize the list to educate activists about the progress of their struggle for home- and community-based attendant services legislation.

Other lists keep the movement abreast of the full scope of issues. Justice For All delivers legislative updates in a timely fashion and elicits necessary advocacy. The GnarlyBone News collects news and resources and also promotes disability arts and cultural items of interest.

Raising the Volume

These “cyber crips,” while informed and on the cutting edge of the disability rights

movement, are but a subset of the millions of people affected by disabilities. Reaching out with mainstream broadcast media is a prerequisite for the popular impact that we seek. Unfortunately, television is much different today than it was during the struggles of the 1960s. Programming is more narrowly defined, and ratings and revenue drive a competitive industry that is slow to accept appearance diversity. Therefore the firsthand reporting of the injustices of the day are left to other media to cover from time to time.

One media voice that is swimming upstream is “On A Roll—Talk Radio on Life & Disability.” This is the only nationally syndicated commercial talk radio program on disability issues. It airs on talk radio stations that also broadcast conservative talk radio voices like Rush Limbaugh, G. Gordon Liddy and Oliver North. These stations also carry local talent that is in congruency with the political viewpoints of their syndicated cornerstone programs.

So in general, commercial talk radio would not seem to be a friendly place for a progressive civil rights voice. Yet, “On A Roll” is making progress. Since it became syndicated in February 1997, it has grown from one locally produced show in the Phoenix market to a network of 18 radio stations across the country. Its most recent affiliate additions are 50,000 watt stations in Dallas, Texas (Talk 1190 AM) and Atlanta, Georgia (WCNN 680 AM). Promotions air during the week in the middle of Limbaugh’s show inviting listeners to hear a different perspective. It’s done with an inviting and sassy attitude. Its style is frank and flip. It has a chance to fill the vacant position of a weekend standard for talk radio. Currently, weekends represent a problem for commercial news/talk program directors who want programming that can generate revenue but don’t want to pay the salaries of local talent.

Why are radio stations so far to the right airing the voice of a disability rights activist? Economics. “On A Roll” is riding the wave of the third major force that, combined with the change in our self-percep-

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tion and the information explosion, make the climate right for significant progress. The third major force is the increasing labor shortage that is facing American businesses.

With unemployment at an all time low of roughly 4%, people with disabilities remain unemployed at rates near 70%. For radio stations, a program that enables corporations to recruit from this large pool of potential talent means advertising dollars to the station, not to mention the increase in their cumulative audience from disabled listeners and their families and friends. It is a classic example of turning a negative, our unemployment rate, into a positive. Part of social change is economic freedom and a program that promotes job openings to an underemployed segment of the population, that in the meantime creates awareness about the full-scope of oppression is innovative advocacy.

"Let's go to New York City and talk to Bob on the line, who is having trouble with his HMO. Bob, welcome to "On A Roll." You've got an incredible story."

"Thanks Greg, well what's happening is my HMO has informed me (breath) that they have denied paying for my backup ventilator. (breath) If my ventilator breaks, I only have 10 minutes until I die. They tell me to call 911, but I can barely talk without using it (breath) so that would be completely useless."

Or on another Sunday: "Did you know that here in Arizona, the motor vehicle clerk can make you take a driving test or get a medical clearance based just on how you look? If you walk funny, use a chair, hold the pen differently, they can make you take a road test? Or get a medical exam? That's discrimination! Let's go to the phones. Dan from Portland, what do you think about that?"

Caller: "I don't think that's bad. It's keeping the roads safe."

"OK, so the kid who walks flawlessly and fills out his paperwork neatly, then goes out to his car and fires up a joint, he's someone you'd rather have on the road?"

Caller: "Now you're being ridiculous. If a person is severely disabled, so much so that driving isn't safe, the state should do whatever it can to keep 'em off the road."

"But if his driving record is clean-no tickets, no points against his license—I don't care if he has to crawl up to the clerk, he

shouldn't have to go through any more hassle than anyone else."

Caller: "But you have to admit that disabled drivers are not as safe as other drivers . . ."

