

38 Years of Landmark Advocacy

Below are a few of the successes resulting from the Bazelon Center's work in Congress and the federal courts to uphold and advance the rights of people with mental disabilities.

The Right to Treatment/Protection from Harm

Before 1972, people with mental disabilities were often simply warehoused in remote state psychiatric hospitals and so-called training schools. Our work in landmark class actions set minimum standards for physical conditions, staffing and safeguards of human rights in psychiatric and mental retardation institutions and ultimately mandated community care for residents.

- *Wyatt v. Stickney* sets minimum standards for physical conditions, staffing and safeguards of human rights in Alabama's psychiatric and mental retardation institutions (1972) and ultimately mandates community care for residents (1999). The standards ultimately become national regulations.
- *Morales v. Turman* establishes standards to protect children in Texas juvenile facilities (1974).
- *New York State Association for Retarded Children v. Carey*, to protect residents of Willowbrook State School from harm, requires their transfer to appropriate community-based programs (1975).
- Federal nursing home reform legislation establishes protections against restraint of residents, including chemical restraints, and mandates attention to residents' psychosocial well-being (1987).

The Right to Liberty and Due Process Protections in Civil Commitment

As part of the move to end the warehousing in state hospitals of people whose relatives or neighbors — for altruistic or sometimes venal reasons — wanted them confined, advocates across the country challenged civil commitment practices. In its early days, the Center offered technical assistance in many such suits and represented the plaintiff in a seminal Supreme Court case.

- *O'Connor v. Donaldson* establishes the right of a non-dangerous person to freedom from purely custodial confinement (1975).
- American Bar Association's Commission on Mental Disability publishes the Bazelon Center's legislative guide, *Legal Issues in State Mental Health Care: Proposals for Change* (1977).

- *Addington v. Texas* sets the standard of clear and convincing evidence of the need for commitment (1979).
- *Streicher v. Washington* requires meaningful periodic review of civil commitment orders (1997).

The Right to Receive Services in the Community

Integral to the fight for standards to prevent arbitrary commitment to institutions was advocacy for the right of people who were institutionalized to receive the services they need in the “least restrictive setting” — in the community. Judge Bazelon had found this for people with mental illnesses in the 1960s and the *Wyatt* court referenced it in 1972. Since then, case law and federal legislation, along with many mental health professionals’ findings, have advanced the concept as valid.

- *Dixon v. Weinberger* mandates creation of community-based alternatives for people unnecessarily in or at risk of confinement in the District of Columbia's St. Elizabeths Hospital (1975, implementation ongoing).
- *Wuori v. Zitnay* sets standards for community-based programs serving former residents of a Maine facility for people with mental retardation (1979).
- To challenge “transinstitutionalization” from state hospitals to nursing homes, Congress in 1987 mandates preadmission screening and annual review of the need for nursing care of people with diagnoses of mental illness or mental retardation (PASARR). Those found not to require nursing home care must be served in an alternative setting, e.g., at home.
- In *Olmstead v. L.C.*, the U.S. Supreme Court upholds the right under the Americans with Disabilities Act of people with disabilities to receive services in the “most integrated” setting consistent with their need (1999).
- *DAI v. Paterson* affirms that *Olmstead* applies not just to public institutions but to for-profit residential facilities receiving state funds to serve people with mental disabilities (2009). The court orders the state to develop supportive housing for more than 4,000 people with mental illnesses.

The Right to Live in the Community

As people with mental illnesses were moved out of institutions, many were transferred to group homes and other board-and-care facilities. Communities reacted with NIMBY (Not in My Backyard), imposing zoning ordinances and other restrictions based on stereotypes about mental illness. The Center undertook a sustained campaign to combat NIMBY.

- *Stoner v. Miller* upholds the constitutional right of people released from institutions to live in a New York community (1974).
- In *City of Cleburne v. Cleburne Living Center*, the U.S. Supreme Court bans zoning that discriminates against people with mental retardation (1985).
- The Fair Housing Amendments Act of 1988 makes it illegal to deny access to housing based on disability. The Bazelon Center developed a body of case law to enforce the amendments.

- *Horizon House v. Town of Upper Southampton* holds that a requirement of minimum distance between group homes for people with disabilities in Pennsylvania violates the federal Fair Housing Act (1992).
- *Oxford House v. Babylon* establishes that a group of people with disabilities living together is a "family" for zoning purposes and therefore cannot be excluded from a neighborhood of single-family homes (1993).
- *Potomac Group Homes v. Montgomery County* holds that jurisdictions cannot use different safety standards or neighbor-notification rules for housing to be occupied by people with disabilities (1993).
- When repeal of the Fair Housing Amendments Act is threatened (1998-1999), the Bazelon-led Coalition to Protect the Fair Housing Act successfully protects it.

