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The Mental Health Law Project’s 20 Years

by Lee A. Carty

I. Introduction

In 1989-90, the Social Security Administration (SSA) paid $50 million to 5,000 people with mental illness—benefits retroactive to the date on which they were dropped from the federal disability rolls.

In February 1992, a new nonprofit housing developer, ACCESS Development Fund, opened its first project for homeless people in New York: 54 single-room occupancy units linked to support services.

Both of these events grew out of a single lawsuit, and they exemplify the Mental Health Law Project’s (MHLP’s) use of legal advocacy to change the way society responds to people with mental disabilities. The suit, Bowen v. City of New York,¹ was part of MHLP’s four-year campaign for fairness in SSA’s treatment of people applying for disability benefits on the basis of mental impairment. ACCESS was spun off from MHLP’s New York office, which began identifying and assisting class members—many of them homeless after losing benefits—in claiming back benefits and obtaining a place to live after the Court’s decision in City of New York.

This article offers an overview of MHLP’s history, beginning with its founding 20 years ago by lawyers and professionals working in areas involving mental health and mental retardation, a collaboration among traditional adversaries that was viewed with suspicion in both the legal and psychiatric camps.²

II. The Formation of MHLP

The field of modern mental disability law is itself little more than 25 years old. Its case law dates from two 1966 decisions written by David L. Bazelon, Chief Judge of the District of Columbia Court of Appeals. In Rouse v. Cameron,³ the court found a statutory right to treatment for persons involuntarily confined in Washington, D.C.’s psychiatric hospital. Citing a theory propounded by Morton Birnbaum, a physician and lawyer,⁴ Judge Bazelon further suggested that the Constitution might require either appropriate treatment for or the release of someone like Charles Rouse, who was hospitalized after being acquitted of a crime by reason of insanity. In Lake v. Cameron,⁵ the court held that a civilly committed mental patient had a statutory right to treatment in a setting less restrictive than a 24-hour hospital. Of Rouse and Lake, Judge Bazelon wrote, “I would consider these decisions meaningful if they only lead the law to address seriously the manifold problems raised by the institutionalization—or deinstitutionalization—of disturbed or disturbing individuals.”⁶

By the end of 1971, only a few lawyers around the country had taken up this challenge, suing state institutions and educational systems for violating the constitutional rights of children and adults with mental disabilities. These test cases included Wyatt v. Stickney,⁷ which alleged that staff cuts in Alabama’s institutions deprived mental patients and retardation facility residents of the treatment and training to which they were entitled in exchange for deprivation of their liberty. In Mills v. Board of Education,⁸ plaintiffs asserted that the public schools’ exclusion of children with disabilities violated the children’s rights to equal protection and due process. And the New York Civil Liberties Union (NYCLU),

2. A short article such as this cannot cover mental disability law or even MHLP’s record as the leading national legal advocate in the field. Rather, this article highlights impediments faced and progress made in defining, establishing, and implementing the rights of children and adults with mental disabilities. Except for two 1966 opinions, the judicial decisions discussed include only cases in which MHLP played a major role, as counsel, cocounsel, or of counsel. We apologize to the dozens of legal services attorneys and other effective advocates whose efforts helped shape the law but are necessarily omitted here.

which had a project to represent people with mental
disability-related civil claims, sought damages for Ken-
neth Donaldson, who had been civilly committed to a
Florida hospital for 15 years without treatment. 9

Discovery in these cases confirmed the depth of the
problems. States' large, remote mental health and mental
retardation institutions were little more than human ware-
houses. People often arrived there by default because
relatives or neighbors were worried about or uncomfort-
able with them and the community mental health centers
and public schools could not or would not serve them.
While some were forgotten, to remain institutionalized
for life, others were released when states began to trim
their budgets. Many were "transinstitutionalized" to
nursing facilities and wretched board-and-care homes or
simply dumped to become "revolving-door patients," their
conditions deteriorating until they were readmitted.

The attorneys and experts involved in Wyatt pro-
posed a new organization in January 1972, which they
called the National Council on the Rights of the Mentally
Impaired. Its interdisciplinary approach was designed to
address the technical and ethical issues arising when
courts are asked to weigh individual rights against both
the judgment of treating professionals and the desire of
society for protection against people that it perceives to
be threatening or unmanageable. Ten months later, the
program was incorporated in the District of Columbia as
a nonprofit, public interest organization, the Mental
Health Law Project.