"I think disabled drivers are better than nondisabled drivers. Our equipment gives us better control, we know our limitations better, and we drive more defensively. We gotta move on. More "On A Roll," right after this . . ."

Filling the Room

While the disability rights movement has thrived for more than 20 years on the passion of thousands of staunch activists, those involved with the movement are but a small percentage of the massive disabled population. The late disability rights leader Evan Kemp, who was Chairman of the Equal Employment Opportunities Commission (EEOC) under the Bush administration and a key writer of the Americans with Disabilities Act, once commented that the entire movement could fit into one room.

Unfortunately, this has been a very true assessment of those actively involved in creating social change for a people now projected to be over 52 million strong (US Census, 1994 projections) in America. But changes that come with a new millenium mean momentum and empowerment for people with disabilities.

The oppressed revolt only if they are aware of their oppression. Most of the 52 million US citizens with disabilities don't fully understand the oppression that faces them as a class of people. Rather, they understand that life is tough for them individually, often ignoring or making excuses for the failures of social systems to provide equal access and opportunity for a full life.

Mainstream broadcast media offer an opportunity to spread this message, and for the disability rights movement to build its numbers beyond those who could fit in one room by creating awareness of our struggles, common bond, and opportunities for economic freedom.

Greg Smith is the founder of "On A Roll Radio." He has had muscular dystrophy his entire life and rides a power wheelchair. For more information, contact him at greg@onarollradio.com; (937)767-1838.

Resources for Disability Activism

ADAPT

<http://www.adapt.org>
PO Box 9598
Denver, CO 80209
303/333-6698

Dendron

<http://www.efn.org/~dendron>
Support Coalition
PO Box 11284
Eugene, OR 97440-3484

Disability Rights Action Center (DRAC)
2757 South 300 West Suite B
Salt Lake City, UT 84115
DRACHQ1@ibm.net

Disability Rights Activist

<http://www.teleport.com/~abarhydt>

Disability Rights Education and Defense Foundation (DREDF)

<http://www.dredf.org>
2212 Sixth Street
Berkeley, California 94710
(510) 644-2555 (Voice/TDD)

Justice For All

jfa@mailbot.com
<http://www.mailbot.com/justice>

Mothers from Hell

<http://www.apexcomm.net/~debiski/mfhhome.html>
P.O. Box 21304
Eugene, OR 97402

Mouth: Voice of the Disability Nation

61 Brighton Street
Rochester, NY 14607-2656
(See Not Dead Yet for URL)

Not Dead Yet

<http://www.acils.com/NotDeadYet>
Progress CIL
7521 Madison Street
Forest Park, IL 60130
(708) 209-1500, TTY (708) 209-1826

Ragged Edge/Electric Edge

<http://www.ragged-edge-mag.com>
P.O. Box 145,
Louisville, KY 40201

Reviewing *Altered Selves*

BELL GALE CHEVIGNY

Staring Back: The Disability Experience From the Inside Out

Edited by Kenny Fries. Plume. 414 pp.
Paper \$15.95.

Gloriously free of self-pity, piety and cant, *Staring Back: The Disability Experience From the Inside Out* combines nonfiction, poems, stories and plays by thirty-eight disabled writers. Established figures like Lucy Grealy, Marilyn Hacker, Ved Mehta, Larry Eigner and Stanley Elkin join little-known writers. "How Much It Hurts," David Mix's story, is a knockout; a raucous adventure—amputees from a veteran's hospital raid a draft counseling center to piss on files—ends in a passionate reflection on war. Some write about famous physically impaired figures: Marc O'Brien interviews Stephen Hawking; Anne Finger imagines an encounter between Helen Keller and Frida Kahlo. What they share is a vigorous commitment to voicing their own idiosyncratic perspectives.

