

Disabled Clients, Constituencies, and Counsel: Representing Persons with Developmental Disabilities

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CODES OF LEGAL ETHICS ARE PREDICATED ON clients who can communicate and make informed decisions regarding the representation. Clients with developmental disabilities do not always fit this conventional model. Nicholas Romeo, age 33 with the mental capacity of an eighteen-month child, could not talk. He could not directly complain of the 63 physical injuries he suffered at the Pennhurst State School and Hospital, or the shackles he was required to wear. Yet, his lawyer was able to file a civil rights suit that led the Supreme Court of the United States to rule that persons committed to state institutions for the mentally retarded have rights to minimally adequate training, and freedom from unreasonable bodily restraints.¹ Phillip Becker, age 14 with Down's Syndrome, could talk and learn the skills to hold a job eventually and to live semi-independently. His parents, however, took a dim view of his prospects and repeatedly refused to consent to corrective surgery for his heart defect. To save his life, lawyers for his foster parents and for disability organizations persuaded the California courts to transfer Phillip's guardianship to the foster parents who would meet his future medical needs.²

As these examples illustrate, the legal process can protect the interests of clients, who, individually or collectively, may have diffi-

¹ *Youngberg v. Romeo*, 457 U.S. 307 (1982).

² *Guardianship of Phillip Becker*. 139 Cal. App.3d 407, 188 Cal. Rptr. 781 (1983).

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culties being an advocate for themselves. That process can result in new rights being created, old rights being enforced, and new duties being imposed. Unlike the more familiar context of self-advocacy by the physically disabled, the developmentally disabled population draws upon advocacy by nondisabled persons to win political and legal gains. Although sharing many broad goals and philosophies with other disability movements, developmental disability advocacy often presents different issues, accommodations, and problems of representation.

Client-centered legal representation of persons with developmental disabilities poses several challenges. In principle, clients with physical disabilities already enjoy the benefits of such representation, and like any other client can expect to participate actively in an attorney/client relationship guided by norms of informed consent. Application of those norms is problematic, however, if the client has cognitive limitations. This article first provides an overview of developmental disabilities advocacy. It next examines the traditional allocation of responsibilities between attorney and client, and identifies the ethical guidelines intended to aid in the representation of individuals under a disability. It then turns to the problems presented when an advocate seeks to represent a class of disabled individuals in a class action in court or in legislative advocacy.

Developmental Disability Advocacy

The Clients

Developmental disability advocacy is as diverse as the population bearing that label. As defined by state laws, this class of individuals includes persons with mental retardation, autism, cerebral palsy, epilepsy, and other developmentally linked neurological impairments (Matson and Mulick 1983). Federal law adopts a functional approach, defining a developmental disability as a severe, chronic impairment, occurring prior to age 22, which results in substantial limitations in three or more "areas of major life activity."³ Although mental retardation can fall under this legal definition, persons with mental re-

³ 42 U.S.C. §6001(5) (Supp. 1989) (major life activity includes self-care, learning, capacity for independent living, language, self-direction, and economic self-sufficiency).

tardation range from those with mild impairment who can speak for themselves and function independently to those with profound impairment who are noncommunicative and need support to survive.

These disabled persons need lawyers for many reasons. In civil commitment and guardianship proceedings, courts can appoint counsel to protect the person's liberty and service interests (Sales, Powell, and Van Duizend 1982). In infancy or old age, their access to life-sustaining treatment may depend on adjudication in the courts⁴ or some other public forum (Annas and Glantz (1986). Under such rubrics as the rights to training, habilitation, or protection from harm, residents of institutions for the mentally retarded have gained improvements of living conditions or release.⁵ Handicapped children now enjoy a right to a free, appropriate, publicly supported education that is enforceable through judicial or administrative processes.⁶ For adults, lawyers not only help with routine criminal or civil legal problems, but with rights-based claims to welfare benefits, habilitation services, and personal freedom.⁷

The Constituency Organizations

In the field of developmental disabilities, the term "constituency organizations" refers to the organized supporters of disability rights, such as cerebral palsy associations, self-help groups, associations for autistic citizens, and some professional organizations committed to clients' rights. Many groups claim to speak for, or espouse the rights of, persons with developmental disabilities. For example, the Association for Retarded Citizens of the United States (ARC/US) identifies the nation's 6,000,000 persons with mental retardation, their families, and friends as its constituency. This broad notion of constituency

⁴ E.g., *In re Guardianship of Infant Doe*, No. 1-7782A157 (Ind. Sup. Ct. April 14, 1982; *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977).

⁵ *New York State Association for Retarded Children v. Rockefeller*, 357 F. Supp. 752 (E.D.N.Y. 1973), subsequent history omitted (hereinafter *the Willowbrook case*); *Clark v. Coben*, 794 F.2d 79 (3d Cir. 1986).

⁶ E.g., *Doe v. Honig*, 108 S. Ct. 592 (1988).

⁷ E.g., *Jackson v. Indiana*, 406 U.S. 715 (1972); *Society for Good Will to Retarded Children v. Cuomo*, 737 F.2d 1239 (2d Cir. 1984) (right to training to prevent deterioration in self-care skills).

encompasses not only a body of active supporters and sympathizers, but a large mass of often uninvolved beneficiaries of ARC's advocacy.

The ARC/US, United Cerebral Palsy, and similar organizations are part of a network with a strong civil rights orientation. ARC has an extensive grass-roots organization involved in initiating new legislation, commenting on proposed regulations, lobbying for service appropriations, and supporting litigation. By 1975 its 250,000 dues-paying members organized in over 1,800 state and local units had the sophisticated leadership and political clout to obtain new declarations of legal and human rights (Matson and Mulick 1983), such as the Education for All Handicapped Children Act.⁸ On state levels, its local affiliates helped secure "bill of rights" laws, antidiscrimination provisions, civil commitment reforms, and expansion of community-based habilitation services. When confronted with service provision laws that were woefully underfunded or institutions that maltreated their residents, ARCs mounted individual and class-action lawsuits.

Some developmental disabilities professionals also contributed to the protection of clients' rights. Their associations promulgated position papers on rights, served as parties in landmark cases, and joined coalitions for national legislation in issues ranging from Baby Doe to the Fair Housing Amendments.⁹ But the consensus of experts was strained when litigation attempted to mandate the closure of institutions or the cessation of aversive behavioral conditioning.