To perpetuate its collaborative strategy, MHLp had
three cosponsors in its early years: the Center for Law
and Social Policy (CLASP), which housed MHLp's head-
quarters; the American Civil Liberties Union Foundation,
which raised its startup funding; and the American Or-
thopsychiatric Association (AOA), which gave it access
to experts for policy development and litigation.

MHLp's organizing lawyers were Charles Halpern,
a founder of CLASP, who had represented Charlie Rouse
in his appeal before Judge Bazelon; Paul Friedman, who
had come from Yale Law School to work on mental health
issues at CLASP; and Bruce Ennis, head of NYCLU's
mental health law program. The three had come together
in Wyatt, representing the leading national organizations
of professionals and consumers. After the court had found
a constitutional right to treatment for people that the state
depri ves of liberty "upon the altruistic theory that the
confinement is for humane therapeutic purposes," 10 the
court asked these organizations to intervene as participat-
ing amici. 11 Together, the attorneys and experts devised
minimum, enforceable standards for physical conditions
such as sanitation and nutrition, for staffing ratios that
would permit affirmative treatment and habilitation, and
for safeguards to protect individual rights.

The process suggested to Halpern, Friedman, and
Ennis and their experts that a multidisciplinary, legal
advocacy strategy might help to reform the public sys-
tems serving people with mental disabilities. To reverse
the historic paternalism of these systems, MHLp would
combine the litigation strategies of the civil rights move-
ment of the 1950s with the legislative and educational
approaches more recently used by the consumer move-
ment. Rather than taking a purely civil libertarian
approach, MHLp's litigation and policy reform activities
would seek resources that could meet consumers' needs
by reflecting their choices (or proper substitute choices
for those found incompetent) about where to live and
what treatment to receive.

Patricia M. Wald, who had been cocounsel in Mills,
joined MHLp as it began operations. Hoping to end
states' woeful neglect of children with mental disabili-
ties, she began by assembling a group of organizations as
amici in Morales v. Turman, 12 establishing standards to
protect the right to treatment for children in Texas juve-
nile facilities.

While MHLp operated out of Washington, Bruce
Ennis remained in New York working out of NYCLU. He

inghouse No. 10,918).

11. Amici were AOA, the ACLU, the American Psychological
Association, and the American Association on Mental Disabili-
ties, later joined by the American Psychiatric Association,
the National Association for Retarded Citizens, and the
National Association for Mental Health.
reh'g, 383 F. Supp. 53 (E.D. Tex. 1974) (memorandum
opinion) (Clearinghouse No. 5723).
believed that the cost of implementing the right to treatment would force states to close their antiquated institutions and reallocate their mental health and mental retardation budgets to create community-based systems. To this end, NYCLU and MHLP brought a suit to replicate Wyatt at the Willowbrook State School on Staten Island. The Willowbrook case took a different turn, however, ultimately becoming a national model for community placement of people with mental retardation.

In April 1973, after a six-week trial, Judge Orrin G. Judd issued a preliminary ruling in New York State Association for Retarded Children v. Rockefeller that the 5,209 residents at Willowbrook had a constitutional right to protection from harm. A consent decree negotiated over the next two years listed in detail what staff needed to do to protect residents, set as Willowbrook’s primary goal the preparation of each resident for life in the community, and required a comprehensive community placement plan.

Judge Judd wrote that the right to protection from harm required such extensive relief “because harm can result not only from neglect but from conditions which ... prevent development of an individual’s capabilities.” During the three years of litigation, he added, “the fate of the mentally impaired members of our society has passed from an arcane concern to a major issue both of constitutional rights and social policy.” The mental disability rights movement had hit its stride.

III. Litigation for Patients’ Rights

Lawyers representing clients with mental disabilities welcomed the expertise available through MHLP to assist them in cases and organize amicus briefs on appeal. Charles Halpern worked with Michigan Law School Professor Robert Burt (now at Yale Law School and chair of MHLP’s board of trustees) on the amicus brief filed for the Supreme Court’s review in Jackson v. Indiana. Amici, four professional organizations, argued that indefinite confinement violated the constitutional rights of a criminal defendant with mental retardation who had been found incompetent to stand trial. The justices agreed, stating that the nature and duration of a commitment must bear a reasonable relationship to its purpose.