The disability rights movement may be advancing despite cutbacks, but consciousness of disability experience has barely gotten off the dime. As Kenny Fries notes in his introduction, Western culture has generated a succession of compelling types—the demonic cripple (Shakespeare's Richard the III, Melville's Ahab), the charity cripple (Dickens's Tiny Tim), the outcast (Carson McCullers's and Nathaniel West's creatures) and the survivor (Bellow's Einhorn). Playwright Victoria Ann-Lewis brought disabled writers together to explore some of these types. The result was the play *P.H.*reaks: The Hidden History of People with Disabilities*. The "Physically Handicapped" move in this Brechtian revue from being displayed by church and circus (and later telethon) to being concealed and classified by hospital and state, to finding active self-definition and social redefinition in the disability movement. In a climactic scene 200 demonstrators in San Francisco, demanding implementation of the 1072 Rehabilitation Act, occupy a Federal Building for twenty-eight days. They discover mutual dependence—"everyone was acting as an attendant"—and accep-

tance: "I'd never felt so safe and powerful in my life. It was so—well—people fell in love. I'm not kidding."

The passage of the Americans With Disabilities Act in 1990 registered a shift in meaning: No longer figured as loss or deviation from the norm to be compensated for, disability is considered a physiological variation, to be accommodated by environmental adjustment. People with disabilities are repudiating the "medical model" of disability that pathologizes difference. In this model, the person either overcomes the impairment—like F.D.R.—or is overwhelmed by it: success is measured by emulating the "able-bodied" and mimick-

stripped of any condescension they may harbor, even unwittingly. Intrepid, intergalactic travelers, voyagers in uncharted waters, they bring back, in language tailored to the emergency, news of exotic and hazardous regions, places that many of the nondisabled will visit.

One major theme is the individual's adaptation to impairment, which is often the discovery and creation of a world. Some poets induct us into sensory universes. Take Edward Nobles's "Heart Ear":

To half hear
is to be without direction. Everything
moves toward you from the right.
Even a lover's kiss, on the earlobe of the
left, is felt, but slightly; the alluring
breath
streams around the head and enters at
the other end of night.

The disability rights movement may be
advancing despite cutbacks, but
consciousness of disability experience has
barely gotten off the dime.

ing the hearing, while failure means child-like dependency. Fries prefers a model in which society itself is disabling, its structures defining—and denying full participation to—physically impaired people. This "social model" frees people with disabilities to fight against external definition and for their rights, in the process finding themselves in a vibrant community.

It is this model that informs Lynn Manning's poem "The Magic Wand": "Quick-change artist extraordinaire,/I whip out my folded cane/ and change from black man to blind man/with a flick of my wrist." To account for his "profound metamorphosis—/. . . From rape driven misogynist/to poor motherless child," the poet says, "I only wield the wand;/You are the magician." Summoning contradictory magical responses to two social designations ("race" and "disability"), Manning's poem "stares back," jarring nonblack, sighted readers into reflecting on their assumptions.

Most contributors here deploy neither the medical nor the social model—both are external and objectifying—as much as their own subjective reality. Readers should be

Stephen Kuusisto shares his "Harvest" with the sighted:

My Chinese doctor tells me to sit in the
park, that green,
the very color, will forestall blindness,
and so I sit
under the Hemlocks planted by Baptists.
My temporal task is to hear music,
drink a cup of chrysanthemum tea,
admire the white moon of the morning,
even if my eyes tell me there are two
moons.
It's almost a game: this superstition,
my slow idolatry of leaves,
the sparrows hopping as if on fire.

Other writers are consumed by the psychodynamics of identifying with the altered self. In "Falling Into life," Leonard Kriegel recalls his terror during his polio rehabilitation program of learning to fall and his joyous mastery of it. Falling well protected him not only from physical hurt but from being overwhelmed by a future remote from the "normal": "Learning to fall was learning that most essential of American

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lessons: How to turn incapacity into capacity," he writes, and losing the use of his legs helped him envision "a strange but potentially interesting new self."

Feminism spurred Nancy Mairs to alternative self-creation. Considering two questions—how she copes with M.S. and how she discovered her writing voice—she finds in "Carnal Acts" that each holds the answer to the other. Her illness demanded her mind's sharp attention, ending the mind-body split and enabling her to speak of her body's embarrassing messiness in a frank and clear way. "Forced by the exigencies of physical disease to embrace my self in the flesh," she says, "I couldn't write bodiless prose." Embracing the shameful to make others recognize her on her own terms, Mair chooses the label "cripple."