Despite such tensions, parent organizations, professional associations, and self-help groups often work together to safeguard basic rights. These rights include the rights to live in the least restrictive individually appropriate environment, to exercise choices within the individual's capacity to make decisions, and to be protected from cruel treatment or abuse (American Association on Mental Retardation 1973). Self-advocacy groups which are led by persons with developmental disabilities can strengthen their members' abilities to assert their own interests (Williams and Schoultz 1982). Although such groups are more involved in mutual support than in policy-making arenas, these "self-advocates" increasingly focus on rights (Gant 1988).

⁸ P.L. 94-142, 20 U.S.C. §§ 1232, 1401, 1405-06, 1411-20 and 1453 (1982).

⁹ Child Abuse Prevention and Treatment Act, P.L. 98-457, 98 Stat. 1749 (Oct. 9, 1984); Fair Housing Amendments Act, P. L. 100-430, 42 U.S.C. §§ 3601-3614 (Supp. 1989).

On a wide range of issues—from the abolition of capital punishment for mentally retarded persons to the extension of early special education to handicapped infants—this advocacy network often takes a unified position.¹⁰

The Counsel

Lawyers play a role in framing those positions and reconciling the interests of individual clients and constituency organizations. A specialized bar exists in the mental disability field that maintains close ties to both professional and consumer organizations. Its ranks include “protection and advocacy systems” created under federal law,¹¹ legal aid programs for the poor,¹² state-funded agencies such as the New York Mental Hygiene Legal Service or the Ohio Legal Rights Service, public interest law firms such as the Mental Health Law Project and the Center for Public Interest Representation, law school clinicians, and private practitioners. This article will refer to those specialist lawyers as the “disability counsel.” Over the past two decades, they have developed considerable legal and policy expertise through frequent representation of individuals with developmental disabilities and their constituency organizations. In addition to drafting positions that can serve as the basis for joint amici curiae briefs, or proposals for legislative or executive branch action, disability counsel often select cases or issues with strategic value for highly visible advocacy.¹³

Lawyers have the potential to dominate their developmentally disabled clients and usurp decisions that nondisabled clients would expect to make. This risk stems from several factors. The number of such

¹⁰ E.g., Amici brief of American Association on Mental Retardation (AAMR), American Psychological Association, and seven other organizations, *Perry v. Lynaugh*, No. 87-6177, 57 U.S.L.W. 4958 (June 26, 1989). (Eighth Amendment does not categorically prohibit execution of person with mental retardation); Maryland Act of May 25, 1989, House Bill No. 675 (to be codified at Md. Ann. Code art. 27, § 412) (exempting persons with mental retardation from the death penalty); Education of the Handicapped Act Amendments of 1986, P.L. 99-457.

¹¹ Developmental Disabilities Act Amendments of 1978, 42 U.S.C. § 6012 (1982).

¹² Legal Services Corporation Act Amendments, 42 U.S.C. § 2996(a) (2) (C).

¹³ See, e.g., Amici Brief of American Association on Mental Retardation et al. in *City of Cleburne v. Cleburne Living Center*, 473 U.S. 432 (1985).

practitioners is still limited. The clients are frequently impoverished and often depend on free, low-cost, or contingent-fee services to gain access to the justice system. Furthermore, the temptation to be paternalistic is enormous when representing clients with developmental or other mental disabilities. Some clients may not only have certain expectations of how their lawyers should behave, but their lawyers may come to perceive themselves as expected to be bright and articulate. If some clients have narrow experience, their representatives are supposed to be worldly and sophisticated. If some clients are emotional and subjective, lawyers hold themselves out as analytical and objective. These images and stereotypes enhance the power of counsel to set the goals of representation, and even to confer "client" status on some disabled persons but not on others.

Occasionally, lawyers may be tempted to impose their own goals and ideologies on clients. The process of client-centered counseling is time-consuming, and adequate consultation with disabled clients and constituency organizations may require extraordinary patience. As a result, a few lawyers short-circuit this consultation process. In one landmark "right to treatment" case for mentally disabled persons, the lead plaintiff lawyer would later unabashedly proclaim: "I played God. I never met [the named class action plaintiff] or his guardian. And I never needed to do so. I knew what needed to be done." At least in the case in question, the lawyer achieved substantial material gains for members of the plaintiff class notwithstanding any psychological or political harm he may have caused by neglecting their views. But the scenario of a class action commander with decision-making authority becomes even more disturbing when one considers the possibility of a lawyer whose goals in conducting the litigation are neither benevolent nor consistent with the clients' interests. And other forms of legal representation are subject to less outside scrutiny than the class action, which at least requires that a judge approve any settlements or dismissals as fair, adequate, and reasonable.¹⁴

¹⁴ Federal Rule of Civil Procedure 23(e).

Client Control and Lawyer Discretion

The Traditional Bipolar Model

Under the legal profession's conventional norms, the client has the last word on ends and the lawyer has effective control over means. Although the client is to set the objectives of representation, the lawyer retains considerable latitude in determining the strategies and tactics by which to pursue those objectives. The traditional model of the professional/client relationship assumed that the client would be best served by a trusting delegation of decision-making power to the lawyer (Rosenthal 1974). Although newer client-centered approaches encourage clients to participate in weighing alternatives and determining means (Binder and Price 1977), many lawyers are skeptical of participatory models and many clients choose not to question their lawyer's methods.

The traditional model focused on the context of an autonomous client coming to a law office and presenting a legal problem to a single attorney. Under the American Bar Association's Model Code of Professional Responsibility (known as the Code), the attorney was then duty-bound to represent the client zealously, subject to discipline for intentionally failing to "seek the lawful objectives of his client through reasonably available means permitted by law."¹⁵ Clients were to control major decisions, such as acceptance of a settlement or waiver of affirmative defenses or substantial rights. The lawyer's authority to make decisions without the client's inputs thus appears to be narrow and technical.

Failures of Traditional Representation

For the client with a mental disability, this traditional model simply did not work. As a result of economic, cultural, and social forces, these potential clients seldom came to law offices and lawyers were infrequent visitors to institutions. On those rare occasions when lawyer and potential client met, problems of communication often hindered the pursuit of the client's goals. For example, an attorney delayed filing a civil rights claim of medical malpractice because he believed

¹⁵ American Bar Association, Model Code of Professional Responsibility DR 7-101(A) (1) (1969).

the retarded client—who had recently been released from the state mental hospital—was too confused and too frantic to discuss the complex issues involved. This resulted in a two-year delay in bringing the suit and the eventual dismissal of the client's damage award.¹⁶ If instead, third-party support and assistance had been sought early in the counseling process, the attorney and client might have achieved a more effective working relationship, and prevented the claim from being barred by the statute of limitations. Interested third parties can not only clarify what the client wants, but can also offer emotional support to the client and practical guidance to the attorney.

