

SUMMARY OF THE COURT'S DECISION IN ROSIE D. v. ROMNEY

February Q&A
Center for Public Representation

I. Background

Rosie D. v. Romney is a class action lawsuit that was brought under the EPSDT provisions of the Medicaid Act to compel Massachusetts to provide intensive home-based mental health services that will enable children with severe emotional disturbance (SED) to receive treatment and support in their homes and home communities. The plaintiffs include eight named children and a class of over 15,000 other Medicaid recipients throughout the Commonwealth with serious psychiatric and emotional disabilities. The defendants are Governor Mitt Romney; the Secretary of the Executive Office of Health and Human Services; the Secretary of the Executive Office of Administration and Finance; and the director of the Massachusetts Office of Medicaid. Attorneys from the Center for Public Representation, Wilmer Cutler Pickering Hale and Dorr, LLP, and the Mental Health Legal Advisors Committee represent the plaintiffs.

After extensive discovery that included over fifty depositions and 200,000 pages of documents, U.S. District Court Judge Michael A. Ponsor presided over a six-week trial in May-June 2005. The parties presented 45 witnesses and introduced over 500 exhibits. Sixteen experts, plus family members, providers, and treating clinicians testified for the plaintiffs about the effectiveness of intensive home-based services, the state's failure to provide these services, the thousands of children who need these services, and the harm to the children who are denied this treatment.

On January 26, 2006, in a landmark decision with national implications, Judge Michael A. Ponsor issued a 98 page decision finding that the Commonwealth of Massachusetts is violating the federal Medicaid Act by failing to provide home-based mental health services to an estimated 15,000 children with serious emotional disturbance. "The result of this failure is that thousands of Massachusetts children with serious emotional disabilities are forced to endure unnecessary confinement in residential facilities or to remain in costly institutions far longer than their medical conditions require." The judge called the state's efforts to comply with the requirements of the federal law "woefully inadequate, with detrimental consequences to thousands of vulnerable children." He added, "(The) defendants' failure to provide adequate assessments, service coordination and home-based supportive services for Medicaid-eligible children with serious emotional disturbances was glaring from the evidence and at times, shocking in its consequence."

II. The Legal Claims and Conclusions

The EPSDT provisions of the Medicaid Act entitle Medicaid-eligible individuals under the age of 21 who are screened and diagnosed with behavioral, emotional or

psychiatric disabilities to preventative care and to medically necessary treatment to correct or ameliorate mental health conditions. 42 U.S.C. §§ 1396d(a)(4); 1396d(r)(5). The plaintiffs maintained that the Commonwealth violated EPSDT and the reasonable promptness and equal access provisions of the Medicaid Act, 42 U.S.C. §§ 1396a(a)(8) and (30)(A) by failing to inform children and their families about the services to which they are entitled; promptly provide needed home-based services to children, and afford children throughout Massachusetts equal access to certain pilot programs for home-based services.

The Court found that the defendants violated both the EPSDT and reasonable promptness provisions of the Act. It described EPSDT as “breathtaking” – a Congressional directive that “no Medicaid-eligible child in this country, whatever his or her economic circumstances, will go without treatment deemed medically necessary by his or her clinician.” After detailing the breadth of EPSDT’s informing and treatment components, the Court stressed that the Act requires States to provide all twenty-eight categories of medical assistance, regardless of whether they are in the State’s Medicaid Plan. One of these categories – rehabilitative services – obligates States to ensure that eligible children are offered all “diagnostic, screening, preventative, and rehabilitative services, including any medical or remedial services...for the maximum reduction of physical or mental disability and restoration of an individual to the best functional level.” 42 U.S.C. § 1396d(a)(13). The only condition on this expansive mandate is that the service must be medically necessary. And the Court defined this term without reference to state restrictions or limitations:

If a licensed clinician finds a particular service to be medically necessary to help a child improve his or her functional level, this service must be paid for by a state’s Medicaid plan pursuant to the EPSDT mandate.

