

Contents

- 1 Anniversary celebration
Foster care settlement
- 2 Challenging segregation
in adult homes
- 3 Combatting custody
relinquishment
- 4 Picture album from the
celebration
- 5 Mock grand jury hearing
- 6 New publications
Appreciation of donors
- 7 Website relaunch

CAUSE FOR CELEBRATION

The Bazelon Center celebrated its 30th anniversary with a gala dinner at the National Museum of Women in the Arts in Washington DC last November 14, a mock "grand jury hearing" the next morning, a book on the Center's 30 years of groundbreaking advocacy (see page 6) and the exciting announcement of a \$4 million grant by the John D. and Catherine T. MacArthur Foundation to the Pursuit of Justice Endowment Fund.

"The Bazelon Center has been a crucial institution in working to secure the rights of people with mental illness in this country and returning to them a sense of dignity," said Jonathan F. Fanton, the foundation's president, in a message read at the dinner. The endowment grant "acknowledges that its work will be important and relevant into the future."

Income from the endowment fund helps to support the Bazelon Center's ongoing campaign to reshape the debate on the nation's mental health policy.

"People with mental disabilities have a great friend in the MacArthur Foundation," said Bazelon Center executive director Robert Bernstein. "Few funders can or will make the sort of commitment to a cause that the MacArthur Foundation has made."

more from the celebration on pages 4-5



Board chair Rud Turnbull presents a gift to MacArthur Foundation senior program officer Laurie Garduque in appreciation of the foundation's generosity—a painting by a student with the Washington DC Very Special Arts program.

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NEW HOPE FOR 50,000 CALIFORNIA CHILDREN

Katie A. is one of 50,000 children in the Los Angeles County foster care system—most of them with mental health needs. When Katie was four, her mother was living on the street and her father was in prison. The county placed Katie in care and over the next 10 years shuffled her from one placement to another—37 in all, including eight psychiatric hospitals and a succession of group homes. She last lived with a family in 1995, when she stayed in two different foster homes for a total of five days.

Despite repeated assessments that showed she needed mental health care, Katie never received any individualized services in the community. Bright and articulate, she read like an 8th grader when she was nine, but five years later her reading skill had fallen a grade. Still, she is now an engaging teenager hoping to be a pediatrician when she grows up. And because of a lawsuit brought by the Bazelon Center, she at last has a chance of stability

continued on page 8

CHALLENGING CONTINUED SEGREGATION

THE BAZELON CENTER (IN BRIEF)

For more than 30 years the Bazelon Center for Mental Health Law has been the nation's leading legal advocate for adults and children with mental illnesses or developmental disabilities. Our mission is to protect and advance their rights to exercise meaningful life choices and to enjoy the full benefits of community living. We work to end their segregation, incarceration and marginalization and the disintegration of their family structure, and to assure them access to needed services and support.

IN BRIEF is an occasional newsletter highlighting a few aspects of this work and listing some of those who make it possible.

Across the nation, hundreds of thousands of men and women who were supposedly transferred from state psychiatric hospitals to the community were simply shifted to large congregate-care facilities. Conditions in these facilities are often horrendous, as revealed by a Pulitzer Prize-winning series of articles by Clifford Levy in *The New York Times* in April 2002.

Yet even if they are clean and well-run, and whether they are called “board-and-care,” “group homes” or “adult homes,” these places are far from being part of “the community.” By segregating their residents from the real community, such facilities violate the mandate of the Americans with Disabilities Act (ADA) that public services must be provided in the most integrated setting consistent with an individual’s need. A new Bazelon Center lawsuit seeks to enforce that right as affirmed by the Supreme Court’s 1999 *Olmstead* decision.

After the *Times* series called attention to the squalor and chaos in New York City’s adult homes, Governor George Pataki announced plans for reform. However, little changed for the 4,000 residents in the 26 largest of these institution-like facilities. On July 1, 2003 the Bazelon Center and a group of New York lawyers filed *Disability Advocates v. Pataki* in federal district court, alleging that New York State is violating federal law by unlawfully segregating these men and women.

Many of New York’s adult homes are larger than any of the state’s psychiatric hospitals, yet they lack proper staff and resources. Local advocates have filed a lawsuit challenging the sordid conditions in the “homes” and their neglect of residents. The Bazelon Center’s action instead challenges the residents’ isolation and the state’s failure to integrate them into the community or promote their independence.

The suit requests the creation of supported apartments, where appropriate rehabilitation and other services could

be provided to residents who wish to live outside an institution. The state and city already license and provide funding for such apartments, but in far too small a number. The state’s own study shows that providing integrated care in supported apartments costs no more than the current cost of housing and (supposedly) providing care in adult homes. In fact, it may cost less.