Through systems of appointed representation, disabled clients often received routine or ineffective assistance.¹⁷ Because of unresolved ethical and practical problems, even conscientious lawyers shunned representing people labelled as mentally retarded. The problems were myriad. For example, what capacities did an individual have to possess to be a client? Since the lawyer derives authority as the agent of another, that agency assumes a capacity on the part of the principal to make decisions. Second, after an attorney/client relationship was established, how should the attorney act if the client's goals or strategy seemed at war with the client's interests? Similarly, if the client was so vacillating as to make representation difficult, should the relationship continue? Additionally, how should the lawyer react to the client who is overly dependent on the lawyer and cedes all decisions to the presumably more experienced counsellor? And finally, because many prospective disabled clients are poor or lack control over their assets, lawyers in private practice will often look to third-parties for payment. But those third-parties, whether relatives, guardians, or constituency organizations, may have interests at odds with those of the disabled person. When such clients also have difficulties articulating personal interests, the ethically sensitive lawyer must consider how to allocate decision making between disabled clients, their personal representatives, constituency organizations, and counsel. To these and other perplexing dilemmas, there are no pat solutions (Perlin 1989).

¹⁶ *Cobb v. Nizami*, 851 F.2d 730 (4th Cir. 1988).

¹⁷ See, e.g., *State ex rel Memmel v. Mundy*, 75 Wis. 2d 276, 249 N.W. 2d 573 (1977); *Michigan Association for Retarded Citizens v. Wayne County Probate Judge*, 79 Mich. App. 487, 261 N.W. 2d 60 (1977).

Visions of Normalization

The legal profession's ethical codes have offered little guidance on how to represent the client with a serious mental disability. They permit lawyers to adopt a stance as the partisan champion of the client's expressed wishes, or the benevolent protector of the client's best interests. Although the controversy over the attorney's role has raged for nearly two decades in the civil commitment context between what can be termed the "client-centered expressed interests" model versus the "best interests" model (Schwartz et al. 1983), neither the Code of Professional Responsibility nor the newer Model Rules of Professional Conduct have taken sides on that controversy. Indeed, the ethics codes foster confusion about the lawyer's proper roles. When coupled with the disabled client's poverty, physical isolation, or unusual legal problems, the absence of clear ethical guidelines may also contribute to substandard legal representation.

The Code offered platitudes on the lawyer's assuming additional, but largely undefined, responsibilities for the disabled client. Those responsibilities were to vary "according to the intelligence, experience, mental condition or age of a client, the obligation of a public officer, or the nature of a particular proceeding."¹⁸ Thus, the lawyer was said to have "additional responsibilities" for a client whose mental or physical condition "renders him incapable of making a considered judgment on his own behalf."¹⁹ In the straight-forward case of a person adjudicated incompetent acting through a guardian or "other legal representative," the lawyer must look to such a representative for direction. In the harder cases of a questionably competent client or a client incompetent in fact but without a representative, the rules simply failed to give any meaningful guidance. They condoned a form of defacto guardianship, permitting the lawyer to make decisions on behalf of the client in court proceedings. In such uncomfortable instances, the lawyer was admonished to "consider all circumstances then prevailing and act with care to safeguard and to advance the interests of his client."²⁰ In effect, the Code told lawyers to act prudently but left to their discretion how to define client interests.

The legal profession had to look elsewhere for ethical advice on

¹⁸ Model Code of Professional Responsibility, EC 7-11.

¹⁹ Ibid. EC 7-12.

²⁰ Ibid.

representing persons in disabilities cases. Although the Code made a bow toward client participation, it left the lawyer considerable freedom to rely on the client's judgment or to override it; to secure a legal representative for an "incompetent" or to "call the shots" in the absence of a duly qualified guardian. Code provisions were criticized as vague and offering "little guidance" for the representative in a commitment proceeding (Perlin and Sadoff 1982). With the disability rights movement and case law reinforcing expectations that lawyers would perform adversary roles for their disabled clients, lawyers who did not meet those expectations could face criticism and even discipline.²¹

The legal literature revealed other difficulties in lumping together disparate conditions under the term "disability." The problems of representing a client mute as a result of profound mental retardation (Baron 1978) are obviously different than those of an elderly client confused as a result of illness or bereavement. The former client has no hope of "recovery" to a competent state and no history of expressed wishes that can guide a lawyer. In urging the appointment of a guardian solely for the purpose of litigation to articulate the interests of such a client, Mickenberg (1979) called for more scholarship to determine legitimate representation of the noncommunicative client. Annas and Glantz (1986) stressed that the critical issue in treatment refusal is the adult patient's incompetence not age. But age clearly matters when a child is too young or too cognitively limited to provide effective guidance to a court-appointed attorney (Guggenheim 1984). Patterson (1980) recognized that the lawyer has greater discretion in representing disabled clients than nondisabled clients, but faces difficulties in identifying the client with a mental disability and determining the rights and duties affecting the legal representation. Luban (1981) justified a lawyer's paternalism only when there is some non-circular test of the client's incompetency, a least restrictive constraint on the client's liberty, and a threatened risk of severe and irreversible damage to the client. Thus, the literature acknowledged the slipperiness of concepts of incompetency and the heterogeneity of the "disabled" population.

The Model Rules of Professional Conduct attempt to bring the

²¹ Massachusetts Bar Association Committee on Professional Ethics, Opinion No. 80-4 (attorney in civil commitment proceeding must act as the client's advocate and cannot initiate guardianship proceedings against the client).

norms for representing the disabled client closer to the general norms. The new rule on representing a client "under a disability" states: "When a client's ability to make adequately considered decisions in connection with the representation is impaired, whether because of minority, mental disability or for some other reason, the lawyer shall, as far as reasonably possible, maintain a normal client-lawyer relationship with the client."²² This broad principle is both commendable and noncontroversial. It parallels the "normalization principle," a human services theory which holds that a person with a disability should be afforded, as far as possible, culturally normative ends through culturally normative means (Wolfensberger 1972). Similarly, disabled clients are entitled to counsel who are diligent, competent, and communicative, and are to be treated with "attention and respect" since even the legally incompetent client "often has the ability to understand, deliberate upon, and reach conclusions affecting the client's well-being."²³ In as many respects as possible, the attorney should accord the represented party the status of a client.