Courts construing EPSDT requirements have ruled that so long as a competent medical provider finds specific care to be “medically necessary” to improve or ameliorate a child’s condition, the 1989 amendments to the Medicaid statute require a participating state to cover it, *citing Collins v. Hamilton*, 349 F.3d 371, 375 (7th Cir. 2003); *John B. v. Menke*, 176 F.Supp.2d 786, 800 (M.D.Tenn. 2001).

The district court canvassed most of the leading EPSDT decisions, and then focused specifically on three that involved children with mental disabilities: *Collins, Pediatric Specialty Care v. Arkansas Dep’t of Human Servs*, 293 F.3d 472 (8th Cir. 2002), and *Chisholm v. Hood*, 133 F.Supp.2d 894 (D.La. 2001). It reasoned that there were three factors that informed the courts’ analyses in these cases: (1) whether the requested service was a form of medical assistance under the Act; (2) whether the State failed to provide the requested assistance, based upon a showing that the service is deemed medically necessary by a treating clinician and the needed service is *actually* being provided rather than simply described on paper; and (3) what the appropriate remedy should be, after giving the state an initial opportunity to fashion its own proposal.

Applying these three factors, the Court determined that Massachusetts violated EPSDT by failing to offer various mental health services, including comprehensive assessments, case management and clinical oversight, and in-home behavioral supports that are comprised of behavior specialists, crisis services and other related medical services necessary to maintain a child in her home and home community.

Relying on a long line of reasonable promptness decisions concerning waiting lists for persons with disabilities, beginning with *Doe v. Chiles*, 136 F.3d 709 (11th Cir. 1993), the district court held that Massachusetts violated § 1396a(8) by failing to provide needed medical treatment on a timely basis, even if it offered other forms of treatment to the child. As the Court explained: “The fact that Defendants provide some services does not relieve them of the duty to provide all necessary services with reasonable promptness,” citing *Boulet v. Cellucci*, 107 F.Supp.2d 61, 70 (D.Mass. 2000).

The Court ruled in favor of the defendants on the equal access claim, 42 U.S.C. § 1396a(30)(A), finding that the plaintiffs had not presented sufficient evidence of any disparity between Medicaid and non-Medicaid recipients in Massachusetts in obtaining intensive home-based services. Although the Court previously had ruled that this provision of the Act was enforceable by recipients under § 1983 even after *Gonzaga* and the First Circuit’s ruling in *Long Term Care Pharmaceutical Alliance v. Ferguson*, 362 F.3d 50 (1st Cir. 2004) (holding that providers could not enforce this section under § 1983), in a footnote it referenced the intervening decision of the Ninth Circuit in *Sanchez v. Johnson*, 416 F.3d 1051 (9th Cir. 2005) (holding that the equal access provision cannot be enforced by either recipients or providers). The district court was obviously reluctant to rely upon the equal access provision when it could order full relief under EPSDT and the reasonable promptness provisions of the Act.

III. The Children

Within six months of filing the Complaint, the Court certified a class consisting of “all current and future Medicaid-eligible children under twenty-one years of age who are or might become eligible to receive, but are not receiving, intensive home-based services, including professionally acceptable assessments, special therapeutic aides, crisis intervention, and case management services. The *Rosie D.* class includes an estimated 15,000 children across the Commonwealth who are eligible for Medicaid (MassHealth) and who suffer from severe emotional, behavioral and psychiatric disorders.¹ Many of these children have been hospitalized in locked psychiatric wards or detained in residential facilities because the state failed to develop and fund intensive home-based services that would allow them to be treated at home and in their communities.

¹ A planning document from the Department of Mental Health submitted to CMS found that, based upon national prevalence data, there were over 112,000 children in Massachusetts who had SED. Approximately half of these children are considered to have *severe* emotional disturbance, which would include most serious psychiatric conditions. Since approximately 25% of the children in Massachusetts are eligible for Medicaid, the Court estimated that there were approximately 15,000 Medicaid-eligible children with severe and long-term SED.

