By Stephanie Thomas

This year is the 20th anniversary of the Americans with Disabilities Act (ADA), considered by many to be the civil rights act of the disability community. The past twenty years have brought many changes to our physical and social environment, and, in many ways, disability is much more integrated into our society.

Previous to passage of the ADA, people with disabilities could be refused service in public accommodations such as restaurants. Public sidewalks lacked curb ramps to allow access out of the street and traffic. Deaf people who went to the hospital often received no interpretation services, so their communication with medical professionals was limited at best. People with visual disabilities could easily have been refused access to ballots for voting. Public transit was only for people who could climb steps.

ADAPT and other groups fought hard for the passage of the ADA and for the basic civil rights it provided. At the time, ADAPT’s main goal was access to public bus transit. Getting around the community is, after all, a vital part of integrating into the mainstream of society.

In 1990 the passage of the ADA teetered in the balance. Strange amendments were being introduced, and the bill’s supporters in Congress seemed to be getting cold feet.

ADAPT organized a national action in DC that year. To illustrate what lack of access means to people with disabilities, ADAPT members descended from their wheelchairs to crawl up the steps of the US Capitol, took over the Capitol rotunda and told Congressional leaders that “they should walk a mile in our shoes to see from our point of view why the ADA was so critical.” Then, in a display of strength and their desire for recognition of humanity and equality, 101 protesters in wheelchairs chained themselves together and were arrested in the rotunda.

Skillful negotiation and lobbying by many disability groups brought about final passage of this critical legislation. Access to mainline buses was the first part of the legislation to take effect.

Beyond buses to housing justice

Yet even as they celebrated, ADAPT members felt that “the institutional bias in long-term care” was still a tremendous barrier to equality for people with disabilities. What this refers to is the implicit oppression of people with disabilities...
includes people with disabilities of all ages, from children to seniors.

Give us all a real choice

Many of those who fought so hard for the ADA were people who had to literally fight for their lives and freedom, to fight their way out of nursing homes or state institutions. They were the ones who dared to risk arrest, block buses, take over meetings and put it all on the line to show that the disability community was not going to be refused basic rights. Now they did not want to leave their "brothers and sisters" in glorified human warehouses.

Thus was born ADAPT’s “Free Our People” campaign which eventually crystallized its goals in the Community Choice Act. The concept is fairly simple: people should have an equal and real choice as to how and where they receive services. They should have a say in what services they receive and the manner in which those are funded (through an agency or directly to the affected person).

Services should be based on functional need rather than on diagnoses, age or other arbitrary categories. It should not make a difference if you need help getting dressed because of a spinal cord injury, a stroke or multiple sclerosis. Our lives should not be over-medicalized with nurses or similar expensive professionals doing daily living tasks (things that might be medical in an acute care setting but are daily living tasks for people with long-term disabilities).

When the campaign started it was thought that the Community Choice Act (CCA) was a conservative first step that could be expanded later. Fifteen or so years later, we have really learned how hard it can be to effect change! While we have had some victories since the ADA, the CCA is not yet passed, its concepts still far from being widely implemented. While the ADA has made a tremendous difference in the lives of many people with disabilities, there remain many
ADAPT Keeps Fighting  
continued from page two

prejudices and barriers to full societal integration of people with disabilities.

Strange bedfellows

Sometimes politics and legislation force us to face some bizarre choices. With Democrats we get funding and paternalism that can be suffocating in its desire to control our lives. With Republicans we get support for independent living ideology but little to no funding. Public service unions often (though not always) oppose community services and efforts to reintegrate people into the community because employment in institutional settings often means higher wages and benefits like health care and paid leave. Community services, on the other hand, often compensate the direct care workers at wages lower than the fast food industry, because state rates for community services are set so low. The decisions of family are often put before those of the disabled individual, despite the fact that few adults would chose to be bound by their parents’ desires for the entirety of our lives.

Long-term care is, in many ways, particularly a women’s rights issue. According to the most recent data from the Centers for Medicare and Medicaid Services, 68 percent of nursing facility residents are women. According to a 2003 National Alliance for Caregiving/AARP survey, six out of ten informal caregivers are women, and over seventy percent of paid caregivers are women, the majority women of color, and they get older each year, acquiring disabilities of their own.

Sadly, people on the left are commonly insensitive to the views and desires of members of the disability community, often valuing the position of family, union or professional positions over that of the person with a disability. The ADA and community integration of people with disabilities are still seen by many as a uphill battle, ADAPT has used many prongs on our pitchfork for social change: legislative, legal and direct action, media and administrative.