Unfortunately, a subsequent rule departs from this vision of normalization by permitting a lawyer to "seek the appointment of a guardian or take other protective action . . . only when the lawyer reasonably believes that the client cannot adequately act in the client's own interest."²⁴ Although softened to make such action discretionary rather than imperative,²⁵ this rule contains no definitions, standards, or examples to guide the lawyer's exercise of this discretion. Yet, disclosure of a client's disabilities can have stigmatizing consequences, such as a finding of incompetence or an involuntary commitment.

The professional codes do not, however, provide much aid to effective, client-centered advocacy. Disabled clients who cannot count on their lawyers to preserve confidences when the client's conduct is not criminal, fraudulent, or suicidal may be reluctant to trust lawyers at all. The lawyer can exert unwarranted control over clients who have only a mild or suspected disability. Since the American Bar Association (1984) uses the term disability to refer to functional

²² American Bar Association, Model Rules of Professional Conduct, Rule 1.14 (hereinafter cited as Model Rules).

²³ Comment to Rule 1.14.

²⁴ Rule 1.14(b).

²⁵ American Bar Association, Model Rules of Professional Conduct (discussion draft 1980).

limitations (i.e., impaired ability to make adequately considered decisions in connection with representation), the ranks of the “disabled clients” may be remarkably wide. In their view, a client’s disability may stem not only from “insanity or retardation” but from “illiteracy, lack of education, fear, anger or other emotional factors, physical or mental stress, alcohol or drug addiction.” Although there must be a reasonable belief that the client cannot act for his or her own interest, Rule 1.14(b) does not require that the attorney also believe that this inability is caused by mental disability rather than by inexperience, folly, stubbornness, or simple mistaken judgment. The professional codes do not demand an inquiry into the causes of the client’s poor choices. Furthermore, the average lawyer is ill-equipped to assess the client’s capacities for informed judgment or to make an appropriate intervention under Rule 1.14(b).

Representing Individuals

Direct Representation

Who speaks for the client with a disability? In most cases, the client is quite capable of speaking for himself or herself. Under the presumption of competence, an individual is presumed competent until the contrary is proven in a court of law (Herr, Arons, and Wallace, 1983). Although some analyses have stressed the position of the severely and profoundly retarded (Rothman 1984), they constitute only 5 percent of the retarded population.

Lawyers are trained to represent the expressed wishes of their clients rather than to divine their best interests. Since the client’s wishes are of primary concern, the lawyer’s initial task is to ascertain the client’s objectives and the scope of legal representation.²⁶ But the lawyer’s duty to abide by the client’s decisions is qualified when the client appears to be “suffering mental disability.”²⁷ In serving such a client, an analytical framework is needed to resolve a series of issues. Can the client express a coherent wish as to the purposes of the legal representation? If not, is the problem one of communication or competency? If there is a communication problem, the lawyer may require

²⁶ Model Rule 1.2.

²⁷ See comment to Model Rule 1.2.

an “interpreter,” an individual who knows the client and is familiar with the client’s idiosyncratic or distinctive way of communicating. If the problem is the individual’s competency to make “adequately considered decisions,” the lawyer may need to consult a clinician to determine if the client can be trained (or restored) to this level of competence. The problem may be one of information or capacity. Information deficiencies can be remedied by training the client, for example, rendering a criminal defendant competent to stand trial through instruction as to courtroom roles (Ellis and Luckasson 1985). Resolving capacity problems, however, can prove more complex. If the problem is a long-term one, or if the legal matter requires urgent attention and treatment approaches to attain competence would take too long, the client will need an appropriate surrogate decision-maker. In selecting the least restrictive form of protective action suited to the client’s circumstances, the lawyer must consider the risks of the contemplated legal action, and the type of legal assistance to be provided (e.g., counseling, negotiation, administrative appeal, litigation).

If it appears necessary to establish incompetency, a judge must review evidence of the alleged disabled person’s incapacity to protect his or her personal or financial interests and decide whether to appoint a guardian to safeguard those interests. As legal representative of the incompetent person, the guardian may act in the name of the ward. However, if no one has instituted a guardianship action whether for reasons of expense, ideology, or simple inertia, a person may be incompetent in fact but not incompetent in law.

Surprisingly, there is virtually no case law or legal commentary on an individual’s capacity to be a client. In practice, the lawyer has unfettered discretion to refuse to accept an individual as a client (Simon 1988). The lawyer may agree to represent the client with a developmental disability directly or through a third-party proxy, who can be a family member or close friend acting with the client’s approval, or a judicially appointed guardian. The lawyer may be tempted to seek a “full guardianship” proceeding—where the client is found totally incompetent and deprived of all civil rights. But the practice of full guardianship can be overused and harmful (Frolik 1981).

Guardianship may be appropriate, however, in cases of profound and irreversible mental incapacity where many decisions will have to be made over time for an individual who is profoundly retarded, severely brain damaged, comatose, or chronically mentally ill (Brakel,

Parry, and Weiner 1985). Lawyers may directly represent such individuals without a guardian when appointed in civil commitment or guardianship proceedings, or when challenging the actions of a guardian.²⁸ But these situations can be uncomfortable, forcing lawyers to act as de facto guardians to fill a decision-making vacuum.

Limited Guardianship

“Limited guardianship” tailors the guardian’s powers and restricts the ward’s freedom only to the extent essential to the disabled person’s well-being. Modern guardianship rules honor the disabled person’s consent to the appointment of a guardian, provided that person had sufficient mental capacity at the time the consent was executed.²⁹ Courts will consider the form of guardianship that is appropriately less restrictive and assign to the guardian “only those duties and powers which the individual is incapable of exercising” (Sales, Powell, and Van Duizend 1982, 462). Rather than impose a guardian to control all decisions over the ward’s personal and financial affairs, the court has the flexibility to establish a guardianship over the person, or over the estate. Thus, limited guardianship reflects the normalization theory by excising no more decision-making power than is justified by the client’s demonstrated mental or functional limitations.