Legal director Ira Burnim is heading the Bazelon Center’s challenge—part of a broader effort to implement the landmark *Olmstead* decision. “In addition to ending New York State’s continuing disregard for the legal rights of people with mental disabilities,” he says, a victory in this case “will send a loud, clear message to other states that would ignore federal civil rights laws.” Indeed, the Bazelon Center is working with legal advocates in other states on potential challenges to such segregation of people with psychiatric disabilities.

The named plaintiff, Disability Advocates, Inc., is the New York protection and advocacy system. It is co-counsel with the Bazelon Center in the case, as are three local public-interest organizations—New York Lawyers for the Public Interest, MFY Legal Services and the Urban Justice Center—and a law firm providing pro bono representation: Paul, Weiss, Rifkind, Wharton & Garrison LLP.

The complaint can be accessed online at <http://www.bazelon.org/nycomplaint>. In a new publication, *Last in Line* (see page 6), the Bazelon Center examines the reasons for such segregation in a sampling of states and recommends various policies and advocacy approaches to end it.

COMBATTING CUSTODY RELINQUISHMENT

Imagine a child with diabetes being torn from his family in order to get basic health care. I can't, but for children with mental health needs, it happens every day in communities across the country." So testified staff attorney Tammy Seltzer on July 15 before the U.S. Senate Committee on Governmental Affairs. Her testimony was the latest thrust in our campaign to end the cruel and inappropriate dumping of children into public care for access to needed mental health services.

A Bazelon Center report, *Relinquishing Custody: The Tragic Result of Failure to Meet Children's Mental Health Needs*, documents the problem and its causes. Since its publication in 2000, media outlets across the nation, from local weeklies to network television, have highlighted families who exhausted their insurance coverage, even impoverished themselves, to pay for the intensive services needed by a child with serious emotional disorders. Left without options, parents have turned to the public system—to be told their child can qualify for Medicaid only if they relinquish custody to the state. At the Bazelon Center's urging, Congress asked the General Accounting Office to investigate. The GAO documented at least 12,700 such cases in 2001—a number that may be the tip of an iceberg because it reflects data from only 18 states.

Relinquishment leaves children feeling abandoned by their families. It also leads to their placement in costly residential facilities, often far from home. And parents who have relinquished custody have no say about their children's day-to-day lives—what they eat or wear, who their friends are, where they worship. Some parents are not even told where their children are. "Ultimately, children who need the most emotional support and stability are being ripped from their homes to live with complete strangers," Seltzer told the Senators.

"But I have good news," she continued, "custody relinquishment need not happen." She outlined a set of

legislative solutions, including a bill, the Family Opportunity Act (FOA), for which the Bazelon Center has advocated vigorously. The FOA has maintained bipartisan support for more than three years, but has yet to become law.

The FOA would expand Medicaid coverage to children whose families would not otherwise be eligible, and give states greater flexibility to use Medicaid's Home- and Community-Based Services Waiver to serve children with serious emotional and behavioral disorders. Three states (Vermont, New York and Kansas) have used the waiver of federal rules to serve these children, greatly reducing custody relinquishment and cutting the cost of the children's care by half. The reason more states haven't followed is a requirement that, to be eligible, a child must need the "level of care" of a hospital or nursing home. Children seldom stay long in such facilities but, instead, when institutionalized, are placed in psychiatric "residential treatment centers"—a level not covered under the waiver. The FOA would eliminate this barrier.

Seltzer listed other opportunities for Congress to end, or at least reduce, custody relinquishment.

- As a first step, insurance reform. Congress should prohibit private insurers from denying access to needed services through limits on mental health care that are not placed on physical health services.
- In reauthorizing the Individuals with Disabilities Education Act (IDEA), Congress should keep the requirement (and add funding to expand compliance with it) that schools address a student's problem behavior by conducting a "functional behavioral assessment" to determine the reasons behind a student's behavior and by providing positive behavioral interventions and support



Carol Malka of Flemington, N.J. is thrilled to have Robert, 14, home for a visit. But, as reported by the Philadelphia Inquirer's Kathy Boccella on June 10, 2003, he can visit only with approval by a social worker because Carol had to give up custody of her son so Medicaid would pay for the mental health services he needs. Photo by Sharon Gekoski-Kimmel/Inquirer.

to the student, as described in a new Bazelon Center publication, *Suspending Disbelief* (see page 6).

- Congressional oversight could expand states' use of a Medicaid option that increases access to home- and community-based services for children. As documented in a recent Bazelon Center report, *Avoiding Cruel Choices*, few states have chosen to use this option for children with disabilities.

To date 13 states have enacted laws prohibiting child welfare workers from requiring custody relinquishment for parents to get mental health services for their children. However, Seltzer told the Senators, without resources that only Congressional action can provide, "a ban alone will not reduce the number of children placed in the child welfare system solely for mental health purposes.... A coordinated effort between states and the federal government aimed at removing barriers" is needed.

