

THE WHITE HOUSE
OFFICE OF DOMESTIC POLICY

CAROL H. RASCO
Assistant to the President for Domestic Policy

To: Stan (x 65570)

Draft response for POTUS
and forward to CHR by: _____

Draft response for CHR by: _____

Please reply directly to the writer
(copy to CHR) by: _____

Please advise by: _____

Let's discuss: _____

For your information: _____

Reply using form code: _____

File: _____

Send copy to (original to CHR): _____

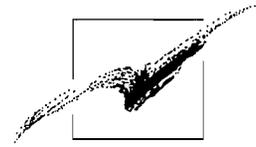
Schedule ? : Accept Pending Regret

Designee to attend: _____

Remarks: Let's talk about the
X'd item!
might be neat!

file: Mothers of Invention AUG -8 REC'D

Inbox



FOUNDATION
— for —
TECHNOLOGY
A C C E S S

August 3, 1994

Carol Rasco
Assistant to the President for Domestic Policy
The White House
1600 Pennsylvania Ave.
Washington, D.C. 20500

Dear Ms. Rasco:

On behalf of the entire Alliance for Technology Access, I want to thank you for addressing our group at the Seventh Annual Institute of the Alliance for Technology Access. It was an honor and a great pleasure to have you join us on July 19th.

Your remarks touched us all very deeply. As parents, family members and people with disabilities ourselves, we related thoroughly to your experiences as a parent, your philosophy of life, and your important work with the President. We enjoyed hearing about your experiences with Hamp, especially when you talked about his introduction to technology at our center in Little Rock. Ginny Heiple represents the Alliance well as she strives to bring these empowering tools to children and adults with disabilities in Arkansas.

Thank you, also, for your kind words about our new book, *Computer Resources for People with Disabilities*. Like Joe Shapiro's article, "The Mothers of Invention," I see our book as a mechanism for bringing hope, and information, to people everywhere. It's another way to reach out to people who might not otherwise know about some of life's more intriguing possibilities.

I want to second your idea about having a reunion with the "Mothers of Invention." It would be a thrill and an honor to share stories and plan future initiatives with a room full of mothers of kids with disabilities. After all, we all began because we knew that something needed to be done, and we were just going to do the best we could to get that something achieved. Imagine the potential of all that energy engaged in discussion, planning and thought!

Janice Nakayama, Executive Director of the Mattel Foundation, joined us at your luncheon table. Upon hearing about your interest in a reunion, she immediately offered the Mattel Foundation as a host and funder of such an event. If you are interested in having her work with you or a member of your staff, I know she would be delighted.

Thank you again for joining us. We all believe strongly in the power of individuals when motivated by their children. It is such a simple—and powerful—concept to be driven by the child and children we love.

Sincerely,

Jacquelyn Brand
Executive Director

SEP 14 REC'D

MEMORANDUM TO JANICE NAKAYAMA

FROM: Stanley S. Herr *Stan*
✓ CC: Carol H. Rasco
SUBJ: Reunion of the Mothers of Invention
DATE: September 13, 1994

Per your request, please find the attached U.S. News article on the Mothers of Invention.

The main profiles are of Carol, Governor Barbara Roberts, Jacquelyn Brand, Julie Beckett, Mary Tatro, Kim Connor, Patricia McGill Smith, Martha Ziegler, and Marina Medina. Others mothers (and at least one father, Rud Turnbull) are noted in passing.

Carol's schedule appears to preclude a November reunion, but perhaps Friday, December 9th might work out. Would this give us enough lead time to plan and to invite? I add that this date is a very provisional one that would have to be confirmed with Carol.

Thank you again for your materials to Carol and your Foundation's interest in sponsoring such an event.