Alternatives to Guardianship

One defect of the ABA rules is their emphasis on the appointment of a guardian and lack of specificity as to the “other protective action” that might be undertaken. Many attorneys are unfamiliar with the alternatives to guardianship, or the advances in habilitation that might foster more normal attorney/client interaction. Furthermore, many clients recognize their own limitations and would accept the offer of voluntary protective or supportive social services (Regan 1981). Although guardianship is the only protective action specifically identified in the professional codes, such an appointment may be “expensive or traumatic for the client.”³⁰ The client’s assets may be consumed to

²⁸ E.g., *Developmental Disabilities Advocacy Center v. Melton*, 689 F.2d 281 (1st Cir. 1982).

²⁹ E.g., Maryland Rule R77 a. 2.

³⁰ Comment to Model Rule 1.14.

pay for the proceedings. Guardianship may also divest clients of important personal and civil rights they are able to exercise, further reducing their self-esteem. Less drastic options need to be explored.

If litigation is filed, a plaintiff who is a minor or under a mental disability must sue through a "next friend." Next friends can be relatives, personal friends, concerned professionals, or other interested citizens.³¹ Although the client under the disability is the real party in interest, the next friend acts to set representation goals and guide counsel. This procedure is economical, convenient, and nonintrusive. Since rules of civil procedure generally do not specify qualifications, the plaintiff's lawyer names the next friend, subject only to judicial review in contested cases.³² No preliminary judicial proceeding is required, and no determination of legal incompetency results from the designation of a next friend. One potential drawback of this approach, however, is its degree of attorney control.³³

A legally competent person may confer a "power of attorney" that authorizes a specified "attorney in fact" to make decisions on his or her behalf. Although such powers generally lapse on incompetence, so-called "durable powers of attorney" can survive the individual's disability and guide the individual's chosen decision-maker. By analogy to "living will" statutes that authorize certain medical treatments should the patient become incompetent, such powers can offer direction to a surrogate decision-maker for the provision of legal services, protective services, housing, financial matters, and habilitation plans.

Various administrative agencies can appoint representatives for disabled persons receiving benefits. The Social Security Administration can designate a "representative payee" to receive and manage the beneficiary's payments. "Protective payees" can perform similar functions for other state or federal benefit programs.³⁴ Under the Education for All Handicapped Children Act, a "surrogate parent" can approve individualized educational plans (IEPs), engage counsel, and otherwise assert the rights to education for pupils whose parents are deceased

³¹ E.g., *Duane Youngberg v. Nicholas Romeo, an Incompetent, by his mother and next friend, Paula Romeo*, 457 U.S. 307 (1982).

³² F.R.Civ.P. 17(c).

³³ E.g., *Institutionalized Juveniles v. Secretary of Public Welfare*, 758 F.2d 897 (3rd Cir. 1985) (lawyer for the plaintiff class designated himself as their next friend and guardian ad litem).

³⁴ 42 U.S.C. § 606(b) (2); 45 C.F.R. § 234.70 (1972).

or unavailable.³⁵ Common features of these appointments are their limited purpose, relative informality, and limited or no cost.

Reliance on concerned next-of-kin is another informal solution that has both pragmatic and theoretical appeal. A close family member is often familiar with the client's values, and has the emotional and social bonds to have a stake in securing the client's best interests. Although controversial, the Supreme Court in *Parham v. J.R.*³⁶ recognized the parents' role as proxy decision-maker for the minor subject to mental hospitalization. The *Parham* decision only dealt with disabled minors, however, and most jurisdictions do not permit family members to give legally binding consent for disabled relatives who are over the age of majority (Tremblay 1987). Accordingly, when representing a client who is partially competent, a lawyer may prudently seek the concurrent consent of the client and a concerned family member (Turnbull et al. 1977). But concurrent consent is not legally binding if a court should later find that the client was incompetent, or if serious conflicts of interest existed between the client and her family over institutionalization,³⁷ or control of financial resources (Burt 1979).

Alternatively, the lawyer might seek a citizen advocate's or self-advocacy group's support as a means of validating the partially competent client's goals and communications. "Citizen advocacy" is designed to offer a client with a mental disability a mature, effective "citizen volunteer representing, as if they were his own, the interests of another citizen" and to fill needs for practical or emotional support (Wolfensberger 1972). Although such volunteers do not have specific legal missions, they do protect their protégé's right by locating professional services.

"Self-advocacy groups," membership organizations led by and composed of persons with disabilities, assist their members to assert their rights, make choices, and assume responsibilities as full participants in society (McTaggart and Gould 1988). Such groups sometimes refer their members to lawyers, and can provide the lawyer and client with ongoing training and consultation to increase the client's competence

³⁵ 20 U.S.C. § 1415(b) (1) (B).

³⁶ 442 U.S. 584 (1979).

³⁷ *Guardianship of Becker*, 139 Cal. App.3d 407, 188 Cal. Rptr. 781 (1983); *Association for Retarded Citizens of North Dakota v. Olson*, 561 F. Supp. 473, 484 (D. N.D. 1982).

to participate in an attorney/client relationship. They can also offer peer support for clients faced with the unfamiliar, anxiety-provoking, and often protracted business of pursuing a legal matter to the end. Although these approaches have great promise, unfortunately they may not be available in all communities and may introduce delays when legal action must be swift and certain.

Professionally staffed protective services offer another alternative to guardianship. Some are organized on a private basis, in affiliation with nonprofit constituency organizations. For instance, the Maryland Trust for Retarded Citizens, a subsidiary of the Maryland Association for Retarded Citizens, provides personal trust and visitation services for over 200 disabled clients whose families have paid a lump-sum membership fee. If the trust's social worker uncovers abuse of a client's legal rights, the trust would authorize counsel to take necessary legal action. Under adult protective services laws, a case manager can obtain legal services to assist the disabled adult to live safely in the community without resort to civil commitment or guardianship (Brakel, Parry, and Weiner 1985).

In summary, the lawyer representing an individual with a mental disability may face difficult choices. A lawyer who believes the client is about to make a seriously injurious decision must decide when persuasion becomes manipulation, and when the failure to invoke some form of protective action becomes unconscionable neglect. In such cases, he or she must consider the potentially massive infringement of plenary guardianship on individual liberty, and the conflicts between acting on the client's wishes and sparing the client from possible harm. Other clients may make untutored choices, or yield their decision-making powers unconditionally because no one has taken the time to improve their capacities for becoming a participatory client.

