Litigating System Reform Cases on Behalf of Individuals With Developmental Disabilities and Mental Health Needs

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Several experts in the field have recognized barriers exist within the present service system in regard to providing appropriate treatment and support to individuals with developmental disabilities and mental health needs. A review of the professional literature on this topic reveals that three principle areas of concerns are often identified as obstacles, limiting the quality and scope of services provided to this population. Given that litigation continues to be one of the most effective tools to bring about the necessary systemic reforms, the role of the expert is of paramount importance.

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As several experts in the field have already recognized, many complex—and sometimes apparently intransigent—barriers exist within the present service system in regard to providing appropriate treatment and support to individuals with developmental disabilities (DD) and mental health (MH) needs. A review of the professional literature on this topic reveals that three principle areas of concerns are often identified as obstacles limiting the quality and scope of services provided to this population. First, because most state services agencies are structured to serve individuals who present either a developmental disability or a mental illness—but not necessarily those with a co-morbid diagnosis—the special medical, psychiatric, and psychological needs of this population are often overlooked, inaccurately identified, or ignored altogether. Second, there is an insufficient amount of expertise available to provide such specialized care. Finally, securing necessary services and supports, particularly in an era where budget cuts in social services are pervasive, can be very difficult, if not virtually impossible. Given such entrenched, systemic difficulties—which are often far beyond the control of those who are providing care to these individuals—it perhaps should come as no surprise that class action litigation has sometimes been necessary to bring about necessary reforms. While most health care providers rarely view litigation as a means of advancing a curative end, a great deal of professional discussion among legal scholars has taken place in the last several years regarding the creation of a “therapeutic jurisprudence”, e.g., using the law, including litigation, as a “therapeutic agent” to create therapeutic outcomes in a variety of legal contexts, including mental disability law cases. Application of these therapeutic legal principles, in concert with the participation of health care providers themselves, has indeed improved services for individuals with DD and significant MH needs.

Because examples of such litigation seek, in the broadest sense of the word, to “cure” an admittedly problematic service delivery system, experts in the field are an essential element in bringing such cases to a successful, and appropriately therapeutic, end. In this article, we will address the various roles of experts in this type of litigation, with a particular emphasis on the creative use of the expert witnesses to bring about lasting systemic reforms for individuals with DD with MH needs. In the first part of this article we will discuss commonly cited barriers that prevent persons with dual diagnoses of DD and mental illness from receiving the appropriate care and treatment. We will then discuss the development of the legal right to treatment in institutions and the right to supports and services in the community. Finally, we will discuss the role of experts in “right to treatment” litigation on behalf of individuals with dual diagnoses, with a particular emphasis on the creative uses of experts in these cases.
TREATMENT ISSUES: OBSTACLES TO ADEQUATE AND APPROPRIATE TREATMENT AND ITS CONSEQUENCES

FUNDING PROBLEMS: COMPETING INTERESTS BETWEEN MENTAL HEALTH AND DEVELOPMENTAL DISABILITY SERVICE PROVIDERS AND SYSTEMS

It has been well documented that one of the most significant barriers in providing appropriate supports and services to individuals with dual diagnosis is the chronic lack of funding faced by state agencies charged with serving this population. At present, several states are currently struggling with serious budget deficits and, as a result, frequent proposals have been made which would make potentially harmful cuts in programs for people with disabilities. Given that an apparently ever-shrinking pot of money must be shared among different groups of people with disabilities, fierce competition has often flared between service providers as they attempt to secure program funds. This competition has a particularly adverse effect on the treatment and services available to individuals with dual diagnoses due to the fact that MH and developmental disability service agencies often dispute who should provide care and services to this population.

Such disputes can occur even between agencies within the same governmental department. Disagreements over which agencies obligated to provide services and supports to this population are further exacerbated by the fact that the costs of care generally are greater for such individuals than for persons with DD who do not have MH needs.

Another complication compounding funding problems is the recent move by states participating in the Medicaid Program to narrow the scope of medically necessary services that they must provide under the Medicaid program. In these instances, states seek to limit eligibility so as to reduce the number of eligible Medicaid service recipients they must serve. This recent effort to restrict services could well diminish the already inadequate services available to individuals with DD who have MH needs—many of whom are Medicaid recipients, and who, as a result, are already considered “financially unappealing” by many service providers.