We have challenged states’ compliance with federal disability law in courts, and one case, Olmstead v. LC & EW, in which two women from Georgia challenged their right under the ADA to get services in the community, went all the way to the Supreme Court in 1999 in the first such Supreme Court case involving the "integration mandate" of the ADA. The Court required pain in the keester, a frill—and then activists wonder why few people with disabilities participate in their events and meetings. Whatever the root of this attitude, progressives and conservatives alike should consider how they would feel if they found themselves in the position of the person with a disability.

Diverse tactics for a broad struggle

Though the fight for Freeing our People and passage of the Community Choice Act has most definitely been an uphill battle, ADAPT has used many prongs on our pitchfork for social change: legislative, legal and direct action, media and administrative.

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Poetry by Eli Clare

Learning to Speak

Three years old, I didn’t talk, created my own sign language, didn’t walk but stumped all over the house on my knees growing thick calluses. Words slow dance off my tongue, never leap full of grace. They hear blank faces, loud simple replies. I practiced the sounds th, sh, sl for years, a pianist playing endless hours of scales. I had to memorize the muscle of my tongue.

Tremors

Hands burled and knobby, I tuck them against my body, let tremors run from shoulder blade to fingertip. Tension burns the same track of muscles, pencil slows across blue-lined paper, words scratch like sandpiper tracks at low tide. Kids call cripple. Bank tellers stare silent. Doctors predict arthritis. Joints crack in the vise grip: my hands want to learn to swear. Late at night as I trace the long curve of your body, tremors touch skin, reach inside, and I expect to be taunted, only to have you rise beneath my hands, ask for more.

White, disabled, and genderqueer, Eli Clare happily lives in the Green Mountains of Vermont where he writes and proudly claims a penchant for rabble-rousing. He has written a book of essays, Exile and Pride: Disability, Queerness, and Liberation (South End Press, 1999, 2009) and a collection of poetry, The Marrow’s Telling: Words in Motion (Homofactus Press, 2007) and has been published in many periodicals and anthologies. Eli speaks, teaches and facilitates at conferences, community events and colleges about disability, queer and trans identities and social justice. Among other pursuits, he has walked across the United States for peace, coordinated a rape prevention program and helped organize the first ever Queerness and Disability Conference. He lives on the web at eliclare.com.

Full stories and updated grantee news:  
www.resistinc.org/news

RESIST Newsletter, November-December 2010
Changing the Framework: Disability Justice
How our communities can move beyond access to wholeness

By Mia Mingus

In my time doing social justice work, I have found that disability is something most people know very little about—and that includes seasoned, fierce and well-respected community organizers and activists. People usually think of disability as an individual flaw or problem, rather than as something partly created by the world we live in. It is rare that people think about disability as a political experience or as encompassing a community full of rich histories, cultures and legacies.

Disability is framed as lacking, sad and undesirable: a shortcoming at best, a tragedy at worst. Disabled people are used as the poster children of environmental injustice or the argument for abortion rights. For many people, even just the idea that we can understand disability as “not wrong” is a huge shift in thinking.

Towards interdependency

Our communities and movements must address the issue of access. There is no way around it. Accessibility is concrete resistance to the isolation of disabled people. Accessibility is nothing new, and we can work to understand access in a broad way, encompassing class, language, childcare, gender-neutral bathrooms as a start.

We must, however, move beyond access by itself. We cannot allow the liberation of disabled people to be boiled down to logistics. We must understand and practice an accessibility that moves us closer to justice, not just inclusion or diversity.

As organizers, we need to think of access with an understanding of disability justice, moving away from an equality-based model of sameness and “we are just like you” to a model of disability that embraces difference, confronts privilege and challenges what is considered “normal” on every front. We don’t want to simply join the ranks of the privileged; we want to dismantle those ranks and the systems that maintain them.

In no way am I saying that accessibility is not important—it most definitely is. We cannot have disability justice without it, but we want to question a culture that makes inaccessibility even possible. Just because disabled people are in the room doesn’t mean there is no ableism (a set of beliefs that favors non-disabled people) or that people wouldn’t pretend we’re invisible.

This work is about shifting how we understand access, moving away from the individualized and independence-framed notions of access put forth by the disability rights movement and, instead, working to view access as collective and interdependent.

With disability justice, we want to move away from the “myth of independence,” that everyone can and should be able to do everything on their own. I am not fighting for independence, as much of the disability rights movement rallies behind. I am fighting for an interdependence that embraces need and tells the truth: no one does it on their own and the myth of independence is just that, a myth.

The power of disability justice

Disability justice has the power to not only challenge our thinking about access but to fundamentally change the way we understand organizing and how we fight for social change.

It has the power to bring our bodies back into our conversations. What do we do with bodies that have limitations, that are different (no matter how much we want to change them)? How do we acknowledge that all bodies are different, while also not ignoring the very real ways that certain bodies are labeled and treated as “disabled?”