Representing Classes of Disabled Individuals

If the difficulties in representing an individual can be great, the ethical challenges in representing whole classes of disabled individuals can be numbing. Examples are numerous. In Willowbrook where over 5,209 persons were housed when litigation was filed—ranging from individuals with profound retardation to those of normal intelli-

gence—the lawyers would help shape the policies that determined which class members had priority in leaving a destructive institution for decent community alternatives (Herr 1983; Rothman and Rothman 1984).³⁸ In Saint Elizabeths Hospital, a class action mandated less restrictive alternatives for its patients but was implemented in a way that perhaps increased the number of homeless persons on Washington's streets.³⁹ During the lengthy *Pennhurst* case, some parents of mentally retarded plaintiffs rejected the goal of institutional closure and claimed that the plaintiffs' lawyers paid insufficient attention to individual differences and alternative remedies.⁴⁰ Those dissenting parents, through a variety of legal procedures, pressed their claims against transfers to community living arrangements.⁴¹ Although *Pennhurst* was ultimately closed, a parent could still appeal the professional judgment to move a resident to the community or another institution before the "independent neutral retardation professional."⁴²

Conflicts in Class Actions

In class actions, counsel and constituencies gain powerful levers to change disability policy. Many of those actions precede and help create a factual record for legislative reform. Thus, *Mills v. Board of Education*⁴³ and *Pennsylvania Association for Retarded Children v. Pennsylvania*⁴⁴ provided the equal protection rationale and conceptual

³⁸ *NYSARC v. Carey*, 393 F. Supp. 715 (E.D.N.Y. 1975) (the *Willowbrook Case*).

³⁹ *Dixon v. Weinberger*, 405 F. Supp. 974 (D.D.C. 1975).

⁴⁰ *Halderman v. Pennhurst State School and Hospital*, 446 F. Supp. 1295 (E.D. Pa. 1977), aff'd in part, rev'd and remanded in part, 612 F.2d 84 (3d Cir. 1979) (subsequent history omitted).

⁴¹ *Halderman v. Pennhurst State School and Hospital*, 612 F.2d 131 (3d Cir. 1979) (motion to intervene by Pennhurst Parents-Staff Association and six Pennhurst residents for purposes of appeal denied); 465 U.S. 89, 94, n.2 (1984) (intervention subsequently granted and Parents-Staff Association was heard before the Supreme Court); 707 F.2d 702 (3d Cir. 1983) (transfer of 12-year-old profoundly retarded resident to a more beneficial community placement denied since parents' rights to determine child's upbringing received insufficient consideration).

⁴² *Halderman v. Pennhurst State School & Hospital*, No. 74-01345, Final Settlement Agreement (E.D. Pa. April 12, 1985).

⁴³ 348 F. Supp. 866 (D.D.C. 1972).

⁴⁴ 343 F. Supp. 279 (E.D. Pa. 1972).

underpinning for the Education of All Handicapped Children Act.⁴⁵ Similarly, the institution reform cases, such as *Wyatt v. Stickney*⁴⁶ and the *Willowbrook* case,⁴⁷ inspired Medicaid intermediate care facilities for the mentally retarded (ICF/MR) standards and the Developmental Disabilities Assistance and Bill of Rights Act.⁴⁸ After reviewing court testimony of 90 inmates locked on wards with a single aide and of men left in solitary confinement for seven years, Congress mandated protection and advocacy (P&A) programs to prevent such horrors from reoccurring. But not all class actions have proved successful,⁴⁹ or arguably have been guided by counsel committed to the goals of integration and least drastic interventions.⁵⁰ Because such actions have the potential for adverse impacts—binding precedents on class members and negative fiscal or policy consequences on nonparty disabled persons—the disability rights movement and disabled clients can ill afford lawyers who operate as loose cannons.

Conflicts among class members and their representatives seldom surface or are adequately resolved. Some class action lawyers may ignore or paper over differences between class members, hoping that the legitimacy of their overall goals and the process of developing individualized treatment plans will produce benefit for the class as a whole. Plaintiffs rarely terminate class action counsel; and even if they do, the counsel may still be able to represent other named plaintiffs or factions in the suit. Dissident class members may also seek to intervene on the grounds that their interests are not adequately represented by the existing parties. But some courts have interpreted

⁴⁵ P.L. 94-142, codified at 20 U.S.C. §§ 1411-1420 (1982) & Supp. III (1985).

⁴⁶ 344 F. Supp. 387, (M.D. Ala. 1972), *aff'd in part Wyatt v. Aderholt*, 503 F.2d 1305 (5th Cir. 1974).

⁴⁷ *New York State Association for Retarded Children v. Rockefeller*, 357 F. Supp. 752 (E.D.N.Y. 1973), consent decree approved *sub nom. New York State Association for Retarded Children v. Carey*, 393 F. Supp. 715 (1975).

⁴⁸ 42 U.S.C. §§ 6000, *et. seq.* (1982).

⁴⁹ *E.g., Burnham v. Department of Public Health*, 349 F. Supp. 1335 (N.D. Ga. 1972), *rev'd*, 503 F.2d 1319 (5th Cir. 1974), *cert. denied*, 422 U.S. 1057 (1975) (limited factual investigation and ultimate dismissal of right-to-treatment suit).

⁵⁰ *Behavior Research Institute v. Leonard*, No. 86E 0018-G1 (Mass. Probate and Family Court, Bristol Co., 1987) (advocacy of drastic, aversive behavioral techniques); *McEvoy v. Stevens*, No. 74-2769-M(T) (D. Mass. July 12, 1977) (consent decree stressing institutional repair rather than less restrictive placements).

interest to mean a legally protected interest, not merely a policy preference. Thus, in a state-wide suit to close state schools for the retarded, the U.S. Court of Appeals for the Fifth Circuit rejected the Parent Association for the Retarded of Texas and two class members as would-be intervenors where they sought to advocate a particular policy (institutional reform instead of closure) rather than a legal right.⁵¹ Other courts and commentators have not drawn this distinction, however, recognizing that the policy functions of public law litigation should expand the parties and interests represented (Chayes 1976).