LACK OF EXPERTISE IN PROVISION OF CARE, SUPPORTS, AND SERVICES FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES WITH MENTAL HEALTH NEEDS

As briefly discussed above, another significant obstacle for individuals with dual diagnoses in obtaining appropriate services, supports, and treatment, is the relative lack of specialized expertise available in many areas throughout the country. While most communities in the United States have MH or developmental disability care providers, the number of those who specialize in providing the necessary services for those with dual diagnosis is, nonetheless, quite limited. Availability of services is made additionally problematic due to the sheer complexity of the treatment issues presented by this population, which present admittedly daunting challenges to even the most well-meaning of services providers. Furthermore, because many individuals with dual diagnoses often behave in a manner that is difficult, if not impossible, to quickly and easily control—it has frequently been noted, for example, that the rate of aggression and self-injurious behavior is particularly high among this population—such individuals may not appear to be particularly “attractive” to service providers, or even perceived as being “amenable” to treatment. When one considers that even trained providers who are committed to providing good treatment to these individuals are still very likely to experience emotional stress and burnout when faced with such challenging behaviors, it is thus all more likely that others who lack requisite training or an initial sense of commitment will, in turn, lack the requisite motivation that is necessary when dealing with long-standing behavioral challenges.

As a consequence of these various gaps in community supports and services, persons with DD who have MH treatment needs are often either hospitalized or incarcerated following an incident of aggression, self-injurious behavior, or some other crisis.

Once hospitalized, these individuals commonly deteriorate because they are typically placed in psychiatric facilities not prepared to provide sufficiently specialized psychiatric, medical, and psychological care.
Upon discharge, the untreated individual again returns to a community system that has already proven itself unable to provide the requisite supports and services. Thus the cycle of shuttling between community placement and psychiatric facility begins again, at great detriment to the individual, who has yet to receive comprehensive treatment in the community or hospital setting.

**The Right to Treatment and the Significant Role of Experts in Right to Treatment Cases on Behalf of Individuals With Dual Diagnoses**

Given the many obstacles that individuals who have DD and MH needs face in obtaining the appropriate care and treatment, the key question is: what can be done to break the cycle of harm and make true and lasting systemic changes? Ideally, the answer would be that society would voluntarily provide the necessary resources to provide the supports and services that these individuals need. Unfortunately, the reality is that we, as a society, for the most part, has chosen otherwise, thus, leaving few options for change and necessitating litigation.

**The Right to Treatment in Institutions**

Systemic change for individuals with DD and/or mental illness through litigation is not a new or innovative idea. The legal concept of the right to MH treatment first emerged in the 1960’s when legal scholar Morton Birnbaum wrote The Right to Treatment.32 Following Professor Birnbaum’s article arguing that there is a legal right to MH treatment, the first “right to treatment” cases were filed and litigated in the 1960’s and 1970’s.33,56 One of the most notable cases and often considered the grandfather of right treatment cases was *Wyatt v. Stickney.*56 In Wyatt, Judge Johnson took on a “judicial activist” role after finding that the state defendants had denied institutionalized patients with mental illnesses constitutionally adequate conditions of care by ordering sweeping institutional reforms at a state psychiatric hospital in Alabama.33 These reforms included, but were not limited to increased staffing, individualized treatment plans and treatment, and humane and psychological care and treatment.

Following Wyatt, a number of “right to treatment” cases were litigated in both state and federal courts. Throughout the 1970’s and the early 1980’s, the “right to treatment” litigation was met favorably by the Courts with numerous positive decision developing the “right to treatment” doctrine. In the mid-1980’s, however, the climate began to change and courts increasingly became less willing to take on the judicial activist role that Judge Johnson took in Wyatt.20 A significant indicator of this growing judicial conservatism was the Supreme Court’s decision in *Youngberg v. Romeo.*57 In Youngberg, the mother and guardian of an institutionalized individual with severe mental retardation brought an action against a state-operated institution alleging constitutionally inadequate conditions of his confinement, including inadequate medical care, habilitation, freedom from restraints, and personal security.23 The Supreme Court held that individuals who are committed to state-operated institutions have a due process liberty interest in freedom from bodily restraint, safety, medical care, and treatment.58