Intimate connection with others is a second theme in this collection. Susan Nussbaum opens a performance piece: "I gotta bad case of mishuganismo. That's when a Jewish woman goes crazy for a Latin guy." This affliction dominates her rueful and witty recall of Cuba, a string of lovers and disability activism. "How to Talk to a New Lover About Cerebral Palsy," by Elizabeth Clare, begins, "Tell her: *Complete strangers/ have patted my head, kissed/ my cheek, called me courageous.*" Tell this story more than once." It ends, "and remember to listen: she might surprise you." In Raymond Luczak's clever and stirring story, "Ten Reasons Why Michael and Geoff Never Got It On," such telling is inhibited by Michael's deafness and Geoff's resistance to learning American Sign Language—new variations on the perennial theme of faint-heartedness.

Lovers face unusual obstacles, and the course of love runs no smoother than for anyone else. In Katinka Neuhof's startling play, it is the symbolic power of her wheelchair, Blue Baby, that draws the nondisabled man, a magician and faith healer, and the disabled woman together and later divides them. She is horrified when people disturbed by her cerebral palsy offer her money, but he sneaks out in her chair to rake it in. "Beauty and Variations" is the resonant title of a verse cycle by Kenny Fries, who was born with bones missing in both legs. A handsome lover plunges the poet into an agony of doubt: "Can only one of us be beautiful? Is this your/ plan?" he asks. "Why don't you let

Most contributors here deploy neither the medical nor the social model—both are external and objectifying—as much as their own subjective reality.

me leave my mark? With no/flaws on your skin—how can I find your heart?" he goes on. "Beauty is a two-faced god. As your fingers soothe/ my scars, they scrape against my heart."

Avidity for the larger world and insight into its trouble may also be sharpened by disability. Adrienne Rich announces this third theme in "Contradictions: Tracking Poems":

The problem, unstated till now is how to live in a damaged body in a world where pain is meant to be gagged

uncured un-grieved-over. The problem is to connect, without hysteria, the pain of any one's body with the pain of the body's world.

John Hockenberry offers such connection poignantly. His feeling acutely "out of place" after an accident left him paraplegic may have helped propel him to remote locations in crisis. National Public Radio listeners heard his dispatches about riots, volcanoes, Middle East hot spots, but never—it was his private rule—about how he managed with (or without) his wheelchair. Only in this moving account of riding a donkey out of Iraq among thousands of refugees, "Walking With the Kurds," does he break that rule: "My entire existence had become a mission of never saying no to the physical challenges the world presented to a wheelchair . . . I had vowed never to allow the world to push me. I would pull it instead." Contemplating the American mission, he questions his own.

This stimulating anthology makes a claim for the new field of disability studies. Rosmarie Garland Thomson's provocative study *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* reframes disability as another culture-bound difference to consider along with race, gender, class, ethnicity and sexuality. Resistance to engaging this difference is greater, Thomson believes, because disability is more deviant, more bodily messy and—in its random and un-

predictable character—more menacing to the nondisabled. But the payoffs for engaging this notion (and this anthology) are greater freedom from socially constructed limitations of thought and feeling, and more complex acceptance of the inherently unstable human body.

A case in point is Andre Debus's "Dancing After Hours," the only piece told from a nondisabled person's point of view. Emily, a 40-year-old bartender in a Massachusetts beach town, is impaired only by the conviction that she has always been homely. She has retreated from teaching and from men to avoid the pain of disappointment, but there's no escape from her empathetic imagination. When Drew, a white quadriplegic in a wheelchair, and Alvin, his black attendant and friend, drop in for an afternoon drink, Emily's first response is conventional: "She believed she could not bear such helplessness, and would prefer death." The manager of the bar tells Emily about a friend, paralyzed in Vietnam, who willed himself to be happy. Eventually Emily talks with Drew about the physical and emotional risks he's taken—parachute-jumping and marriage. They stay after hours to dance—one of the waitresses with the man in the chair—and plan a fishing expedition.