Alternative solutions focus on the creation of subclasses or polling a representative sample of the class. For lawyers who are client-centered, this involves forming consultation groups or steering committees to aid in making critical strategic decisions for the class, especially those involving nonlegal considerations.⁵² If class members are too disabled to participate in that process, such groups might consist of former institutional residents, or members of constituency organizations such as associations for retarded citizens or self-advocacy groups. Such groups only imperfectly serve, however, as proxies for institutionalized plaintiff classes. And as the size of the class increases, so does the risk that the class remedy may be slower and less desirable than individually tailored solutions, or may generate unintended policy consequences.⁵³

Executive Branch Rights Enforcement

Even more problematic are suits undertaken in the name of the United States government to remedy patterns of civil rights violations. Because the government's interests are not identical to those of the inmates, those suits have often resulted in inadequate decrees which ignore rights to placement outside institutions, or lack effective monitoring of rights related to treatment conditions. Yet, the courts have

⁵¹ *Lelsz v. Kavanaugh*, 710 F.2d 1040, 1046 (5th Cir. 1983).

⁵² E.g., *Brewster v. Dukakis*, No. 76-4423-F (D. Mass., Dec. 6, 1978) (consent decree requiring extensive deinstitutionalization of mentally disabled residents of Northampton State Hospital); 675 F.2d 1 (1st Cir. 1982).

⁵³ E.g., *Souder v. Brennan*, 367 F. Supp. 808 (D.D.C. 1973) (nationwide action to enforce Fair Labor Standards Act may have reduced vocational activities and increased idleness in some mental facilities).

turned aside attempts by private advocacy groups to intervene in cases brought by the Justice Department under the Civil Rights of Institutionalized Persons Act.⁵⁴ As with class actions which require judicial approval of a settlement or dismissal as fair, reasonable, and adequate, the adequacy of representation of the residents' interests by the United States should be subject to judicial hearing and oversight. In cases with such far-reaching impacts, judges need to hear a range of perspectives.

Recent legislation avoids a monopoly in civil rights enforcement for handicapped persons. Although the U.S. Attorney General is empowered to go to court to remedy discriminatory housing practices, mentally or physically handicapped persons can opt to bring such complaints before a court or an administrative law judge under the Fair Housing Amendments.⁵⁵

Reforms by Nonprofit Advocacy Organizations

Nonprofit advocacy organizations can keep civil rights enforcement "honest" and provide authentic representation for classes of disabled persons. Legal aid and protection and advocacy (P&As) offices have developed state-specific manuals, standards, and guidelines for representing persons with mental disabilities in typical proceedings (i.e., civil commitment, guardianship, special education). They have advised private counsel who are unfamiliar with disability issues, and monitored patterns of individual representation. If representation is glaringly ineffective or a sham, they can bring suit to appoint new counsel or to change the system for delivery of legal services. In one notorious episode, over 100 mentally retarded persons were placed under guardianship in an assembly-line court session lasting little more than an hour.⁵⁶

Public interest lawyers can also reduce the barriers that separate potential clients with disabilities from the justice system. In collaboration with self-advocacy groups, they have litigated for advocacy

⁵⁴ 42 U.S.C. § 1997 (1982); *U.S. v. Connecticut*, No. N-86-252 (D. Conn. Dec. 22, 1986); *Dober v. Meese*, No. N-86-195 (EEB) (D. Conn. Sept. 15, 1986).

⁵⁵ 42 U.S.C. §§ 3613-3614 (Supp. 1989).

⁵⁶ *Michigan Association for Retarded Citizens v. Wayne County Probate Judge*, 79 Mich. App. 487, 261 N.W.2d 60 (1977).

projects in institutions,⁵⁷ organized pro bono representation projects for those in homeless shelters, and developed a literature on how to represent vulnerable clients in unconventional settings (Schwartz et al. 1983). Since public interest lawyers often choose their clients rather than vice versa, they have great latitude in setting their own agendas for law reform.

This is especially true of legislative advocacy where the lobbyist for organizations representing disabled clients or constituencies can aggregate diverse interests to advance certain rights. Despite a Reagan administration hostile to entitlements and detailed regulation, the disability advocates defeated efforts to dilute special education laws. In response to unfavorable Supreme Court opinions, they obtained congressional overrides that now permit discrimination actions against any part of a federally assisted program, attorneys' fees in special education cases, and child abuse protections for imperiled newborns. With the passage of the Fair Housing Amendments Act of 1988⁵⁸ that extends civil rights safeguards to disabled persons and a mounting campaign to reduce the institutional care bias of the Medicaid program for the developmentally disabled, there is fresh evidence of the viability of federal legislative strategies. The passage of the Protection and Advocacy for Mentally Ill Individuals Act of 1986 is a reminder of those dynamic possibilities in even conservative periods.⁵⁹

The Role of Constituency Organizations

Typically, the constituency organizations offer lawyers more direction in class action litigation and legislative advocacy than in individual cases. As repeat players in various disability fields, the disability counsel tend to develop a sense of connection to a body of supporters that may include past and potential clients, consumer groups, allied professional associations, advocacy organizations, and their own legal peers. When highly visible legal interventions are undertaken, they are likely to consult with, or "hear from," other disability rights activists.⁶⁰ Consumer groups may decide to join or to intervene in

⁵⁷ *Coe v. Hughes*, No. K-83-4248 (D. Md. April 4, 1985).

⁵⁸ P. L. 100-430; 42 U.S.C. §§ 3610-3631 (Supp. 1989).

⁵⁹ 42 U.S.C. §§ 10801-10851 (Supp. IV 1986).

⁶⁰ E.g., *Homeward Bound v. Hissom Memorial Center*, No. 85-C-437-E (N.D. Okla. May 1988), appeal docketed, No. 88-1119 (10th Cir. Aug. 15, 1988) (segregation of retarded persons in institutions ruled illegal).

their lawsuits. Professional associations may contribute amicus curiae briefs or offers of expert assistance. By raising a "war chest" to pay the cost of experts and discovery, these organizations enhance a party's negotiation leverage. In short, the lawyer engaged in class or systemic advocacy is subject to some scrutiny over the goals and means being pursued, which the lawyer representing an individual client may not be.

Constituency organizations can reach out to vulnerable individuals in ways that lawyers who may be constrained by time or ethical codes cannot. For instance, a federal court has held that advocacy groups such as the Spina Bifida Association of America and the Association for Persons with Severe Handicaps have standing to sue to prevent a hospital from discriminatory medical treatment based on disability or socioeconomic status.⁶¹ Constituency organizations can also recruit members who might otherwise be unaware of their rights to become plaintiffs in test cases or named plaintiffs in class actions. They can make issues visible that policy makers have previously ignored. Indeed, those organizations have supported litigation implementing legal rights to habilitation, to psychiatric treatment, to freedom from involuntary servitude in mental institutions, and to appropriate public education.

