



Fact Sheet

EXPANDING COMMUNITY SERVICE OPTIONS RIGOROUSLY ENFORCING ACTIVE TREATMENT STANDARDS IN NURSING FACILITIES

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I. Introduction

In 2000, the Commonwealth of Massachusetts entered into a Settlement Agreement that obligated it to transfer almost 1,000 persons with intellectual disabilities¹ or other developmental disabilities who were confined in nursing facilities to integrated community settings with supports. See *Rolland v. Cellucci*, 191 F.R.D. 3 (D. Mass. 2000). In addition, the Agreement required that the State provide specialized services and active treatment to all persons who remained in nursing facilities. Finally, the Agreement mandated that the Department of Mental Retardation (DMR) establish a diversion program, a data collection and reporting system, and an expanded Home and Community-Based Services waiver to serve persons with developmental disabilities as well as additional persons with intellectual disabilities.²

Seven years later, the Commonwealth had transferred over 1,000 *Rolland* class members to integrated community settings, established a moderately effective diversion program that had prevented the admission of hundreds of persons annually. The Commonwealth also reduced the average length of stay for almost 80% of those who were admitted to less than ninety days, and issued 14 detailed reports on placements and services. But it had massively failed to provide persons in nursing facilities with specialized services that met the federal

¹ TASC uses the term “intellectual disability” rather than “mental retardation,” which is an outdated term with a hurtful history of use. The term “mental retardation” is used in this document when it refers to use of the term in a court document or a legal statute.

² A copy of the initial Settlement Agreement is available on the Center for Public Representation website at: <http://www.centerforpublicrep.org/uploads/Rd/ol/Rdol8vCoi8TNeOWTNZ1rng/Rolland-active-treatment-agreement.pdf>

active treatment standard. This failure was due in significant part to the vigorous enforcement of the federal active treatment standards by the plaintiffs through five noncompliance motions and two trials. A summary of this litigation history is set forth in the district court's most recent noncompliance decision, *Rolland v. Patrick*, 483 F.Supp. 2d 107 (D. Mass. 2007).³

II. Strategic Enforcement of Institutional Standards

The litigation and enforcement strategy that guided *Rolland* was carefully considered and rigorously implemented. Like other community integration cases for institutionalized persons with disabilities that have been brought over the past several decades,⁴ courts are reluctant to order institutional closures and states are resistant to enter settlements that require the placement of all, or almost all, residents.⁵ But countless institutions have, in fact, closed, with all, or virtually all, residents transferred to the community as a result of implementation and enforcement activities in class action lawsuits.⁶ Some of these closures were the result of the fiscal disincentives of maintaining large facilities with a diminishing number of residents, required by placement provisions in court orders. Some were the result of political or other apparently non-legal events. But many were the result of concerted litigation strategies that recognize the enormous challenge and cost of upgrading institutional facilities to meet federal standards, as well as

³ The Center for Public Representation has prepared six Q&As or Fact Sheets detailing federal PASARR requirements, federal active treatment standards, court-approved active treatment measurement devices, and litigation strategies for enforcing the federal rights of persons with developmental disabilities in nursing facilities. See *Diversion of Persons with Mental Retardation from Nursing Facilities* (1999); *The Impact of Sandoval on the State's Obligation to Provide Active Treatment to Nursing Facility Residents* (2002); *The State's Obligation to Provide Active Treatment to Nursing Facility Residents* (2003); *Evaluating Active Treatment for Residents of Nursing Facilities with Developmental Disabilities* (2004); *Enforcing Active Treatment Requirements in Nursing Facilities* (May 2007); and *Evaluating Active Treatment* (July 2007), all available at: <http://www.ndrn.org/TASC/pub/qa/chron.htm>

⁴ Prior to the passage of the ADA and the Supreme Court's decision in *L.C. v. Olmstead*, 527 U.S. 581 (1999), advocates brought deinstitutionalization lawsuits under a variety of federal statutes, such as 29 U.S.C. § 504, constitutional provisions, usually the Fourteenth Amendment, and occasionally state statutes, arguing that States are required to provide the treatment or habilitation in the least restrictive and most integrated setting.