CAN NATO BE REINVENTED? ■ TAXICAB SCAMS IN 10 CITIES

U.S. NEWS

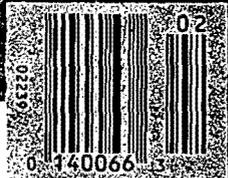
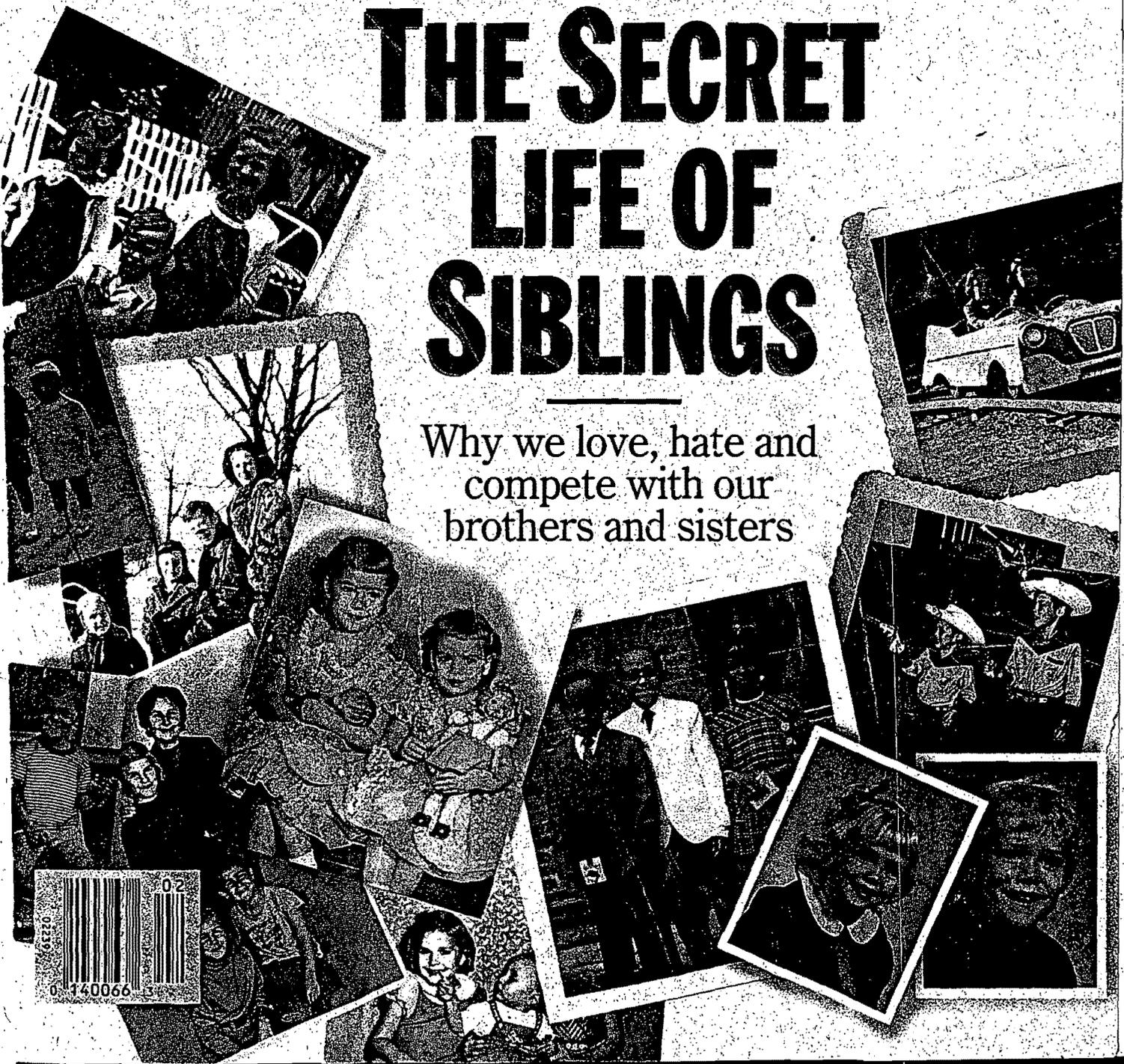
JANUARY 10, 1994