Access to Mental Health Services and Supports

To enable most people with serious mental illnesses to participate in community life, access to supportive services through the public mental health system is as critical as housing. The Center sought much more than just access to medication and an occasional visit to a provider. Our goal is access to whatever services an individual needs to achieve recovery.

- Congress passes and the President signs the Mental Health Systems Act of 1980. A year later, the law is repealed, replaced with a mental health block grant.
- The mental health block grant, level-funded since 1981, is expanded by 23% in 2000 and another 15% in 2001. As of 2009, states receive \$421 million to help them provide community-based rehabilitation and other mental health services.
- For the first time, thanks to a vigorous campaign led with the help of First Ladies Betty Ford and Rosalynn Carter, mental health is included in a national policy debate on health care (1994).
- The first federal parity law requires private insurers to equalize their annual and lifetime limits on mental and physical health coverage (1996). Full parity is enacted in 2009.
- Congress mandates coverage for eligible children of any Medicaid service, whether optional or mandated, through Early and Periodic Screening, Diagnosis and Treatment (EPSDT) (1989).
- The Children's Health Insurance Program (S-CHIP) enables children whose families cannot qualify for Medicaid to access health care (1997). The program's 2009 reauthorization mandates parity of coverage for mental health services and expands coverage to 4 million otherwise uninsured children.
- A jail diversion program is authorized for individuals with mental illnesses who come into contact with the criminal justice system (2001; grants now total \$50 million a year for five years).
- The Patient Protection and Affordable Care Act includes many provisions expanding access to community-based services for people with mental illnesses (2010).

The Right to Education

Until 1975, schoolhouse doors were closed to millions of children with mental disabilities. The Bazelon Center played a key role in establishing the right of all children with disabilities to appropriate education through America's public schools. Although children's right to be in school is today widely accepted, issues persist around the discipline of students with challenging behavior. We have consistently fought efforts to weaken the IDEA's protections and continue to vigorously promote the use of positive behavior support for all students.

- *Mills v. Board of Education* establishes the right of all children with disabilities to appropriate education through the public schools (1972). In 1975, *Mills* is codified in the federal Education for All Handicapped Children Act, now the Individuals with Disabilities Education Act (IDEA).
- Children's right to receive a free, appropriate public education, including when they are suspended or expelled from regular school for behavior related to their disability, survives challenges in the Supreme Court, in *Honig v. Doe* (1988) and in Congress (1980, 1997, 2001).
- *Blackman v. Board of Education* requires a school district to serve children with serious emotional disturbances in their home communities with non-disabled peers rather than sending them to private residential facilities (1998).

Systems of Care for Children

The child welfare system is often, by default, the public mental health system serving children with emotional or behavioral disorders, who are removed from their homes at alarming levels. The Center has challenged these systems' reliance on institutions such as "residential treatment centers," promoting instead systems of care that offer wraparound services and, when needed, therapeutic foster care.

- A far-reaching settlement in *R.C. v. Hornsby* mandates creation of a new system of home- and community-based care for children with emotional or behavioral disorders who are in or at risk of foster care (1991).
- The federal Child Mental Health Services program is created with demonstration grants to 11 states (1992); today the program provides nearly \$92 million in grants to all states.
- *J.K. v. Eden* establishes principles governing operation of a state's Medicaid managed mental health care system for children (2000, implementation ongoing).
- Federal courts in California declare in *Katie A. v. Bonta* that children with emotional or behavioral disorders who are in or at risk of entering foster care are entitled to services in family settings rather than institutions (2006).

Access to Federal Entitlements

Many people with serious mental illnesses rely on federal disability benefits: supplemental security income (SSI) and, if they have worked long enough, Social

Security Disability Income (SSDI). To access public mental health services, they must qualify for Medicaid, which for most adults and many children is through their entitlement to SSI. The Center has long focused on expanding access to these critical entitlements.

- *Minnesota Mental Health Association v. Schweiker* orders the Social Security Administration (SSA) to stop using arbitrary criteria to decide applicants' eligibility for federal disability benefits on the basis of mental impairment (1983).
- Congress reforms the Social Security disability program (1984) and SSA issues new standards and procedures for evaluating mental disability in adults (1985).
- *Bowen v. City of New York* mandates use of the new mental impairment standards and orders the payment of retroactive benefits to all who were dropped from the rolls through use of the illegal procedures (1986).
- SSA revises its children's disability criteria (1990). The Bazelon Center's Children's SSI Campaign results in eligibility for cash assistance and Medicaid for a million children with serious disabilities (1992-1994).
- In *Brad H. v. City of New York*, a federal court ordered adequate discharge planning for people with mental illnesses being released from jail to ensure their timely access to Medicaid and SSI (2000).