⁵ There are some notable exceptions. See e.g. *Halderman v. Pennhurst*, 446 F.Supp. 1295,1326 (E.D. Pa. 1977), *aff'd* 612 F.2d 84, 114 (3d Cir. 1979).

⁶ During the pendency of federal lawsuits, California, Connecticut, the District of Columbia, Florida, Indiana, Illinois, Ohio, Maine, Massachusetts, Michigan, Minnesota, New Hampshire, New Mexico, New Jersey, New York, Oklahoma, Oregon, Pennsylvania, Rhode Island, Tennessee, Texas, and West Virginia closed at least one, and often several, of their large public institutions that confined persons with mental disabilities See: P&A Docket of Community Integration/Medicaid cases on the TASC website at: <http://www.ndrn.org/TASC/pub/dockets/0810Olmstead-Med.pdf> See also Braddock, STATE OF THE STATES (2007) (listing States that have closed large public facilities for persons with developmental disabilities).

the State's lack of resolve to accomplish this goal under the auspices of a federal court. In some states, advocates have successfully achieved the full community integration of all institutionalized residents, and the concomitant closure of facilities, through carefully planned litigation strategies and steadfast enforcement of legal standards.

For instance, in New Mexico, after an almost year long trial in a case seeking the closure of both of the State's developmental centers, the district court refused to order the placement of all residents, the phase down of the facility, or a specific level or type of community services. See *Jackson v. Fort Stanton*, 757 F. Supp., 1231 (D. N.M. 1990). But based upon its finding of numerous constitutional violations at the institutions, it ordered an array of improvements in nineteen discrete areas of institutional conditions. *Id.* at 1302. Through aggressive advocacy, the development of rigorous compliance standards, the strategic use of experts, and several enforcement motions, the State eventually conceded and closed both of its large institutions. Moreover, it did so pursuant to a far reaching community development plan that required extensive improvements in its community service system for persons with developmental disabilities and a massive expansion of service capacity in thirteen programmatic areas.

Similarly, in Florida, where a consent decree required both institutional improvements and the placement of some, but not by any means all, residents of a large psychiatric facility, the plaintiffs used a combination of strict institutional compliance provisions, more flexible community compliance standards, client-centered compliance reviews by a highly-respected court monitor, and the subsequent intervention by the Department of Justice to convince the State to close the facility and place all residents in the community, with appropriate supports. See *Johnson v. Sellars*, 348 F.3d 1334 (11th Cir. 2003).

A similar approach was developed in *Rolland*. When the negotiations that led to the initial Settlement Agreement failed to result in a commitment to place virtually all nursing facility residents into integrated community settings, the plaintiffs insisted upon provisions that required full and immediate compliance with the specialized services provisions of the Nursing Home Reform Amendments, 42 U.S.C. § 1396r(e)(7) and the related PASSAR regulations, 42 C.F.R. § 483.100 *et seq.* Through multiple enforcement actions, several expert reviews of the services actually received by class members, and, most importantly, a creative and expansive interpretation of the State's obligation to provide specialized services, the cost and challenge of compliance skyrocketed. Eventually, after seven court rulings, the appointment of a court monitor, and the adoption of rigorous active treatment compliance standards,⁷ the State finally

⁷ This history and the scope of the court's ruling are discussed in a April 2007 QA: Enforcing Active Treatment Requirements in Nursing Facilities.
http://www.ndrn.org/TASC/pub/qa/2007/0708_med_standards.pdf

altered course and agreed to place virtually all remaining nursing facility residents in integrated community settings *Id. at 1*.