The Court articulated the “professional judgment standard” by which to measure whether these due process rights have been violated.25 Under Youngberg, in order to find liability in a § 1983 civil rights action against MH professionals working at a state-operated MH facility, a plaintiff must show that the state’s professional’s decision was “such a substantial departure from professional judgment, practice or standards as to demonstrate that the person responsible did not base the decision on such judgment.” (footnote omitted)59 In reaching this conclusion, the Court noted that expert testimony should be admitted and is likely to be determinative of whether the professional’s decision violated the professional judgment standard.60

The Supreme Court, in deciding Youngberg, intended that the “professional judgment standard” serve as a guide to lower courts in identifying the state’s interests, hoping to minimize judicial involvement in the daily operation of institutions, and affording the professional decision makers a rebuttable “presumption of correctness.”61 Despite this deference, however, courts must weigh the professional decision-making against individual rights, elevating professional decision-making to a conclusive, non-rebuttable presumption of correctness.62 Since the Youngberg decision, there has been a split within the federal circuit courts regarding the interpretation, with some Courts...
reading the decision more expansively and others more narrowly.34

**Right to Services and Support in the Community**

In addition to right to treatment claims in the institutions, individuals with dual diagnoses also have legal rights to the appropriate services and supports in the community under several legal theories under federal and state laws.

**Title II of the Americans With Disabilities Act**

Under Title II of the Americans with Disabilities Act (“ADA”),2 a state or local entity is prohibited from discriminating against qualified individuals with disabilities. In addition to provision prohibiting discrimination against qualified individuals with disabilities in the provision of services, Title II of the ADA also has an “integration mandate.”1 This requires that a “public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”

Recently, in *Olmstead v. L.C. Zimring*27 the United States Supreme Court held that unjustified institutionalization of individuals with disabilities violates the integration mandate of Title II of the ADA. The Court found that “under Title II of the ADA, States are required to provide community based treatment with mental disabilities when the State’s treatment professionals determine that such placement is appropriate, that affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.”30 However, the Court did not find that the state’s responsibility to provide community treatment is not without limits. Rather, the Court found that a State could defend against the requirement that it make reasonable modifications in its services and programs, if such modifications would constitute a “fundamental alteration” of the services and programs.28 “For example, [if] the State were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State’s endeavors to keep its institutions fully populated, the reasonable modifications standard would be met.”29

**Medicaid**

Individuals with dual diagnoses may also have a right to necessary supports and services in the community under Medicaid law.45 Medicaid is a joint state and federal program to provide funding for needy individuals.53 Although states are not required to participate in the Medicaid program, once a state chooses to do so, “it must comply with the requirements of Title XIX.”316 Each state participating in the Medicaid program must provide certain required services, such as medical and habilitative services.46 There are also a number of other services that the state may elect to provide as optional services.47 If a state elects to provide optional services, then it must provide those services.

States may also request approval from the Center for Medicare and Medicaid Services (“CMS”) to provide medical services designed as an alternative to long-term institutional care. These services are statutorily authorized and referred to as the Home and Community Based Services Waiver (“HCBS”) services.48 These services include, but are not limited to, case management, homemakers, home health aides, personal care, habilitation, supported employment, transportation and respite. Once a state has an approved HCBS waiver program, the state is bound in the provision of waiver services by federal and statutory and regulatory mandates of the Medicaid program governing all other medical services, except for those requirements specifically waived during the approval of the waiver plan.

The effect of those waivers is limited of the waiver to the purposes of the waiver program requirements and the specific language of the waiver. However, a state “may not waive any of the requirements that protect the well-being of Medicaid recipients.”53 Further, waivers are only available where states provide “assurances satisfactory to the Secretary” that the waiver plan includes “necessary safeguards ... to protect the health and welfare of individuals receiving homecare.”49 Assurances regarding the health and welfare of Medicaid recipients are intended to benefit the recipients of waiver services and programs.53 When the state violates these health and welfare provisions of the Medicaid Act and its implementing regulations, Medicaid recipients of such services have an enforceable private right of action against the state.7,52

Among the many requirements that states participating in the waiver program must fulfill to ensure the safety and well-being of Medicaid
recipients include state assurances that state standards or requirements are met for services or for individuals furnishing services that are provided for under the waiver. The program also requires that states ensure that recipients receive evaluations of their treatment and care needs. States must also ensure that these evaluations are done periodically and at least annually. Additionally, states must provide assurances that recipients receive appropriate habilitative services such as prevocational, educational, or supported employment services. States must also provide waiver recipients the requisite day treatment or partial hospitalization and psychosocial rehabilitation services for individuals with chronic mental illness.