The Association for Retarded Citizens (ARC) illustrates a constituency regularly employing the tools of law reform. Founded in 1950, ARC maintains a vigorous governmental relations program on federal and state levels. When political pressure tactics failed to correct human rights abuses, ARC leaders turned to the courts. They began with attacks on two massive problems: the exclusion of two million handicapped children from appropriate schooling, and the containment of some 200,000 persons in warehouse-style custody. Their strategy was built on consolidating litigation gains in national standard-setting laws and regulations. As the federal courts became less sympathetic to activist judicial interpretations, the ARC focused on state courts, rule-making, and legislative agendas. Yet, ARC affiliates still managed decade-long federal litigation in significant right to habilitation cases.⁶² If a case was lost below and the potential for making bad law

⁶¹ *Johnson v. Sullivan*, No. CIV-85-2434-P (W.D. Okla. June 27, 1987).

⁶² E.g., *Connecticut Association for Retarded Citizens v. Thorne*, No. H78-653 (D. Conn., filed Dec. 6, 1978); *Florida Association for Retarded Citizens v. Graham*, No. 79-418 (M.D. Fla., filed Aug. 22, 1979); *Washington Association*

at the Supreme Court was too great, the national organization would persuade its local affiliate not to petition for certiorari review.⁶³ But ARC was prepared to advocate for controversial causes if the stakes were high enough, devoting legal resources to abolish the death penalty for persons with mental retardation.⁶⁴

Since the interests of named clients and class clients—let alone clients and constituency organizations—may not always be consistent, attorneys must be free to make independent judgments that place loyalty to clients above allegiance to broader groups. In the attorney/client relationship, there is a negotiated scope of representation, a standard of care (whose violation can give rise to a legal malpractice action), and professional responsibilities (whose breach can lead to disciplinary sanctions).⁶⁵ The attorney may have a duty to pursue the client's interests even to the detriment of other disabled persons, and is relatively free to reject calls for solidarity with disability groups. In contrast, constituency organizations are organized for political or law reform goals, supporting test-case litigation as parties or amici curiae that advance those goals. But the realms in which they are the primary players are not judicial, but legislative, regulatory, and political.

In egregious cases, however, constituency groups should defend client self-determination and welfare from lawyer neglect. For example, effective assistance of counsel is impossible if one attorney is appointed to represent 23 persons in commitment hearings scheduled for the same time.⁶⁶ Constituency groups can expose due process violations that turn judicial proceedings into hollow gestures.⁶⁷ In other “whistleblowing” roles, they can seek court approval to remove unscrupulous lawyer-guardians or other negligent fiduciaries. In impact litigation, they can work with steering committees to discharge

for *Retarded Citizens v. Thomas*, No. C-78-168 (E.D. Wash., filed June 16, 1978).

⁶³ E.g., *Lelsz v. Kavanagh*, 807 F.2d 1243 (5th Cir. 1987), cert. dismissed sub nom., *Association for Retarded Citizens v. Kavanagh*, 108 S. Ct. 44 (1987).

⁶⁴ *Penry v. Lynaugh*, 832 F.2d 915 (5th Cir. 1987), affirmed in part and reversed in part, 57 U.S.L.W. 4958 (June 26, 1989); Md. Ann. Code art. 27, § 412.

⁶⁵ *State ex rel. Nebraska State Bar Association v. Walsh*, 206 Neb. 737, 294 N.W.2d 873 (1980).

⁶⁶ *Ex parte Ullmann*, 616 S.W.2d 278, 283 (Tex. Civil App. 1981).

⁶⁷ *Quesnell v. State*, 83 Wash. 2d 224, 517 P.2d 568 (1973); *Chalk v. State*, 443 So.2d 421 (Fla. Ct. App. 1984).

lawyers perceived as not meeting disabled persons' needs.⁶⁸ To clarify disability practice, they can request ethics opinions from bar associations.

Self-advocacy and other disability groups have a positive stake in improving the representation of persons with disabilities. They can train their members to be more assertive and effective clients. They can sensitize lawyers to the needs of developmentally disabled clients and the value of consultative help. If general practitioners do not adequately fill those needs, they can create referral or group legal service plans to advance members' interests. They can honor lawyers who model ethical behavior and zealous advocacy for clients with disabilities. And when cases with the importance of *Pennhurst* or *Mills* arise, they can join as co-parties with disabled persons to ensure the adequacy of representation.

Conclusion

In less than two decades, developmental disability advocacy has created new expectations on the part of clients and constituency organizations. Residential care, day activity programs, and special education services that were once dispensed as charity have now been established as legal rights. When those rights are violated, litigants will not only pursue individual claims but complex, multiparty actions that can place an institution or service delivery system under close judicial scrutiny. If legal redress is unavailable, constituency organizations will turn to the political process to secure more subtle rights or more comprehensive solutions. The disability counsel are expected not only to mount effective litigation, but also to campaign for large-scale policy reforms through appeals to legislators, executive officials, and public opinion.

The legal profession and the disability rights movement must now minimize the barriers that clients face in initiating and maintaining an attorney/client relationship. Failure to reduce those barriers has public policy implications: lack of enforcement of established constitutional and statutory rights, limited implementation of integration

⁶⁸ *Northern California Psychiatric Society v. City of Berkeley*, 178 Cal. App.3d 90, 223 Cal. Rptr. 609 (1986).

goals, a dearth of common law actions to compensate the victims of abuse and malpractice, and a systematic underrepresentation of the poorest and most impaired disabled persons. Although there is a substantial body of "law in the books" on disability rights, it will take a revolution in advocacy to turn those rights into realities.

Despite its well-publicized successes, legal advocacy can falter without closer working relations between clients with developmental disabilities, their lawyers, and the constituency organizations. Too often, the bipolar relation between such a client and counsel does not fully protect the client from manipulation. Lawyers should consult with constituencies to become familiar with less restrictive forms of protective action and the newest scientific and professional developments in disability fields. Professional self-regulation alone will not ensure that the client with a disability receives competent and diligent legal representation faithful to the normalization ideal. On both individual and class levels, clients and constituencies need vigorous advocacy to secure their declared rights.

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