Disability justice activists are engaged in building an understanding of disability that is more complex, whole and interconnected than what we have previously found. We are disabled people who are people of color; women, genderqueer and transgender; poor and working class; youth; immigrants; lesbian, gay, bisexual and queer; and more.

We are pushing for an understanding of how ableism affects all of our movements for justice. We are drawing connections between ableism and other systems of oppression and violent institutions. We are pushing for a more nuanced and fierce interrogation of the medical industrial complex and understandings of health, wellness and healing that aren’t continued on page five

RESIST Grants
www.resistinc.org/grants
Download grant applications.
Find out more about eligibility, application deadlines and grant guidelines.
Ed Baker’s Legacy of Justice

This year, RESIST received an extraordinary gift from a remarkable person. C. Edwin (Ed) Baker was a man who walked his talk and stood up for liberty, equality and justice. He was a scholar and a man who lived simply because he believed that luxury dulls one’s understanding of the world’s inequalities and injustices.

Unfortunately, Ed died suddenly in 2009 at the age of 62. He left the bulk of his estate to charity. He did not, however, specify which charities. Instead, he established a committee of four people to determine the most fitting way to distribute both his funds and his legacy. This year, that committee selected RESIST to receive a generous portion of his estate.

Raised in the small town of Madisonville, Kentucky, Ed graduated from Stanford University and Yale Law School and was a Fellow at Harvard on three separate occasions.

For most of his adult life, Ed was a law professor, including the last 28 years when he worked as a professor of law at the University of Pennsylvania and gained much recognition as one of the nation’s leading constitutional law and media policy scholars. He was the author of four books and over 70 law review articles, book chapters and published remarks. As recently as 2009 Ed testified before Congress that the concentration of media ownership and the loss of active newspaper reporters threatened the health of our democracy.

Disability Justice

continued from page four

rooted in ableist notions of bodies and what is considered “normal.”

We are trying to understand how we can build organizing and community spaces that are mixed-ability, cultivating solidarity between people with different disabilities. We are working to move together, as disabled people, through a world that wants to divide us and keep us separate.

Disability is not monolithic. Ableism plays out very differently for wheelchair users, deaf people or people who have mental, psychiatric and cognitive disabilities. None of these are mutually exclusive, and are all complicated by race, class, gender, immigration, sexuality, welfare status, incarceration, age and geographic location.

Finding home

As a queer, disabled woman of color, disability justice feels like a political home for me, a place where I can engage in conversations about disability and race and gender and queerness and capitalism and more.

I tried to look to the disability rights movement, but I saw very few leaders who reflected me, and I found that, for the most part, disability was being talked about as an isolated single issue. Having been involved with racial justice, queer liberation, reproductive justice and feminist movements most of my life, I have rarely encountered spaces that addressed disability or connected it with other issues.

What does it mean to not have the luxuries of deciding when to use the bathroom in the place where you live, having alone time or going to visit a loved one in their home? How do we re-imagine relationships that center interdependency? How do able-bodied people move from simply “supportive allies” to political comrades who are actively incorporating a disability justice understanding into their work and lives?

We cannot fight for liberation without a deep, clear understanding of disability, ableism and disability justice. The bodies of our communities are under siege by forces that leverage violence and ableism at every turn. Ableism is connected to all of our struggles because it undergirds notions of whose bodies are considered valuable, desirable and disposable. How do we build across our communities and movements so that we are able to fight for each other without leveraging ableism?

I imagine a world where our organizing and activism is less segregated, where our movements and communities are accessible and don’t participate in the isolation of disabled communities. I imagine places where we fight for whole and connected people, families and communities.

Mia Mingus is a writer, activist and community cultivator whose current work focuses on disability justice, transformative justice, queer liberation and what it means to create a world where we can be whole and connected. She is a queer, physically disabled Korean adoptee woman of color raised in the Caribbean and currently relocating to the California Bay Area.
ruled that people with disabilities have the right to services in the most integrated setting, in favor of the disability position.

We have challenged state legislatures to live up to this decision. In Texas, where 125,000 people are on waiting lists for services, the state's traditionally conservative legislature passed an act called Money Follows the Person, whereby those people in nursing homes who want to move out to the community can do so with the funds that were paying for their care in the nursing home. This model, along with models from other states, was used to create a national pilot program in which 39 states now participate. But why should one have to go into an institution in order to then get out and receive services?

While the media has provided some coverage on individuals in institutions and some who have gotten out, it generally ignores long-term care, despite its being one of the largest budget problems looming in the near future. Community services, at about two-thirds the cost of equivalent institutional services, are a cost-saving alternative, but because they are optional, financially-strapped states look first to fund the required institutional services and then allocate any leftover funds to the community. And as we all know, there are damn few leftovers in this economic climate. Baby boomers are aging but few have plans to address this long-term care problem for their parents—let alone themselves. Many people erroneously think Medicare will pay for community supports.