& WORLD REPORT

\$2.50

THE SECRET LIFE OF SIBLINGS

Why we love, hate and compete with our brothers and sisters



The mothers of invention

How a mighty grass-roots movement of parents with disabled kids is changing the nation

Bill Clinton's chief domestic policy adviser is not one of the West Wing's Rhodes scholars. In fact, there is little on Carol Rasco's early résumé to suggest she would become the nation's First Policy Wonk. She studied to be an elementary-school teacher, then found happiness working as a grade-school counselor. Until Clinton

Like Rasco, millions of mothers across the United States have been thrust, usually without warning, into becoming advocates for disabled children. Often, such mothers get discounted as isolated parents flailing away to help an "unlucky" son or daughter. In truth, these parents have launched a mighty grass-roots campaign. They have made schools, the law and social-service departments more humane and more efficient. Their work has helped not just the disabled and chronically ill but all those who rely on services from health care to welfare. And it has allowed a generation of disabled children to grow up to make major breakthroughs themselves.

Changing things. Carol Rasco is Exhibit A in the proof that few experiences are more empowering—even radicalizing—than being an advocate for a disabled child. "When Hamp was born, the doctors thought he would either die within 48 hours or I should find an institution for him," recalls Rasco in her large wood-paneled office in the White House West Wing. "I felt I had a lot to offer to keep him at home, but I certainly needed help." What began as her quest to get adequate social services and schooling for her son put her on a path to becoming a presidential confidante and policy guru. Once she learned how to change things for her own son,

Rasco volunteered with an Arkansas children's lobby to organize on behalf of poor children. Her inside knowledge of state programs caught the eye of one of the group's founders, Hillary Rodham Clinton, whose husband, then the state's

governor, hired her for a succession of ever more important jobs.

Fighting for her son's rights forced Rasco, like other similarly situated parents, to find ways to make programs work. Her character-testing experience provided, in effect, a hard-knocks education in the shortcomings of government.

Surely Rasco is the only one in her current post who ever had to struggle to get a son qualified for Social Security disability benefits. No other occupant of the office ever had a Social Security caseworker abruptly cut off a vital but uncompleted meeting with a brusque: "It's 12

CHARLIE ARCHAMBAULT—USNEWS



CAROL RASCO
TOP CLINTON ADVISER

She battled schools on behalf of her son, Hamp—who has multiple disabilities—and helped other Arkansas families. That won Bill Clinton's attention, and now she's his chief domestic policy aide.

summoned her to Washington, she had lived all but the first six months of her life in Arkansas. What propelled her into an extraordinary public life? The birth, 20 years ago, of her multiply disabled son, Hamp:

told her not to bring him back, Roberts took one day a week off from her job as a bookkeeper and lobbied the Oregon Legislature for five months until it passed a 1971 law guaranteeing all disabled kids a right to an education. That law became a model for federal legislation. And Roberts, the timid volunteer crusader who did not even know the names of the lawmakers she buttonholed, is now the governor of Oregon. Similarly, the birth of a severely disabled daughter helped turn Sharon Sayles Belton from a 20-year-old, single-mom college student to a political career that culminated in her November election as mayor of Minneapolis.

Life on the line. Only a handful of militant mothers end up running for political office, of course, but many change the world, or at least their communities. Most have needed services for a child but instead got caught up in a rulebound system or stuck on a long waiting list, says Niki Smith, who is part of a group of Oregon women who call themselves the Mothers from Hell. "When you have a disabled kid, it's like someone drops in on you from outer space and says, 'Your perfect child is not perfect anymore,'" says Smith, the mother of a daughter with Down's syndrome. "You go to the service system and most often it's helpful. But mistakes still happen, or somebody treats you in a way that's unkind or disrespectful, and you get angry. Your kid's life is on the line. That's what makes a mother from hell."