This quiet tale offers a utopian vision of the change that the presence of a person living with disability can generate. And Emily is the ideal nondisabled reader of this anthology. Those of us who are disabled may rejoice in the cultural community in which we have landed. For the nondisabled, the book is a ramp providing access to fresh consideration of us and themselves.

Bell Gale Chevigny, professor emerita of literature at Purchase College, SUNY, and a Soros Justice Fellow, is currently preparing an anthology of PEN Prison Writing. She is a former Resist Board member. This article originally appeared in The Nation, March 30, 1998, and is reprinted with permission.

Solidarity Through Hilarity

Mothers From Hell Organizes for Children with Disabilities

ELIZABETH K. GERLACH

Mothers From Hell (MFH) is a grassroots parent advocacy group, fighting for decent education, community acceptance, and desperately needed services and entitlements for people with disabilities. We offer support and courage for the painful and difficult struggle experienced by families of people with special needs.

Don't let our name scare you. Contrary to the suspicions of many school district personnel, we do not worship the devil, nor do we promote violence as a means of enforcing our children's legal rights. We are, however, a loose-knit (more like velcroed, because who has time to knit) group of women who staunchly advocate for the rights of people with disabilities. We gather under the name, "Mothers From Hell" because we often feel labeled as such by the systems within our society obliged to offer appropriate services to our children, yet who seem to have a terrifically hard time doing just that. We are the kind of mothers who tend to say things like, "This is not in compliance with IDEA (Individuals with Disabilities Education Act)," or "I'm looking for the least restrictive

environment for my child and I don't think the janitor's closet is it." And so on.

Our common bond is our children, all of whom have disabilities of one form or another: Autism, Cerebral Palsy, Down Syndrome, Enigma Syndrome, and Disorders Not Otherwise Specified. We visit our state representatives, participate in local parades, attend atrociously boring sub-committees, budget hearings, and school board meetings. Our public testimony and presentations, including guerilla theater, and participation in community coalitions, forces our communities to face the issues.

By now you may have noticed a slightly irreverent and cheeky attitude. It's called humor, an element we have all felt is sorely lacking in the world of parenting children with disabilities. We are constantly being reminded that our children do not "measure up" to what is considered "normal." So we do what we can to lighten each other's load. We laugh, we poke fun at ourselves and the "professionals."

Our newsletter, *The Brimstone Bulletin*, extends our motto "Solidarity through hilarity" to over 1,500 subscribers throughout the US and other countries. Mothers of children with disabilities have historically been silenced by an unnecessary

shame. No more. Our children are precious jewels; it is society that is disabled. Together we can create more accepting and inclusive environments for them.

MFH encourages people to form their own local support groups and push for change within their own communities. We distribute "how-to" start up packets so parents can form their own support groups.

One of our current projects is a developmental disabilities awareness curriculum. This curriculum, ready for implementation in public schools in grades K-12, will help students become more aware and accepting of people with developmental disabilities. Although there has been a lot of emphasis on diversity in our schools, developmental disabilities issues are often overlooked. The issues of people with developmental disabilities are even different from individuals with physical disabilities, although many people with developmental disabilities have physical disabilities also.

When we started this project, MFH didn't intend to create the curricula, just to find them, and try to get them implemented. We did a nationwide search: spoke to parent groups; university people; government agencies; religious organizations; private non-profits and a for-profit group, "Kids on the Block." There wasn't as much material out there as we had hoped, and a lot of it was outdated or insensitive. We adapted and used ideas from many sources, and created some of our own materials. We put together a curriculum that is complete and readily usable.

One of the most common statements made by parents who write to us is this, "I thought I was all alone; thank-you for being there." Those letters keep us going. That and the tremendous need for justice for our children and all people with disabilities.

Elizabeth K. Gerlach is the editor of the Brimstone Bulletin. For more information, write to MFH, PO Box 21304, Eugene, OR 97402; <http://www.apexcomm.net/~debiski/mfhhome.html>. Mothers from Hell received a grant from Resist in 1997.

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