Records and documents produced by the state during the lengthy discovery process revealed that hundreds of *Rosie D.* class members have been detained inappropriately in institutions, psychiatric facilities, congregate care settings, or totally denied access to services. In addition, children in crisis have been “boarded” in hospital emergency rooms and pediatric wards. Not only were there no open beds for children in crisis, but there were no home-based programs available to prevent hospitalization or other out of home placements. Current statistics indicate that up to over 100 children are “stuck” in private psychiatric hospitals and hundreds more stuck in public hospitals and residential facilities – children who are clinically stable and ready to move to less restrictive settings, but are forced to remain institutionalized due to a lack of available home-based services. Thousands more are “stuck” in the community with no supports and at constant risk of institutionalization.

At the trial, guardians of three of the named plaintiffs testified about their decade-long struggles to secure appropriate mental health services. One parent pointed out that the state will provide for her son’s psychiatric hospitalization, but will not provide less costly services that can prevent hospitalization. Her son’s psychiatrist from the Massachusetts General Hospital testified that these seriously ill children need more than medication to address their behavioral health needs. “They also need behavior modification therapy and crisis intervention that includes working with the family to determine ways to best defuse a situation without necessarily moving the child.”

The Court’s opinion described in detail the turbulent history of each of the named plaintiffs, and found that many had recommendations for home-based services that were ignored. Several were repeatedly admitted to hospitals or crisis programs because of the lack of adequate services in the community. Others were offered acute interventions only to have these short-term interventions terminated even though they were still desperately needed.

Like the named plaintiffs, the Court found that children with serious emotional disturbances (SED) suffer from long-term conditions that require ongoing supports. Judge Ponsor found that the state has failed to recognize that these disabilities represent “chronic conditions that require continuous monitoring, coordination, and modification of services.” In contrast to the children’s chronic, long-term needs for services, he found that the Commonwealth’s programs are short-term and time-limited. He relied heavily upon a clinical review of a sample of children to support his conclusion that the vast majority of children with serious emotional disturbance need, but are not provided, home-based services.

The opinion reflects a unique and often eloquent appreciation of the suffering of children and the struggle of families to secure timely and appropriate care to avoid disruption, displacement, and despair: "The undisputed evidence offered at trial made it clear that children with serious emotional disturbance are among the most fragile members of our society... Prompt, coordinated services that support a child's continuation in the home can allow even the most disabled child a reasonable chance at a happy

fulfilling life. Without such services a child may face a stunted existence, eked out in the shadows and devoid of almost everything that gives meaning to the gift of life."

IV. The Experts

During the years leading up to trial, plaintiffs' attorneys retained sixteen nationally renowned experts to undertake three separate studies and prepare eighteen reports. They conducted a comprehensive analysis of the need for intensive home-based services for children with psychiatric disabilities in Massachusetts, and then devised a plan to address that need. The experts testified at trial about: (1) the effectiveness of intensive home-based services and the dramatic benefits to children in many other states that provide this treatment; (2) the lack of home-based services in Massachusetts and the consequences to children who cannot obtain them; (3) the need for these services in Massachusetts, based upon a random sample of children with serious emotional disabilities; and (4) the cost of providing intensive home-based services as part of the state's Medicaid program.

Based on visits to a dozen programs throughout the Commonwealth, interviews with thirty-five randomly selected children and their families, review of hundreds of medical records, and meetings with parents, guardians, and providers, the clinical experts concluded that the vast majority of children they assessed needed, but were not provided, home-based services. The programmatic experts determined that the specific programs operated by Medicaid's managed care companies (MCOs) and its behavioral health carve-out company (ValueOptions, operating under the name of Massachusetts Behavioral Health Partnership), offered only time-limited, narrowly focused, and disjointed services. Finally, the fiscal expert, who analyzed data and financial models, testified that Massachusetts was wasting over \$22 million dollars a year on unnecessary hospitalization, and that simply by redirecting available funding, it could serve more than 1,000 children annually in home-based programs.