This approach, like the ones adopted in *Jackson* and *Johnson*, is not without risk. In fact, in response to concerns expressed by the P&A advocates over the wisdom of demanding institutional improvements in nursing facilities, the CPR prepared a Q&A that discusses the advocacy conundrum of enforcing institutional standards. As we noted there:

Enforcing the active treatment mandate in nursing facilities, like enforcing federal and constitutional standards in other congregate settings, runs a serious risk of expanding the capacity of these facilities to segregate persons with disabilities. At the very least, it demands that state officials focus efforts and resources on upgrading institutions. It can undermine arguments that such facilities should be closed or phased-down, and may well divert attention from that goal.⁸

III. Community Supports as an Alternative Remedy for Noncompliance with Institutional Standards

A variety of constraints and political realities make it impossible to immediately place all residents of a segregated facility into the community with appropriate supports. These constraints expand exponentially when closure is part of the demand, since political, union, and family opposition often must be overcome. When the State is required to place large numbers of persons or phase down several facilities, system development realities render prompt integration impossible. As a result, placement schedules often extend for many years. Given the enormous cost and overwhelming challenge of *simultaneously* accomplishing institutional improvements and community placements, States understandably seek to be relieved of the former in order to focus on the latter. This creates a conundrum for advocates, essentially demanding that they chose, or at least prioritize, the relief they seek.

The conundrum not only presses advocates to forego often urgent reforms for vulnerable institutionalized residents, but it sometimes demands that they relinquish enforcement of their clients' rights for years. Put simply, the approach requires some compromise of the defendants' obligations to achieve compliance with institutional standards in exchange for their willingness to forego ongoing institutionalization. The more dramatic their commitment to integration, as measured by institutional closure and/or substantial placement commitments, the more compromise is reasonable and necessary. Although all persons are

⁸ ENFORCING THE ACTIVE TREATMENT MANDATE FOR PERSONS WITH DEVELOPMENTAL DISABILITIES IN NURSING FACILITIES: THE ADVOCACY CONUNDRUM, Center for Public Representation, April 2007, page 8.
http://www.ndrn.org/TASC/pub/qa/2007/0705med_act_treat.pdf

entitled to conditions that ensure basic health and safety, avoid any form of abuse, prevent unnecessary restraint, and guarantee minimal conditions of confinement, advocates have to be willing to forego major, expensive improvements in the quality and intensity of treatment, habilitation, or rehabilitation if this strategy is to succeed. Developing creative ways of ensuring the former without foregoing the latter is both the way out of the conundrum and the way into a successful resolution of the lawsuit.

IV. The *Rolland* Active Treatment Settlement Agreement

After the issuance of the Court's landmark active treatment decision in April 2007, the Court approved rigorous criteria for measuring active treatment that incorporated most of CMS' ICF/MR Active Treatment Guidelines and Tags.⁹ The Court then appointed a Court Monitor who developed a detailed, 50 page protocol for applying these criteria. The Monitor implemented the protocol, evaluated a sample of class members, and issued several preliminary reports which concluded that 93% of class members were not receiving active treatment consistent with the Court's Order. After initial, unavailing protests to the Monitor's process and its findings, the defendants finally recognized that compliance with the Court's Order would be exceptionally challenging and extraordinarily expensive.

As a result, *the defendants* subsequently proposed a new approach to compliance, based almost entirely on developing new community placements instead of improving services to persons in nursing facilities. They developed cost models for both alternatives which demonstrated that placements were equal or less expensive than active treatment services. With significant effort, they convinced senior executive and budget officials to sign a new Settlement Agreement (Agreement) that would guarantee community services for approximately 90% of all remaining class members in nursing facilities.¹⁰

The core element of the Agreement, from the State's perspective, is that individuals who will be provided community supports will not have to be provided active treatment. While the placement schedule is ambitious, the scope of the community development commitment necessarily requires a multi-year placement program. As a result, some class members will have to wait for up to four years before they move to the community. This delay in remedial services caused the Court considerable concern. To allay that concern, the Agreement requires the defendants to provide transition services for all persons who are eligible for placement while they remain in a nursing facility. As more fully

⁹ See CPR's Q&A Evaluating Active Treatment (July 2007), available on TASC's website at: http://www.ndrn.org/TASC/pub/qa/2007/0708_med_standards.pdf.