For individuals with dual diagnoses who are Medicaid recipients, the Medicaid statute can be a powerful tool to advocate for appropriate community based services and supports.

State Law

The right to appropriate community services and supports may also be enforced under state law, as there may be state statutes as well as the state constitutional provisions that specifically provide for such services or for a certain level of services, that may or may not exist under federal law. Raising such claims may be particularly useful in the face of increasing conservatism by the federal courts and the uncertainty of success on federal claims.

ROLES FOR THE EXPERTS IN DUAL DIAGNOSIS LITIGATION

Litigation of system reform cases for individuals with dual diagnoses requires significant reliance upon expert witnesses throughout the case. These roles include, but are not limited to: expert witness, court appointed expert, consulting expert, monitor, special master, receiver, advocate, and amicus curiae. In this section, we will address the expert witness, advocate, and monitoring roles and how these roles can be creatively used to bring about systemic reforms for individuals with DD.

EXPERT WITNESS

The Importance of the Expert in Mental Disability System Reform Cases

The Youngberg decision highlighted the great importance of the role of the expert witness in “right to treatment” litigation when raising constitutional claims. Such expert opinion is critical whether the litigation involves plaintiffs with mental illness, DD, or dual diagnosis. Indeed, it is arguable that the role of the expert is particularly important in constitutional right to treatment cases involving the institutional care of individuals with a dual diagnosis of developmental disability and mental illness given the relatively narrow universe of professionals trained to provided the highly specialized care required by such patients.

The significance of the expert witness in dual diagnosis cases involving constitutional challenges to the adequacy of institutional care was illustrated in Thomas S. v. Flaherty. In Thomas S., individuals with DD involuntarily committed to psychiatric facilities in North Carolina, brought a Constitutional challenge to the adequacy of their care. The Court, relying heavily on expert testimony, found that the state defendants failed to provide the patients with DD with adequate care and ordered sweeping systemic reforms.

In reaching this decision, the Court specifically stated:

[I]n deciding this case, the court has carefully considered all of the evidence bearing on each issue, and notes that there have been conflicts in the testimony concerning what constitutes minimally adequate habilitation; what factors compromise class members' safety, when drugs or mechanical restraints are being used excessively and numerous other professional matters. The court made decisions involving credibility and weight to resolve these conflicts. In assessing credibility, the court took into account the demeanor of the witnesses, any interest or bias, and the knowledge education and training of the witnesses in the field of mental retardation.
The role of experts is similarly important in cases involving other types of claims such as Title II of the ADA. Since the determination as to whether the integration regulation of the ADA has been violated turns largely on the facts of the case, particularly on the inquiry as to whether the placement of an individual with a developmental disability in the community is clinically indicated according to the state’s professionals, expert testimony is key.\textsuperscript{17}

**Key Roles for the Expert**

a. **Expert as Advocate in Settlement Negotiations**

As in other types of cases, mental disability law reform cases involve expert consultants and to assist with either the prosecution or defense of a case. Such experts, however, can nevertheless play an advocacy role to help bring about important systemic changes in dual diagnosis cases, particularly in the context of settlement negotiations.\textsuperscript{15} While many lawyers may be leery of deviating from traditional means of settlement negotiations, sometimes the most effective way to resolve these cases and bring about true systemic changes is by using experts in settlement negotiations in creative ways.

Under Rule 408 of the Federal Rules of Evidence, settlement offers and negotiations are not admissible to show liability. The provisions of Rule 408, gives attorneys the opportunity to use expert consultants throughout the settlement negotiation process, regardless of whether this is a formal, such as using mediation, or an informal negotiation. The expert consultant can be used in formal negotiations, such as mediation, by having the expert actually at the mediation, the expert can help guide the attorneys on what is essential to a settlement agreement and what elements can be negotiated more flexibly.