The commitment procedures that so often led to inappropriate or indefinite confinement became an advocacy target, and many states, facing litigation, began to revise their mental health codes. In 1974, the National Institute of Mental Health contracted with MHLP to prepare a comprehensive guide for such legislative reform. Over three years, staff, trustees, and members of an advisory board developed a position on the contentious issue of civil commitment. Broadly, MHLP supported a restrictive standard of dangerousness to self or others as demonstrated by a recent overt act. When this standard was met, MHLP supported procedures that would fully protect due process rights (including the right to periodic review of the continued justification for confinement).

Recent proposals have called for relaxation of the standard to allow commitment or commitment to outpatient treatment of a person who is “gravely disabled.” MHLP has opposed a lesser standard, because it places the individual’s fate almost entirely at the discretion of the treating professional. Similarly, MHLP has opposed outpatient commitment, which not only infringes on individual rights, but has been demonstrated to be unenforceable.

MHLP litigation also contributed to strengthening due process protections. In Addington v. Texas, the Supreme Court required clear and convincing evidence of the need for commitment. The criterion of “imminent danger” to self or others was upheld on appeal in Suzuki v. Yuen. The same—unnanimous—Ninth Circuit decision also struck down a Hawaii law permitting commitment for “danger to property.”

A significant number of those confined in state mental hospitals are not committed by a court but are admitted as “voluntary” patients. The Supreme Court has declared that abuse of this process must end, ruling in 1990 that hospitals may not admit as voluntary, without due process protections, a person who is incapable of giving informed consent.

15. Id. at 718.
16. Id. at 716.
22. Suzuki v. Yuen, 617 F.2d 173 (9th Cir. 1980) (Clearinghouse No. 17,736).
The Mental Health Law Project has focused increasingly on ways to enable people with mental disabilities to achieve integration in the community.

In addition to protecting individual autonomy, MHLP’s challenges to involuntary confinement are designed to reform the systems set up to address the needs of people with mental disabilities. The 1975 decision in O’Connor v. Donaldson, establishing the right of a nondangerous person to freedom from custodial confinement, epitomizes the organization’s focus on civil liberties for the dual purpose of protecting consumers of mental health services from abuse and assuring them the dignity of choice.

In reviewing the lower court’s finding that the state had violated Kenneth Donaldson’s rights by confining him without treatment, the Supreme Court expressly refrained from considering the right to treatment as defined by Wyatt. But, seven years later, in Youngberg v. Romeo, the justices recognized a constitutional right to “minimally adequate or reasonable training” to vindicate an institutional resident’s basic liberty interests of safety and freedom from restraints. Youngberg, however, limited liability to a standard of “substantial departure” from accepted professional standards.

The other side of the right to treatment is the right to refuse treatment, a concept contested by some psychiatrists as encroaching on their discretion. But consumers and their advocates maintain that it is up to the legal system, not doctors, to decide whether citizens may be treated without their consent. MHLP’s advocacy for the right to refuse treatment began with an amicus brief in Kaimowitz v. Michigan Department of Mental Health, successfully asserting that the atmosphere of a psychiatric facility is so coercive as to make informed consent to an experimental procedure (psychosurgery) impossible.

Next, at the request of a task force convened by the Florida Commission for Mental Retardation, MHLP developed guidelines for the legal and ethical use of behavior modification. Further litigation established the right to refuse antipsychotic drugs in nonemergency situations. A consent judgment in Mississippi required the state to issue rules drafted by MHLP and its experts protecting the right of all patients in state institutions to make their own decisions about electroconvulsive therapy.

The widespread problem of institutions’ misuse of seclusion and restraint for punishment or administrative convenience received little attention, however, until last year, when a federal court in Montana decided In re Chisholm, imposing rigorous standards for the use of these procedures. In re Chisholm also represents the largest in a series of damages suits brought in state court that MHLP has used to counter the judicial conservatism and deference to professional discretion reflected in Youngberg. MHLP has successfully settled several such cases, obtaining compensation for individuals abused or mistreated by institutional staff. On a second claim in In re Chisholm, claiming that patients were harmed by unjustified confinement in the state hospital’s forensic unit, the court has already enjoined the abusive practices. However, it separated out for trial in May 1992 the request for damages to all patients so confined.