Often, the things a mother does for her own child end up helping many others. Typical is Jacquelyn Brand. When her daughter Shoshana, who has cerebral palsy and poor vision, began falling behind in school because she could not grip a pencil or speak clearly, Brand and her husband, Stephen, set out to learn all they could about computers. The couple devised a system with a voice synthesizer—similar to the one used by scientist Stephen Hawking, who has Lou Gehrig's disease—that became Shoshana's voice, her paper and her pencil. Today, the 19-year-old high school senior takes small parts in school plays and plans to go to college.

Brand became to technology what

**MARIA MEDINA
CHICAGO ACTIVIST**

She just wanted a neighborhood pool to take her son Moises to swim. But she and other mothers helped start Illinois Fiesta Educativa and won multimillion-dollar programs for Spanish-speaking kids with disabilities.

o'clock, the start of my lunch hour." And certainly she is the first to have her son's multipage application for disability benefits rejected because, among the scores of details she provided on 18 years of Hamp's medical history, she had omit-

ted the five-digit ZIP code of a doctor who had treated him years before. As a result, Rasco is acutely conscious that programs can look good on paper but fail in practice—a fact that she reminds Clinton of as they work together on health care and welfare reform.

Barbara Roberts is another militant mother turned canny politician. When the local elementary school sent home her autistic 6-year-old son, Mike, and



KEVIN HORAN FOR USNEWS

Andrew Carnegie was to books. She created a national network of local lending libraries of the latest devices, which disabled children and adults can try out at home, in school or on the job. Since 1983, the nonprofit Alliance for Technology Access, which the California mother started with grants from Apple Computer and other companies, has established 45 such centers in 34 states.

Costly laws. Frequently, the law itself is the target of a militant mother's work. Julie Beckett's daughter, Katie, spent the first 3½ years of her life in an Iowa hospital; viral encephalitis had struck in 1978, when she was five months old, shutting down her neuromuscular system and forcing her onto a respirator. Beckett quickly learned that Medicaid would only pay for Katie to live in a hospital, even though it was tens of thousands of dollars a year cheaper to let her live at home, where she could breathe on a portable respirator. Beckett wrote letters to lawmakers noting the stupidity—not to mention the cruelty—of a fiscally unsound rule that kept a child separated from her family. In 1981, President Ronald Reagan created what is now known as the Katie Beckett waiver. It has allowed Katie and, today, some 300,000 other "technology dependent" children and adults to leave drab hospital rooms.

**KIM CONNOR
SEEKS NATIONAL SCHOOL PRECEDENT**

She says her daughter Rachel, who is retarded, learns better with nondisabled children. Her lawsuit against the Sacramento school system could force schools across the country to step up the full inclusion of disabled kids.

After her daughter left the hospital, Beckett received hundreds of phone calls and letters from other parents, many of them desperate. She logged the calls and started a center at the University of Iowa to help parents share information and fight for policy. Recently, she started a group called Family Voices to lobby on health reform. Katie, now 15 and a high school honors student, testified before Hillary Clinton at one hearing. "I don't

think it's fair for me to change my career just because of my disability," said Katie, fearful that her job choices will be limited by whether she can get health insurance. The new Clinton reform plan addresses her worry by guaranteeing access to health care. But parents like Beckett still want to fill what they see as a gap that could leave some children, like Katie, without the rehabilitation services needed to stay out of the hospital.

Once children with medical conditions get out of hospitals, they still find obstacles at the schoolhouse door. In this arena, too, militant mothers led a revolution. The 1975 Individuals with Disabilities Education Act—a law won by activist parents who noted that some 800,000 children with disabilities got no schooling at all—gave disabled kids their first guarantee that they could go to school.