In extensive reports filed in the fall of 2004 – all of which were accepted into evidence by the Court -- the experts concluded that the current behavioral health system for children and adolescents in Massachusetts is fragmented and disjointed, and that intensive home-based services are not being provided to children with serious emotional disturbance. The experts recommended that Massachusetts adopt a statewide initiative for intensive home-based services, through a program financed with Medicaid funds under the EPSDT mandate.

V. The Deficiencies of the Massachusetts Mental Health System for Children

The expert reviews formed the core of the trial testimony, supplemented by the direct experience of family members, providers, and clinicians. In addition, the plaintiffs confronted the defendants' witnesses with their own utilization data to demonstrate that the actual level of services available to children fell far short of the need. With the help of PriceWaterhouse, the plaintiffs conducted an analysis of the two programs the defendants claimed offered home-based services (Family Stabilization Teams [FST] and

Community Support Programs [CSP]) and demonstrated that each were short term interventions that served only a few hundred children per year. The Court relied heavily upon this combination of expert evaluation, data analysis, and “real world” experience to conclude that Massachusetts failed to offer children with severe and long-term disabilities adequate treatment.

The Court first noted that the state’s Medicaid system relies on pediatricians to bear the initial responsibility for mental health assessments – a “deficient” approach that lacks consistency, time frames, oversight and most often, comprehensiveness. As he stated, “Without a clinically appropriate, detailed assessment of an SED child, proper treatment is obviously impossible.”

The judge found that clinical assessments and support services are provided haphazardly, without oversight or coordination. He decried the lack or inadequacy of in-home supports, which include trained para-professionals or licensed clinicians who can assist the child in his or her home, provide mobile crisis stabilization as necessary, and prevent or minimize the need for an out-of-home placement.

The judge also determined that the state fails to provide necessary treatment to SED children and their families. Short-term services are designed only to stabilize the child, and as the judge found, “are almost never coordinated with any overall treatment plan.” Similarly, the state has failed to provide adequate in-home supports to prevent crises and minimize the need for out-of-home placements.

Finally, the court noted that the state failed to provide SED children with the most “critical service,” case management. He was deeply disturbed that many case managers, who are responsible for coordination, oversight and implementation of services, have never met the children on their caseloads. “It is impossible to overstate the importance of active, informed case management,” he said.

The judge described the services offered by the state’s largest mental health provider for Medicaid recipients, the Massachusetts Behavioral Health Partnership, as a “patchwork of services” with “arbitrary time limits.” He also pointed out that MBHP’s literature fails to mention EPSDT services; the state’s Office of Medicaid’s literature excludes mental health services from its listing of EPSDT services, such as check-ups, dental examinations and immunizations.

Judge Ponsor held that the state’s two “in-home programs,” FST and CSP, are short-term programs that do not offer the services needed to treat SED children with chronic long-term needs. “Moreover, the availability of these programs is so restricted that they reach only a minute fraction of the children who might benefit from them.” Citing the evidence presented at trial, he said that the imminent termination of FST services for several named plaintiffs and class members in the plaintiffs’ sample “dramatically highlights the shortcomings of the existing system.” The children “were trapped in the same pattern: short-term support services were terminated as soon as the most acute stage of a crisis passed, virtually ensuring that another such episode would

follow.” Similarly, other programs, such the Crisis Stabilization Units, Partial Hospitalization Services, Community-Based Acute Treatment Units, Enhanced Residential Care and Transitional Care Units, “are each inadequate in providing ongoing, coordinated treatment for children with SED,” the judge said, and added, “None is designed to support a child in his or her home for as long as medically necessary.”

The judge concluded that the state’s “provision of services amounts to an attempt to patch together long-term care out of short-term programs. For most SED children, this will not work.” He found that such programs cannot “treat children with chronic conditions, who usually require carefully planned and flexible services for months or years. The absence of these long-term services too often leaves SED children with only one option: expensive, clinically unnecessary and damaging confinement in a long-term residential program or hospital, far from home and family.”

Nevertheless, as the judge labeled “one of the painful ironies” of the case, the Commonwealth is wasting money on residential programs even while it supports less expensive pilot programs with clinical interventions that enable SED children to receive treatment at home and in their own communities.