26. Plotkin, Limiting the Psychiatric Orgy: Mental Patients’ Right to Refuse Treatment, 72 U. L. Rev. 461 (Sept.-Oct. 1977). This article, written by an MHLP staff attorney, includes a comprehensive review of the literature on “the psychiatric armamentarium.”
28. Paul Friedman, former MHLP Director, wrote an article about the guidelines that were developed. Friedman, Legal Regulation of Applied Behavior Analysis in Mental Institutions and Prisons, 17 ARIZ. L. REV. 39 (1975).
32. Two settlements yielded damages for abuse and misuse of antipsychotic drugs. A third resolved a claim against the Central Intelligence Agency’s sponsorship of brainwashing experiments conducted by a psychiatrist in the guise of treatment. See H. Weinstein, Psychiatry and the CIA: Victims of Mind Control (1990).
In addition to abuse and misuse of treatment procedures, a problem almost universal in cost-conscious state institutions 20 years ago was the use of patient labor for maintenance and housekeeping—in the name of “therapy”—without pay. Souder v. Brennan applied the federal Fair Labor Standards Act to all residents of institutions. After winning this case, MHLN participated in a Labor Department task force to develop standards for compensation of people in sheltered employment.

IV. Advocating for Community Living

MHLN has focused increasingly on ways to enable people with mental disabilities to achieve integration in the community. An expanding share of its litigation docket and policy agenda is aimed at creating the necessary resources—housing, job training, health and mental health care, peer support, cash assistance, and other programs. Wuori v. Zitnay developed detailed standards for community programs for people with developmental disabilities. Dixon v. Weinberger established a statutory right to treatment in the least restrictive alternative setting for people labeled mentally ill and subject to confinement in the District of Columbia’s psychiatric hospital.

Winning judicial orders such as those in Dixon, Wyatt, and the Willowbrook case is only the first step toward system change. Implementation is much more complex and laborious. Dixon and Wyatt typify the problem; in the effort to substitute a community-based system for the respective states’ institutions, each of these cases is still before the court, consuming countless hours of lawyers’, monitors’, and experts’ time over the years. Plaintiffs in New York State Association for Retarded Children will have fully achieved their goal with Willowbrook’s scheduled 1993 closing; the dramatic history of the case has been documented in David and Sheila Rothman’s book, The Willowbrook Wars—A Decade of Struggle for Social Justice.

Lessons learned in these cases led MHLN to seek a different kind of consent order in an Alabama case on behalf of emotionally disturbed children in public care. The far-reaching 1991 decree in R.C. v. Hornsby spells out principles of and standards for an entirely new system of care and creates a collaborative implementation process. The system is designed to provide in-home support and other community-based services to prevent removal of children from their families into foster care or institutions.

As the case law supporting rights and service models has expanded, MHLN has increased its work in the policy arena. By the end of the 1970s, federal statutes and regulations incorporated a remarkable range of protections for people with mental disabilities. Most hopeful was the consolidation of many of the fragmented federal initiatives supporting community-based mental health care in the Mental Health Systems Act of 1980. The Act reflected recommendations by President Carter’s Commission on Mental Health, including advocacy and a bill of rights for consumers proposed by the commission’s Task Panel on Legal and Ethical Issues, which was chaired by MHLN director Paul Friedman.

V. Combating Cutbacks

Unfortunately, the Mental Health Systems Act was repealed in 1981. In a changed political climate, poor people suffered many losses. Most deeply cut were income support, health care, and housing—resources essential to those with mental disabilities attempting to live outside of institutions.