But in 1979, Mary Tatro's neighborhood preschool refused to accept 3-year-old Amber because the girl, born with spina bifida, still needed help with a catheter. Tatro said this was a simple procedure—she did it at home—that could be handled by a teacher or a nurse. School officials insisted it was a medical

procedure that needed to be done by a doctor. The effect was to exclude the girl from school. "I'll see you in the Supreme Court," Tatro blurted out at an unpersuaded administrator. And sure enough, a few years later they did meet on the steps of the U.S. Supreme Court, which in 1984 gave Tatro a victory and since has prompted schools to meet the medical needs of tens of thousands of disabled kids.

These days, a new generation of militant parents is pushing school districts to the furthest frontier yet. They insist that their children have a right to take every class with nondisabled kids, rather than be segregated

**JULIE BECKETT
WON HOME-CARE RIGHTS**

When her daughter Katie was forced by Medicaid rules to stay in the hospital, Beckett began a campaign that prompted President Reagan to change the costly rules. Now Katie and 300,000 others get care at home.



KEVIN HORAN FOR USNEWS

**BARBARA ROBERTS
GOVERNOR OF OREGON**

A former bookkeeper, she began her political life when a school refused to teach her autistic son, Mike Sanders. Her dogged lobbying led to a new state law promising all kids an education.

with only disabled ones. Kim Connor says her retarded 11-year-old daughter, Rachel Holland, achieves far more academically and socially when she learns side by side with nondisabled kids. Many school officials say such integration would be too costly and complicated. Yet Rachel, who, Sacramento school officials argued, would never master simple skills and needed to *practice* recess indoors before she could join other kids outside, is now in a private school where she spells, writes poems and even speaks Hebrew. The family's case is rising through the court system and could set a national legal precedent.

Not surprisingly, school districts often hate these pushy parents. But at higher levels of government, there is growing belief that they are a force for good. The U.S. Department of Health and Human Services, in fact, has begun a \$1.8 million program to train parents and their children to become advocates for services, even to the point of agitating for systemic change or leading street protests.

The federal program is modeled after Minnesota's successful Partners in Policymaking, founded in 1987. The idea, says Colleen Wieck, head of the Governor's Planning Council on Developmental Disabilities, was to give



DAVID BUTOW - BLACK STAR FOR US&WR

parents and disabled adults the skills to stand up to obstinate bureaucracies. The program includes training in community organizing tactics. At one Minnesota training session, a community organizer sought to turn parents from ineffectual letter writers into in-your-face agitators. He tipped them to the best time to hold a demonstration (before 11 a.m. for the best media coverage) and how to create a successful protest (appoint "inciters" to

"move about to heat up the action, getting people angrier and encouraging them to show their anger").

"Doing a good job." This is Advocacy 101, straight out of Saul Alinsky's classic rules for organizers. But when the old federal Office on Economic Opportunity and the Legal Services Corporation funded this sort of grass-roots activism, conservative politicians quickly shut down the antipoverty programs. Telling-

ly, it was the Bush administration that funded the new parent programs. Explains Deborah McFadden, President Bush's commissioner for developmental disabilities at HHS: "Parents know best the needs of their children." But schools will resist their suggestions, she says, claiming they are too technical or too expensive. "The unfortunate truth," says McFadden, who changed her agency's mission from research to advocacy training, "is that if you are hated in your school system, you're probably doing a good job."

That is why such mothers organize themselves into neighborhood, nationwide and even international networks, many of them ad hoc and underground. The Oregon Mothers from Hell meet monthly, sometimes over potluck suppers. "We've infiltrated the system," says Kathryn Weit, explaining how many take jobs in far-flung parts of the social-service system, in effect becoming moles deep within the bureaucracy. Weit works for a statewide parent train-

**OREGON'S MOTHERS FROM HELL
SUPPORT NETWORK**

The fight for proper services "is what makes a mother from hell," says Niki Smith (far right). The group meets often to share experiences. Many have gotten jobs in agencies that help the disabled.