VI. The Effectiveness of Home-Based Services

Intensive home-based services constitute a well-established mental health treatment that is designed to meet children’s needs in their birth, foster or adoptive homes, or in the communities where they live. Studies demonstrate that intensive home-based services are cost-effective, because it is cheaper to provide services in the community than in residential facilities and hospitals.

Other states, including Arizona, California, Delaware, Maine, New Jersey, North Carolina, Pennsylvania, Rhode Island, and Vermont fund intensive home-based services as part of their Medicaid programs. These services are based upon a single treatment plan, designed by a single treatment team that includes the family, a case manager responsible for arranging and overseeing the services, and relevant professionals. The services include trained behavioral staff to support a child at home, in school, and in the community; crisis intervention in the home; and other clinical supports. Intensive home-based services are based upon a comprehensive assessment to determine the treatment and supports a child needs.

Massachusetts’ officials acknowledge the effectiveness of these services. In fact, the state offers two pilot programs that have been highly successful in treating children, reducing hospitalization, and saving money. However, both programs have significant limitations. Coordinated Family Focused Care (CFFC) is designed to serve only 50 children in each of five cities: Springfield, New Bedford, Brockton, Lawrence and Worcester. The other pilot project, Mental Health Special Program for Youth (MHSPY), only can serve 70 children in five communities: Cambridge, Somerville, Medford, Malden and Everett. In the remaining 341 communities, Medicaid-eligible children with serious emotional disturbance cannot get intensive home-based services. Instead, they

must rely on short-term, inpatient hospitalization, acute care, medication and brief counseling sessions.

National experts testified about the effectiveness of home-based services, based upon professional literature, national evaluations conducted by SAMHSA, federal reports and studies including the President's Commission on Mental Health, and the experience in other states. To rebut the defendants' contention that Massachusetts offers home-based services as discrete elements of a mental health managed care "menu", local providers testified that they cannot "patch" together these short-term interventions into intensive home-based services. The providers also pointed out the inequity in offering intensive services under CFFC to children in one community, and denying them to children in the next town.

The defendants not only contested – rather ineffectively – the positive outcomes from intensive home-based services, they also attempted to portray it as a *method* or *process* for delivering discrete interventions rather than the treatment itself. Despite the overwhelming testimony about the effectiveness of home-based services, the Court was not convinced that this was a single treatment with a common definition and a well-accepted description of specific interventions. The judge also was troubled by his authority to order a state to provide medical assistance in any particular fashion or through a specific model. Therefore, he declined to adopt the plaintiffs' experts definition of intensive home-based services, and instead analyzed the evidence in terms of the components of intensive home-based services: comprehensive assessments, case management, and in-home behavioral supports, all of which he concluded are clearly covered by Medicaid and mandated by EPSDT.

The Court noted that, in rejecting the plaintiffs' definition of intensive home-based services, it was not altering in any way the nature of the lawsuit or the remedy sought in the case, since the plaintiffs, their experts, and their evidence consistently documented the actual services needed, but missing, as those within the rubric of the term intensive home-based services.

Significantly, as the judge noted, Massachusetts knows how to provide effective treatment in the community for children with serious emotional disturbance; it has just chosen not to do so except for a few isolated pilot programs serving a small fraction of the children who need this type of care. He pointed to three successful demonstration programs: MHSPY, CFFC, and the Worcester Communities of Care (WCC), and noted that each offers effective treatment to SED children, using comprehensive assessments, service coordination, crisis intervention and in-home supports. Yet, as he stated, these programs reach only "a miniscule portion" of children who need these services. The judge cited the impressive outcome data for the programs. He noted that the newest program, CFFC, "is no more costly than the Commonwealth's system of multiple service providers." Furthermore, he found there was no financial, clinical or administrative bar to prohibit the expansion of a MHSPY-type or CFFC-type program throughout the state.

VII. The Remedy

As ordered by the Court, plaintiffs' attorneys will meet with the defendants to discuss proposed remedies and a timetable for their implementation. Judge Ponsor will hold a status conference February 23 in US District Court, Springfield.