In informal negotiations or at mediation, the expert can also be useful when actually being permitted, if both sides consent and there is a clear written confidentiality agreement, to actually meet with the defendants, preferably without counsel, to discuss what changes are actually needed. This process may seem unique or unusual, however, it can be one of the most effective ways to reach a comprehensive settlement. The advantages to this arrangement are that the defendants feel free to speak openly with the expert consultants because the entire process is confidential and any statements, regardless whether they constitute admissions, cannot be used as evidence of liability at trial. By allowing the experts to meet with the opponent and/or their experts to discuss substantive programmatic needs and changes in the settlement context allows the defendants the opportunity to safely discuss their problems and work with the experts to develop the necessary solutions.

b. **Expert as Monitor, Special Master, and Receivership**

Settlements or judgments in cases involving systemic reforms for classes of individuals with DD and/or mental illness often include an oversight component to ensure compliance. Such oversight can be conducted by a special master, receivership, or a monitoring committee.

1. **Special Master & Receivership**

Under Federal Rule of Civil Procedure 53 (c), a federal Court may appoint a Special Master to oversee the implementation of a judicial order or consent decree whereby the master takes on a quasi-judicial role to determine whether defendants have substantially complied with a judgment or settlement. For example, *Thomas S. v. Flaherty*,\textsuperscript{43} the Court appointed a special master to oversee the Court’s order for injunctive relief and to “a. [t]o hear and report on disputes concerning individual mentally retarded adults’ inclusion in the class for purposes of relief; b. [t]o hear and report on disputes concerning the adequacy of treatment being furnished to any class member under the terms of this order; and c. [t]o monitor and report on the Secretary’s overall compliance with the terms of this order...”\textsuperscript{44}

Courts also have the power to order a receivership. In such instances, the receiver literally takes over the operation of a facility such as a psychiatric hospital or a MH or developmental disability service system.\textsuperscript{17} Receiverships are extremely rare and are generally reserved for situations where the Court has given the defendant(s) an opportunity to correct violations but they refuse or cannot be trusted to comply.\textsuperscript{17}

2. **Monitors**

It is now more common for courts to order a monitor or monitoring committee to oversee the implementation of a judicial order in mental and developmental disability institutional and system
reform cases. Monitors are also often built into settlement agreements, regardless of the structure of these agreements.

As a monitor, the expert usually has the primary role of overseeing the implementation of an order or a settlement. In order to fulfill this duty, monitoring often entails conducting review of clinical records and related documents, interviews with individuals receiving the appropriate MH services, interviews with providers, and on-site tours.

While the monitor has the principle task of oversight, the monitor can also serve as an educator and someone who may provide technical assistance to defendants under a Court order or agreement to make systemic changes. This is particularly important role for the dual diagnosis expert, given the relatively few number of expert clinicians in the field.

**Conclusion**

Given that litigation continues to be one of the most effective tools to bring about the necessary systemic reforms to improve the services and supports to persons with dual diagnoses of DD and mental illness, the role of the expert is of paramount importance. Although the traditional role for the expert witness in these cases remains significant, this is not the exclusive role for the expert. Rather, experts can and should be used extensively throughout the settlement and enforcement process. Where possible, creative uses of the expert are encouraged as it is the clinician and not the attorney who has the expertise to assess the substance of a settlement offer and to make recommendations when negotiating a settlement. By using the expert in these innovative ways, it is more likely that any settlement that is reached will be more swift and comprehensive.

**References**

7. 42 C.F.R. § 441.302(a).
8. 42 C.F.R. § 441.302(a)(2).
9. 42 C.F.R. § 441.302(c).
10. 42 C.F.R. § 441.302(c)(1)(ii).
11. 42 C.F.R. § 441.302(j).
12. 42 C.F.R. § 441.302(j).


45. Title XIX of the Social Security Act: 42 U.S.C. § 1396, et seq.


52. Wood v. Thompkins, 33 F. 3d 600, 601 (6th Cir. 1994).

53. Wood v. Thompkins, 33 F. 3d 600, 602 (6th Cir. 1994).


58. Youngberg v. Romeo, 457 U.S. at 310.

59. Youngberg v. Romeo, 457 U.S. at 323.

60. Youngberg v. Romeo, 457 U.S. at 323, n. 31.