DAVID BUTOW - BLACK STAR FOR US&WR



DAVID BUTOW - BLACK STAR FOR US&WR

**PATRICIA MCGILL SMITH
WASHINGTON LOBBYIST**

After working to get good schooling for her disabled daughter, Jane, she became a parents' representative. Now she's helping Russian families start a similar movement.

ing group; another mother assists a lawyer who brings disability complaints, and still another, who works for a large philanthropic organization, teaches the mothers how to write grant applications. Pooling their talents, these activist moms wrote, filed and won *Mothers from Hell v. Eugene School District*, a legal action that ended the exclusion of disabled kids from summer school.

"Terrible isolation." Because shared knowledge is power, parents have started 67 federally funded Parent Information and Training Centers. These are run almost solely by activist mothers to teach others how to get services and technology, and legal and medical advice. Says Martha Ziegler, who started the first center, "Most parents of children with disabilities go through a period of terrible isolation and loneliness. Many of us come out of it wanting to help other parents not suffer quite so much." One mother, Patricia McGill Smith, acts as the Washington voice for these parents. She runs the National Parent Network on Disabilities and carries their message on health care and other issues directly to lawmakers.

Although militant parents have won new laws and federally funded support programs, for the most part, parent groups run on a shoestring and volunteer power. Yet their amateur status belies their sophistication. Typical is the National Down Syndrome Congress, begun in 1972 by parents concerned by reports that doctors did not act aggressively to keep such children alive at birth. These mothers have cultivated sympathetic doctors and nurses across the country, who now tip off the parents almost anytime a child with Down's syndrome is born. The new mother gets a phone call, usually within 48 hours, offering an instant network of support and advice.

Although the first parent ad-



vocates were almost always white and often wealthy, today's activists include poor and minority parents, like the mothers of Illinois Fiesta Educativa. These Latino women were angered by the lack of services in their Chicago neighborhood. Maria Medina took her son Moises, who has Down's syndrome, by two buses and a train, an hour each



**MARY TATRO
SUPREME COURT WINNER**

A school balked at performing a simple medical procedure for her granddaughter Amber, who has spina bifida. The court ruled in her favor and the case helped win care for tens of thousands of kids.

way, just to reach the one suburban swimming pool that would teach her son to swim. She and other mothers, many of them single and unemployed, wrote to the city asking for a similar program for their kids. At first, since they didn't really know to whom they should write—or what exactly to say—their letter got no response. But with the help of a community organizer, they learned to target the state and city officials who made such decisions. When Gov. James Thompson snubbed their invitation to talk in 1989, 250 mothers marched to his mansion. The resulting television and newspaper coverage forced the governor to meet with the mothers and support a parks program.

Since then, the group's victories have included a \$2 million "respite program," to provide temporary in-home care for Spanish-speaking families. Fiesta Educativa has also forced schools to hire special-education teachers who are bilingual. Perhaps the surest sign of success, says Medina, is that the mothers now have an amicable partnership with state officials and can call up whom they want, when they want and get attention.

New tensions. Nationwide, the movement is not without growing pains. There is emerging tension, for example, between parents and their disabled children, as children grow into adult self-advocates and start groups that compete for funding and stature. And although militant mothers and fathers are more expert than ever, their issues have become more complicated and harder to resolve, says parent advocate Rud Turnbull of the University of Kansas. Distributing limited health care resources, for example, can pit those who benefit from expanded access to basic services against those who may need costly and exceptional ones.

Still, the most enduring legacy of militant moms is their militant kids. Having watched how their parents fought for them, many disabled people grow up to be forceful self-advocates. It is disabled people themselves who are emerging to take the lead on most disability issues, starting their own organizations to work alongside the ones begun by their parents.

One such advocate is Robert Williams, who was recently appointed by President Clinton to head the Administration on Developmental Disabilities at HHS. Says Williams, who has cerebral palsy: "For children to believe in themselves, they have to see that their parents believe in them and are willing to go to bat for them." ■

BY JOSEPH P. SHAPIRO