¹⁰ The new Settlement Agreement on Active Treatment is available on CPR's website at: <http://www.centerforpublicrep.org/uploads/Rd/ol/Rd0l8vCoi8TNeOWTNZ1rng/Rolland-active-treatment-agreement.pdf>

described below, the Agreement includes multiple other commitments and safeguards to promote placement, prevent admissions, protect class members, and phase- down nursing facilities.

A. *Community Placements*

1. The Process and Schedule

Pursuant to the same standard for community placement that was incorporated in the original Settlement Agreement and used successfully over the past seven years, the Massachusetts Department of Mental Retardation (DMR) evaluated all class members in nursing facilities and determined that, as of November 2007, 666 persons were appropriate for community placement. These individuals are included on the Rolland Community Placement List (List). Persons admitted to nursing facilities after this date who remain longer than ninety days will be evaluated using the same standard and added to the List. If a class member's needs change, so that he no longer meets the placement standard, he may be removed from the List.¹¹ Conversely, as part of the active treatment planning process for these individuals, they can be returned to, or otherwise included on, the List.

The Agreement provides that 640 class members will be transferred from nursing facilities to the community over the next four years, beginning in FY09 (July 1, 2008 – June 30, 2009). Each year DMR must place at least 160 persons. To ensure that class members who have been institutionalized for years are afforded a priority for new community placements, the Agreement imposes annual caps on the number of individuals who are recently admitted to nursing facilities.

2. Efforts to Promote Community Placement

Perhaps the most challenging component of the Agreement is the task of persuading a significant number of guardians, families, and some class members to accept community placement. Because of the untoward consequences of prolonged institutionalization, or the unusual circumstances that led to the person's institutionalization, the benefits of community living may not be immediately obvious or easily understood. The Agreement addresses this issue with five strategies.

First, DMR will create an education program, undertaken by the DMR with assistance from the plaintiffs, to inform class members, guardians, and families about the benefits of community living. Second, DMR will fund an outreach program that uses a family-to-family model developed by the intervenor the Arc of Massachusetts. Third, DMR will ensure that the corporate guardianship entities with which it contracts fully understand and assist in implementing the

¹¹ In that event, the individual must be provided active treatment promptly.

Agreement. Fourth, DMR will develop a targeted education and outreach initiative for persons with developmental disabilities. Fifth, and perhaps most importantly, DMR has the statutory authority and duty not to allow persons to remain in nursing facilities when there is another institutional or community setting that is more appropriate and more integrated. As a last resort, DMR will exercise this authority to persuade persons to accept available community placements as part of its PASARR program.

3. The Role of Monitor

The Monitor has a critical role under the community placement provisions of the Agreement. She is invested with two important responsibilities in the application of the placement standard and the creation of the Rolland Community Placement List. First, she must review all persons not initially included on the List, any new admissions not added to the List, and anyone removed from the List. This provides an important clinical and professional safeguard that class members are not excluded from community placement opportunities for inappropriate reasons, as well as that class members are not randomly added to the List and removed from active treatment monitoring when placement is not realistic or possible.

Second, the Monitor has a role in the community placement dispute resolution process, if she disagrees with the decision of DMR not to include a person on the List. If this process fails to resolve the dispute, the plaintiffs seek the intervention of an independent professional to determine if the individual should be added to the List. This ensures that DMR cannot exclude a person for reasons unrelated to sound professional judgment.

B. Diversion from Admission to Nursing Facilities

Through new procedures, protocols, and strategies, DMR has substantially increased the number of diversions from nursing facilities and dramatically decreased the length of stay of those who are admitted, so that only 20% of admitted persons remain longer than ninety days.

These system improvements are incorporated into the Agreement. If, despite these improvements, the diversion rate drops, a corrective action plan is required. New admissions who remain longer than ninety days will either be placed on the Rolland Community Placement List or promptly provided active treatment.