SSA began using arbitrary standards to assess mental impairment, terminating benefits to hundreds of thousands of people whose only income came in monthly disability or SSI checks. Advocates mounted a full-fledged campaign for reform of the disability program under the Social Security Act. MHLN won federal court orders declaring SSA’s actions illegal, participated in the development of new mental impairment standards, and assisted legal services and other lawyers across the nation in protecting their clients’ eligibility. One victory after another was won. In 1984, Congress enacted the Social Security Disability Benefits Reform Act. In 1985, SSA issued new standards for deciding mental disability claims. In 1986, the Supreme Court ordered SSA to pay back benefits to all New York

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State residents whose eligibility had been denied or terminated and who were now found eligible under the new mental impairment standards. The American Psychiatric Association recognized MHLP's role in these successes by presenting it with the 1987 Arnold L. van Ameringen Award in Psychiatric Rehabilitation.

Children, too, were victims of SSA's arbitrary approach to disability determinations. In 1984, MHLP enlisted 38 national children's advocacy and pediatric professional groups to request formally that SSA revise its criteria for determining a child's eligibility for SSI based on mental impairment. MHLP staff attorneys assisted Community Legal Services of Philadelphia with a national class action challenging SSA's procedures for evaluating children's claims.

It took six years, but this advocacy for children also prevailed. In February 1990, the Supreme Court held, in Sullivan v. Zebley, that SSA must individually assess a child's ability to do the things that other children the same age can do. In December 1990, SSA issued new children's mental impairment criteria, based largely on the draft of a work group in which MHLP had participated.

And in February 1991, SSA issued interim final regulations to implement Zebley. MHLP has published booklets, training aids, and a comprehensive manual to help parents and advocates use SSA's new rules, and has organized a national Children's SSI Campaign, using the public media to inform families about how their children can obtain SSI benefits.

Children with disabilities were also threatened with loss of their education rights in 1982, when the federal government proposed "deregulation" of the Education of All Handicapped Children Act. This law had codified the right to education established by Mills v. Board of Education and a Pennsylvania case settled by the Public Interest Law Center of Philadelphia on behalf of children with mental retardation. It opened the doors of the nation's schools to millions of children with mental and physical disabilities once excluded as "ineducable." In 1977, MHLP and the Children's Defense Fund had organized a nationwide Education Advocates Coalition to press for enforcement of the law. In 1982, in response to the proposed deregulation, the Coalition undertook an aggressive national campaign to protect children's education rights. It worked: the proposed rules were withdrawn.

In the mid-1980s, MHLP reoriented much of its children's advocacy toward implementing a new federal program for preventing or ameliorating disability in infants and young children. The program was created in 1986 as Part H of the Education of the Handicapped Act Amendments of 1986, reauthorizing federal assistance for special education. It provided for five years of funding to states planning comprehensive, interagency, early intervention service systems. MHLP organized a national network of advocates and policymakers engaged in planning and implementing these systems, to whom staff provide technical assistance, training, and support.

42. City of New York, 476 U.S. 467.
49. Today, as the Individuals with Disabilities Education Act, the program serves more than 4.5 million children through the public school system. U.S. DEP'T OF EDUC., THIRTEENTH ANNUAL REP. TO CONGRESS ON THE IMPLEMENTATION OF THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT (19xx).
publications in a series called Early Intervention Advocacy Notebook.

Of particular concern is whether the early intervention systems will protect the rights of the children and families they serve, and whether they will reach low-income, minority, and other traditionally underserved families. MHLP organized two task forces to address these issues. One developed and published policy recommendations for the procedural safeguards required by the Part H legislation; the other is engaged in training and policy advocacy to encourage culturally competent outreach and services.

Perhaps the greatest disaster in the early 1980s for people with mental disabilities was the loss of single-room

51. MENTAL HEALTH LAW PROJECT, STRENGTHENING THE ROLE OF FAMILIES IN STATES’ EARLY INTERVENTION SYSTEMS (1990) (produced for the Division for Early Childhood, Council for Exceptional Children).
occupancy (SRO) units and other low-income housing—a deficit dramatized by the increase in homelessness. Working with the disability and low-income coalitions, MHLP obtained allocation of federal funds for transitional and permanent housing for homeless people at risk of institutionalization. In collaboration with both HUD and the mental health provider and consumer communities, MHLP is promoting the development of housing linked to support systems for people with mental disabilities. In addition to several successful conferences and policy efforts resulting in new housing programs, MHLP developed such units through its New York housing development project, spun off in 1990 as ACCESS Development Fund. A parallel enterprise in Washington is in the organizational stage.