To purchase *Relinquishing Custody* or *Avoiding Cruel Choices*, visit our online bookstore or email pubs@bazelon.org.

A GALA CELEBRATION OF 30 YEARS

WJLA-TV news anchor Maureen Bunyan, left, presided over the ceremonies. Here she talks with Mickey Bazelon Knox at dinner.



L to r above: Board chair Rud Turnbull greeted Dana and Jill Bazelon as they arrived at the National Museum of Women in the Arts, site of the gala dinner commemorating the Bazelon Center's 30 years of advocacy.



Speeches were held to a minimum but awards were a feature—each in the form of a painting by a Very Special Arts (DC) student. Honored for their pro bono assistance in Bazelon Center litigation were the firms of Howrey, Simon, Arnold and White, LLP, Swidler Berlin Shereff Friedman, and Shea and Gardner—here represented by John Townsend Rich (above right), receiving the center's expression of appreciation from Ira Burnim.



Above, l to r, staff and guests of CIGNA Healthcare: Nancy Valentine, National Nursing Executive; Robyn Lipner, Executive Director, Jacob's Institute of Women's Health; Janene Adams, Assistant Director Health Policy; Andrea Gelzer, Vice President Health Policy; Rhonda Robinson Beale, Chief Medical Officer; and Millicent Gorham, Executive Director, National Black Nurses Association



At left, consumer/survivor activists Mary Ann Beall and Jacki McKinney



ALL PHOTOS ON THESE PAGES AND ON PAGES 1 AND 8 BY DOUG DEMARK.



Below, executive director Bob Bernstein is flanked by Dan Fisher and Laurie Ahern, co-directors of the National Empowerment Center, honored for their leadership in the psychoatric consumer/survivor self-advocacy movement.



Paul Friedman, the first executive director of the Mental Health Law Project—the Bazelon Center's precursor—catches up with Judge Patricia Wald, who was legal director of MHLP in the 1970s.

Left to right: Judge Wald solicited the views of “jurors” Marianne Means, Hearst newspapers columnist, J. Rock Johnson, consumer/survivor activist, Gary Gates, Ph.D., Urban Institute, Clarence Sundram, consultant on mental health systems, and health policy consultant William Goldman, M.D.

LOST IN THE SYSTEM: COMMUNITY INTEGRATION ON TRIAL

Bazelon Center trustee and consumer leader Sally Zinman (seated on the left) played the role of plaintiff in a mock grand jury hearing hosted by many of Judge Bazelon's law clerks. *In the Matter of Sally Z.* was staged



to examine the barriers to community integration of people with mental illnesses. Ira Burnim, as “prosecutor,” elicited “Sally Z’s” (fictional) description of her life in a succession of segregated settings, from hospitals to group homes.

Q: How do you spend your days?

A: Doing nothing. There is nothing to do. I watch TV. Other people smoke, I don’t smoke so it bothers me. There is a bench outside, a bus stop and I sit there—sit there a lot and watch people.

Q: Why do you sit at the bus stop?

A: I would love to be able to do what all those other people are doing. They are getting on the bus and they are doing things...going to work. And they have families. They have children. And you can hear them talking about their social life. So I fantasize what it would be like living like other people.

Testimony by “expert witnesses” contrasted Sally Z’s experience with the Americans with Disabilities Act ban on such segregation, explained by Georgetown Law professor Chai Feldblum, and with program models that promote true integration, described by their innovators, Ann-Marie Louison of New York City’s Nathaniel Project and Alabama mental health commissioner Kathy Sawyer. Tipper Gore, appearing by videotape, noted that “these problems persist, not for a lack of solutions, but rather because we have yet to muster the political will to enact necessary reforms.”

Finally, the “grand jury” headed by Patricia Wald, retired Chief Judge of the Circuit Court for the District of Columbia, further questioned Sally Z. and discussed the barriers to development of community programs “that take account of the humanity and the potential contributions” of mental health consumers.

Asked by foreperson Wald what steps they would take right away “if you were

governor or federal HHS secretary,” the jurors proposed various remedies, from the fiscal to the political. Clarence Sundram’s reply, for instance, directly addressed Sally’s plight: “I would create as a cornerstone an individualized planning process in which a sum of dollars is allocated...and essentially leave it to the individuals, their allies and case managers to figure out a package of services that would support people in pursuing their own dreams in the community.”