Protections Against Discrimination

Stigma and stereotypes about mental illness raise barriers for people with psychiatric disabilities, not only in access to housing in the community but also most notably in education and employment.

- *Souder v. Brennan* applies federal labor laws to residents working at institutions, who, until then, were widely exploited as free institution-maintaining labor (1973).
- *Allen v. Heckler* prohibits discrimination in the terms and conditions of employment on the basis of mental disability (1984).
- The Americans with Disabilities Act (ADA) outlaws discrimination against people with physical or mental disabilities, in employment, public services and all aspects of public life (1990).
- *Clark v. Virginia Board of Bar Examiners* declares that broad questions about a person's history of mental health treatment violate the ADA (1994).
- In cases challenging the ADA's legitimacy, the U.S. Supreme Court rules in *Tennessee v. Lane* that states may be sued for damages for failing to provide access to the courts (2004) for a person with a disability and, in *Goodman & United States v. Georgia*, that the ADA applies to people with disabilities in correctional facilities (2006).
- Settlements in *Jordan v. Nott* and *Doe v. Hunter* lead to revision of many universities' punitive policies that discriminate against students who seek mental health services (2006).

- The Americans with Disabilities Act Amendments Act (ADAAA) restores ADA protections, weakened by courts, for all people with disabilities, including those who take psychiatric medications (2008).

Access to Advocacy

While at the beginning our lawyers could count on few allies, today hundreds of advocates across the nation work to uphold the rights of people with mental illnesses. Our proselytizing for mental health advocacy bore its first important fruit when the President's Commission on Mental Health in 1978 included in its report the recommendation of its task panel on advocacy for the creation of advocacy systems and a "bill of rights" for people with mental disabilities.

- Congress creates the protection and advocacy systems for people with developmental disabilities and Bazelon Center receives funding to provide technical assistance to them (1977).
- The Civil Rights of Institutionalized Persons Act authorizes the U.S. Department of Justice to initiate or intervene in lawsuits to protect the rights of people in state hospitals and developmental disabilities facilities (1980).
- The Mental Health Systems Act of 1980 includes a bill of rights for mental health consumers, which survived repeal of the Systems Act to be incorporated in federal programs funding mental health services.
- The bill of rights forms the basis for congressional establishment and annual funding of the protection and advocacy systems for people with mental illnesses in 1986.

Protections for People Subject to Intrusive Procedures

The "right to refuse treatment" is widely understood to mean the right to refuse forced administration of psychotropic medication. The Center's work for consumer protections has sometimes been erroneously characterized as opposing medication. To the contrary, we have walked a fine line between advocating for consumers' right to refuse forced administration of drugs and safeguarding the proper use of professional discretion in their administration. And throughout, we have fought the all too frequent use of intrusive procedures, such as seclusion and restraint, as punishment.

- *Wyatt v. Hardin* establishes procedures to be followed before an institutional resident may be sterilized (1974) and sets standards governing the use of electroshock in Alabama institutions (1975, revised in 1992).
- *Rogers v. Okin* establishes a competent patient's right to refuse treatment except in emergency situations (1980).
- *Ihler v. Chisholm* recognizes constitutional limitations on the use of seclusion and restraint in Montana's mental hospital (1991).
- Federal rules for the first time govern seclusion and restraint in Medicaid-funded hospitals (1999) and set standards for their limited use in residential treatment facilities for children (2000).

Self-Determination and Privacy

The mental health world has changed greatly in almost four decades. In 1972, the Center's founders had few allies. Today, thousands of mental health consumers, family members, advocates, enlightened providers and others join us in promoting recovery as the goal for people with mental illnesses.

- Template on the Bazelon website enables individuals who may later be subject to a finding of incompetence to create an advance directive for mental health treatment (1999).
- The Bazelon Center joins with Duke University to create the [National Resource Center on Psychiatric Advance Directives](#) (2004).
- New federal health rules give mental health consumers access to their own treatment records and protect their privacy (2000).
- The President's New Freedom Commission on Mental Health issues its final report, for the first time in federal policy setting recovery as the goal of the mental health system (2003).
- Pilot programs demonstrate that self-directed care can work for people with mental illnesses and the Bazelon Center publishes a manual for advocates interested in developing such programs (2008).