MHLP's principal housing advocacy goal was to end the historic exclusion of people with mental disabilities from communities through discriminatory zoning and rental practices. An early victory in the zoning battle affirmed for people in board-and-care homes a right to live in the community. The Supreme Court's 1985 decision in City of Cleburne v. Cleburne Living Center, that a city may not use its zoning power to exclude a home for adults with mental retardation, laid the groundwork for other litigation. Finally, in 1988, Congress for the first time included people with disabilities in a federal civil rights statute: the Fair Housing Amendments Act. MHLP's Community Watch program published analyses of the Act’s protections in articles and booklets for consumers, advocates, and landlords. Staff attorneys are now litigating test cases and assisting housing providers, advocates, and state policymakers in enforcing the Act's broad protections.

People with mental disabilities are now beginning to enjoy the most comprehensive federal civil rights protections ever available to them, under the Americans with Disabilities Act (ADA). MHLP battled to include them under the ADA's prohibitions against discrimination in employment, public accommodations, and transportation, and will work with the legal services community to enforce this landmark federal law.

VI. Expanding Advocacy Resources

From its inception, MHLP used training, technical assistance, and policy advocacy to encourage advocates to defend the new rights won for people with mental disabilities. By the mid-1970s, mental disability law was a topic at conferences of all of the major national legal, disability, and social policy organizations.

The pool of trained advocates expanded rapidly. The American Bar Association created a Commission on Mental Disability. During the 1970s, a number of legal services offices, with the Legal Services Corporation's encouragement, created pilot programs to represent people with mental disabilities. From 1980-85, MHLP contracted with LSC as a national support center. In 1986, however, the trustees decided not to seek renewal of the contract because LSC proposed to restrict MHLP's use of its other funds in ways that would impede MHLP's effectiveness.

Congress also multiplied advocacy resources. Beginning in 1977, the Developmental Disabilities Assistance and Bill of Rights Act established protection and advocacy (P&A) systems in every state. The Act also funded national support centers to train and assist the new programs. MHLP operated one, the DD Rights Center, headed by Norman Rosenberg (who later became MHLP's director), from 1977 through 1980.

In 1980, Congress enacted the Civil Rights of Institutionalized Persons Act (CRIPA), authorizing the Department of Justice to sue in federal court to protect the constitutional rights of residents in state mental hospitals, retardation facilities, and other institutions. The advo-

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53. E.g., the Shelter Plus Care program, Title VIII, Subtitle C, of the Cranston-Gonzalez National Affordable Housing Act, Pub. L. No. 101-625, 104 Stat. 4079, 4367 (1990), which provides rental assistance to homeless people with disabilities, requires housing agencies to provide assistance in connection with social services funded from other sources.
Advocates for nursing home residents are the most recent addition to the ranks of those representing people with mental disabilities. They are charged with implementing reforms enacted in 1987 to protect from abuse residents who have mental disabilities and to ensure appropriate care for them, including alternative services in the community for those who do not require nursing home care. MHLP conducts training, offers technical assistance, and is producing a series of issue papers, written in collaboration with specialists in gerontological mental health care, under the heading Mental Disability Law and the Elderly.

VII. The Next Decade

The judicial and policy successes of the past 20 years have expanded MHLP’s agenda for the next decade. Enforcement of the ADA, for example, will focus new attention on employment rights. Litigation may be necessary to clarify the rights of infants and toddlers and their families in states’ operation of their new early intervention systems. Other areas of concern, to date unaddressed by legal advocacy, also demand attention. One is the failure of the nation’s mental health system to provide culturally competent services to members of racial and ethnic minorities, resulting in misdiagnosis, segregation, and overinstitutionalization. Advocacy will surely be needed to ensure adequate coverage of mental health care in the impending struggle to reform this nation’s approach to health financing. Finally, the rights of people with mental disabilities are once again under attack by those who believe that coercion is a solution for society’s failure to provide housing and support to people with mental disabilities. The Mental Health Law Project has a full advocacy agenda for its third decade.

65. Omnibus Budget Reconciliation Act of 1987, 42 U.S.C. §§ 1395i-3(a)-(h) (Medicare) and 1396(a)-(h) (Medicaid) (as amended).

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