C. Transitional Services

Those class members who are on the Community Placement List but who will not move to the community during the first year of the Agreement will receive transition services that include: (1) new support services, delivered by

community providers, that will provide opportunities to participate in community activities and activities in the evening and weekends; (2) refocused specialized services that will shift the focus of day habilitation programs from onsite services at the nursing facility to offsite services in the community; (3) intensified service coordination that will benefit all class members in nursing facilities; and (4) educational and outreach initiatives to facilitate the acceptance of, and transition to, community living.

Transition services will offer class members additional hours of habilitative services and supports in the evening and weekends, as well as a greater focus on community day habilitation programs rather than institutionalized day programming provided at the nursing facility.¹² For those class members who have been institutionalized for many years, transition services may be critical to overcome decades of segregation and institutionalization, to gradually expose the individual to community activities and opportunities, and to facilitate their willingness to accept community placement.

D. Active Treatment Services

The defendants must provide active treatment to all class members in nursing facilities who are not on the List. Similarly, any class member who is removed from the List or who is not to be placed in the community by Massachusetts fiscal year 2012 must receive active treatment. Thus, every class member will receive active treatment unless the individual actually is transitioned to the community by June 30, 2012.¹³

The Monitor will continue to evaluate compliance with the Court's active treatment orders, using the Active Treatment Standards and Protocol approved by the Court, for those individuals who are not on the List.

In addition, where it is clear that a specific nursing facility is not capable of providing active treatment, based upon the Monitor's findings, DMR will not authorize any new admissions to such facility and will encourage residents to transfer to the community or to another facility that is providing active treatment to class members. Conversely, DMR will encourage hospitals, screening entities, and other staff only to refer potential nursing facility admissions to

¹² These four new benefits are not primarily designed to alter the practices, culture, and competency of nursing facilities to serve persons with mental retardation and other developmental disabilities. As a result, these expanded services will not equal active treatment, and will not satisfy the federal active treatment standard adopted by the Court and incorporated in the Monitor's protocol. Nevertheless, they should substantially improve the lives of class members while they are waiting for community placement.

¹³ While this obligation is substantial and will be challenging even for a much smaller number of persons – currently estimated to be approximately fifty-five – it is achievable in a reasonable time because of its limited scope and the fact that almost half of these individuals are in three pediatric nursing facilities.

qualified facilities.

E. Monitoring, Enforcement, and Dismissal

The Agreement contains specific provisions on funding, monitoring, data collection, collaborative implementation activities, and enforcement. If the defendants demonstrate that they have made the requisite number of placements and are providing active treatment to class members who remain in nursing facilities, the Court will dismiss the case.

V. Opposition and Appeal

At the fairness hearing, parents of forty-seven children and young adults at one “pediatric” nursing facility objected to the settlement, claiming that the placement list was arbitrary, that their children could not and should not move to the community, and that the Agreement unreasonably compromises their rights. Although almost half of the objectors’ children were not even on the placement List, and therefore would be provided active treatment promptly, they nevertheless opposed the Agreement because of a fear that they “might be placed” on the List. The Court rejected these objections and approved the Agreement. The objectors then moved to decertify the class, which the Court also denied. The objectors have now appealed.

The appeal is similar, at least in tone and purpose, to those lodged by other parents who oppose community integration settlements. See *Brown v. Bush*, 94 Fed. Appx. 879 (11th Cir. 2006). But unlike the protests of families who want their children to remain in certified ICFs/MR, most nursing facilities do not meet federal standards because they are not providing persons with intellectual disabilities and related conditions with active treatment. Thus, the opposition to placement is not coupled with a claim that they have a right to choose an institutional setting, since there is no right to remain in inadequate federally-funded programs. See *O’Bannon v. Town Court Nursing Center*, 447 U.S. 773, 785-86 (1980). The Court of Appeals for the First Circuit will hear the appeal early in 2009. Affirming the district court’s approval of the Agreement will simultaneously affirm the effectiveness of the plaintiffs’ litigation and enforcement strategy to promote the community integration of persons with disabilities in nursing facilities.