NEW PUBLICATIONS

CIVIL RIGHTS AND HUMAN DIGNITY

An inside look at the Bazelon Center's 30 years of cutting-edge advocacy for the rights of people with mental disabilities. 126 pp. Nov. 2002. B-2 \$9.50

LAST IN LINE

Report on the barriers to community integration of older adults with mental illnesses, with recommendations for change. 25 pp. Feb. 2003. E-7 \$6.50

SUSPENDING DISBELIEF

On moving beyond punishment to promote effective interventions for students with mental or emotional disorders. 28 pp. May 2003. ED-2 \$5

WHAT "FAIR HOUSING" MEANS FOR PEOPLE WITH DISABILITIES

Update of the popular guide for tenants, landlords and housing advocates. 48 pp. May 2003. H-5 \$4

BUILDING BRIDGES

Model law to reduce recidivism by improving access to benefits for individuals with psychiatric disabilities, includes extensive commentary. 34 pp. May 2003. CR-2 \$4

RECOVERY IN THE COMMUNITY

Funding rehabilitative approaches under Medicaid. Volume 1 on federal rules and state definitions. 84 pp. Nov. 2001 AM-1 \$16. Volume 2 on states' implementation. 29 pp. May 2003. AM-2 \$20

A NEW VISION OF PUBLIC MENTAL HEALTH

Model law for a recovery-oriented system. Packet includes suggestions for advocacy aimed at adaptation of the law for states' enactment. Jan 2002. NV-1 \$4

POWER IN PLANNING

Folder with analyses of state laws and consumer/provider views on use of advance directives for psychiatric care, with copy of the Bazelon Center's forms. Mar. 2003. AD-1 \$4

These and many other Bazelon Center publications are available for purchase online, at www.bazelon.org, or call 202-467-5730 ext 110 to request a brochure.

THANK YOU!

The generosity of many individuals, foundations, corporations and other entities makes possible the Bazelon Center's work to protect and advance the rights of adults and children with mental disabilities. We are pleased to acknowledge the support in the past 12 months of the following donors, including members of the Bazelon Society, listed with an asterisk (*) and sponsors of our 30th anniversary events (‡). Please let us know if we have omitted or misspelled your name or placed it in the wrong category of giving.

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BAZELON CENTER RELAUNCHES ITS WEBSITE

A great mental health advocacy resource just got better. In late July, the Bazelon Center relaunched its award-winning website, www.bazelon.org. The site, already one of the most comprehensive online resources on mental health law and policy, now features a sharp new design and improved navigation. Even more useful information is now available, with issue-specific content organized to help advocates more easily find relevant information quickly. The site features new action components and links to state resources, making it even easier to act to support the rights of adults and children with disabilities. To find out more, please visit the Bazelon Center online at www.bazelon.org.

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... and many more whose gifts have helped us advocate for the rights of children and adults with mental disabilities.

KATIE A.

(continued from page 1)

and of receiving the mental health and educational services she needs to attain her goal.

Katie is one of 50,000 children in the county's foster care system—the nation's largest—on whose behalf the Bazelon Center and a group of California lawyers sued the county and the state last year. We asserted that the children have a right to individualized community mental health services under the U.S. Constitution, federal Medicaid law and the Americans with Disabilities Act.

The goal of the class action is overall reform of the foster care system so that children will receive the individualized services they need and families will be preserved—and, if children must be taken into custody, they are placed in stable family settings.

Soon after the suit was filed in July 2002, the county and the lawyers began negotiating an agreement. Even before the agreement was announced in March 2003, the county closed the notorious McLaren Hall children's shelter, a 175-bed dumping ground for children with challenging behavior (Katie stayed there seven times).

Bazelon legal director Ira Burnim, a lead attorney in the litigation, crafted the settlement. Based on national estimates that 60 to 85 percent of children in foster care have significant mental

health problems, he estimates that the agreement will, when implemented, greatly improve the lives of at least 30,000 children.

Following principles similar to those the Bazelon Center developed in the R.C. consent decree, which has reformed Alabama's child welfare system, the county agreed to restructure child welfare operations to:

- keep troubled children with their families when possible and, when removal cannot be avoided, get them help to

move back home as quickly as it's safe;

- have stable foster families for children who can't go home; and
- promptly get needed mental health and supportive services to the children and their families or foster parents.

As a *Los Angeles Times* editorial put it, "the county promises to stop treating these children like hot potatoes."

That obviously won't be easy, given the size of the system and the state's budget woes. An advisory panel of experts, including several who worked with us on the Alabama reform, will help the county fulfill its obligations. In the meantime, the other half of the lawsuit proceeds, seeking Medicaid financing of critical mental health and supportive services for foster children in the rest of the state.

Co-counsel with the Bazelon Center in the *Katie A.* litigation are the Western Center on Law and Poverty, the Center for Law in the Public Interest, the Youth Law Center, Protection and Advocacy, Inc., the American Civil Liberties Union of Southern California and the law firm of Heller Ehrman White & McAuliffe, LLP.



Four generations of Bazelons participated in the center's 30th anniversary events. Here Rick Bazelon, the Judge's son and an eminent Philadelphia attorney, helps grandson Eli Sabin celebrate. Eli's mother is Emily Bazelon, a senior editor of Legal Affairs magazine.



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