Despite the considerable and consistent push from disability groups to do better, the recent health care reform legislation addressed these issues in only the most minimal fashion. ADAPT continues to participate in direct action for several reasons. When decision makers do not respond to our community integration demands, the powerful organized voice of the people is one of the most effective responses available. The pressures to internalize negative beliefs and assumptions surrounding issues of disability are intense, and those of us with disabilities must fight the implicit message that we are lesser persons. Direct action reinforces the self-worth of those who participate, as we learn we do not have to "just take it." Social changes like ending the institutional bias are still needed, and as people become more empowered they are no longer willing to be left behind.

ADAPT members are still strongly committed to passage of the CCA, which will need to be reintroduced in Congress in January 2011. Through our battle for the CCA we have found that we need to add the issue of accessible, affordable, integrated housing, because even as we have won more supports and services in the community, we still need homes to receive these services in! Very low-income housing is hard to find and harder still if it must also be accessible and the housing is integrated (not designated "disability only").

Even after almost three decades of activism and changes in leadership and membership, with over fifteen years focused on the CCA alone, the energy in the ADAPT community remains high. ADAPT members know they are part of something important as critical pieces of our goal have already been achieved and the final goal is nearer to being accomplished than ever before.

Stephanie Thomas is a national organizer for ADAPT. She has been involved in the disability rights movement since 1976 and working with ADAPT since 1984. Her work has included centers for independent living, state cross-disability coalition organizing, policy development, training and, last but not least, grassroots activism.

Sins Invalid is a performance project that celebrates artists with disabilities, centralizing artists of color and queer and gender-variant artists, including performers Ralph Dickinson, Leroy Franklin Moore Jr. and seeley quest (L-R, above). The work of Sins Invalid explores themes of sexuality, embodiment and the disabled body. Learn more at www.sinsinvalid.org.
Introducing RESIST Tote Bags

These new RESIST tote bags are made of sturdy and durable canvas and feature our orange and black logo with the words, "More than 40 years of funding social change."

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Inside this issue:
20 years of the ADA and struggling for disability justice

Meet RESIST GRANT RECIPIENTS

RESIST awards grants six times a year to groups throughout the United States engaged in organizing for social, economic and environmental justice. Below we list a few grant recipients from our most recent allocation cycle in October of 2010. For more information, visit the RESIST website at www.resistinc.org or contact the groups directly. Thanks to intern Melissa Gage for her work on these profiles.

Project on Youth and Non-Military Opportunities (Project YANO)
PO Box 230157, Encinitas, California 92023. www.projectyano.org

Since its founding in 1984, Project YANO has provided young people with an alternative point of view about military enlistment, helping them make educated decisions about their future by giving them the tools to critically examine the sales pitch of the armed forces.

RESIST’s grant of $3,000 will help Project YANO produce literature on military enlistment, alternatives for job training and college financing and careers in social change and organize presentations in hundreds of San Diego-area classrooms by military veterans and other volunteers on the realities of military enlistment.

Southern Appalachian Mountain Stewards
PO Box 352, 301 Wood Avenue, Big Stone Gap, Virginia 24219. www.SAMSVA.org

An organization of community members and their allies working to improve their quality of life, rebuild sustainable communities and stop the destruction of their communities by preventing surface coal mining, Southern Appalachian Mountain Stewards is doing critical environmental justice organizing work in Appalachia.

A $2,000 grant from RESIST will help SAMS continue to fight a proposed 1,200-acre surface coal mine that will impact five local communities, campaign for permanent dust regulations, bring green jobs to Appalachia and educate youth.

Equal Action
675 South Park View Street, Los Angeles, California 90057. www.equalaction.org

Founded in 2009 as a youth-powered, antiracist, multigenerational organization that mobilizes the LGBTQ (lesbian, gay, bisexual, transgender and queer) community to join the fight for social justice and to support the voices of queer youth, Equal Action has organized projects ranging from the first-ever queer high school youth march, to monthly performance spaces, to Pride on the Picket Line, a collaborative political education event.

RESIST’s $2,000 grant to this budding organization will help it expand its programs and infrastructure in 2010.

Indian People’s Action
PO Box 826, Tucson, Arizona, 85701. www.nwfo.org

Indian People’s Action champions direct action to improve the lives and build the voice and power of Montana’s urban Indians as they organize to achieve racial, social and economic equality.

RESIST’s $1,500 grant will help Indian People’s Action continue to push for health care reform, to address the lack of ambulance services in Native communities and to organize for full funding of the Indian Health Improvement Act.