



Memorandum on the Rolland Settlement By Nancy Zollers with Leo Sarkissian

Recently a column (Cullen, June 30) and series of letters (July 6) appeared in the *Boston Globe* attacking the goal of a recent civil rights settlement known as **Rolland or the Nursing Home Settlement**. The letters say little about the goals of the settlement which creates quality community living options for people with developmental disabilities who reside in nursing homes. They also leave much unsaid about the reality of institutions, in this case, nursing homes for people with mental retardation or developmental disabilities, and the progress that The Arc and other advocates have made in achieving an improved quality of life for those with such disabilities.

As we ponder the *Globe's* motives for devoting an inordinate amount of print to one point of view (our friend, Bill Henning, executive director of Boston Center for Independent Living has often pointed out the "Globe editorial board's historical bias"), we take this opportunity to update you on the 10 year old Rolland nursing home litigation and the nature of **The Arc of Massachusetts' values, leadership and ongoing 50-year-plus commitment with regard to citizens with profound impairments and/or complex medical disabilities.**

History

The *Rolland* class action lawsuit filed in 1998 in US District Court in Springfield on behalf of an estimated 1600 nursing facility residents with mental retardation or developmental disabilities. The Arc and the Stavros Center for Independent Living are organizational plaintiffs in the case. The case challenged class members' placement in nursing homes as a violation of the American with Disabilities Act, which requires states to provide people with disabilities with the most integrated services appropriate to their needs.

None of us want our parents, other loved ones or friends ending up in a nursing home. Yet people with intellectual and developmental disabilities, who are significantly younger than most nursing home patients, too often are placed in these facilities. In addition to the number of people inappropriately sent to nursing homes, the facilities often lack any habilitation objectives or active treatment for these residents, which is the federal standard for quality care. In a setting such as Seven Hills Nursing Home or Pediatric Center, families feel their loved ones receive better treatment than in a typical nursing setting, but, according to recent independent reviews by the Court Monitor, they do *not* receive the federal standard of active treatment according to a report submitted to the US District Court.

Under the landmark agreement reached by the parties in January 2000, the state has moved about 1000 class members from facilities to more appropriate community settings. A second settlement will result in the community placement of additional 640 nursing facility residents, as well as new "transitional services" that will assist these individuals in preparing for the move to the community. These new services include visits by staff, community outings, therapies, etc. These new services were due to the settlement and were funded by dollars beyond the typical nursing home reimbursement. A small minority (fewer than 100 people) would remain in nursing homes and these individuals were entitled to receive more attention and treatment than they were

presently receiving. A third group of beneficiaries were the hundreds of people who would have ended up in nursing homes but instead were diverted to community options because of the settlement. They and their families have not had to experience the ordeal of considering an institutional facility. The Arc is proud to be part of these achievements as an organizational plaintiff in the case. We recognize the important role that the attorneys in the case played and continue to play through the Center for Public Representation, Disability Law Center, Mental Health Legal Advisors and Foley Hoag LLP.

Within 2 years of the first settlement (1999), it was clear that specialized services for over 1600 persons with ID/DD who were in nursing homes in the Commonwealth was not sufficient. The advocates returned to court several times on behalf of class members who remained in nursing facilities, who despite the settlement agreement were not receiving appropriate services. The court ruled that such services must meet the federal standard of active treatment – services that when delivered in proper intensity, duration and frequency will enable individuals to maintain and develop skills and prevent regression. In the spring of 2007, a Court Monitor was appointed to review the status of active treatment for the estimated 758 class members who remained in nursing homes.

The Arc and others became convinced that the specialized services could not approach active treatment through these findings. **A better outcome would be to help each individual receive an individualized option in the community.** Settlement negotiations began in earnest in late 2007 and were completed in April 2008.

The Arc of Massachusetts (The Arc) addresses concerns and claims

There are four issues raised by the column and letters to the editor and as we noted earlier, important issues related to civil rights of the nursing home residents that are NOT addressed by the letters at all. We address them in the next four points

1. Who is objecting here?

The recent press activity was generated by families who have loved ones at Seven Hills Pediatric Center (nursing home) and COFAR, the group that has fought to maintain all state institutions. The letters are often quite moving, for they talk about the parents' appreciation of the nursing home settings and their fear of the future of their loved one.

This group wants to be excepted from the settlement. They blame DMR for not notifying them earlier about the Rolland litigation. In fact, the Seven Hills facility has a social services office which received notice of the original settlement in 1999 and receives periodic notices from DMR and DPH about this case at least annually. The facility administrators should have been well aware of the litigation as its parent corporation has developed homes for Rolland class members in the community. The organization would also have been aware of the ongoing litigation since this was stated in public meetings by public officials and others.

Additionally it has been reported to The Arc that the Seven Hills leadership has made statements favoring continued institutional care at their center for their residents so they too may be involved in the advocacy for continued institutionalization.

2. Is it possible to serve persons with complex medical conditions in the community?

Already, **individuals with developmental disabilities and complex medical needs are living in community residences and thriving** because they receive not only high-level medical care but personal attention and opportunities for social growth in a homelike setting. The medical care and expertise may be the same as in health care settings and institutions, but the quality of life—for both the individuals served and their caregivers—is richer. (Depending on your version of this document you [can either click here](#) or go to the end of this memo to see written copy of web page link*)

3. Shouldn't the families/guardians have the right to pick the institution of their choice whether the Seven Hills Pediatric Center or Fernald State School?

A fairness hearing was held on May 22, 2008 to review the new Rolland Settlement. Some families representing class members at the Seven Hills Pediatric Center objected to continuing to be class members. They also sought to avoid compliance with the federal standard of "active treatment." Leo Sarkissian, the Executive Director of The Arc of Massachusetts, was asked for his response to the parents' opposition. He affirmed The Arc's position as "steadfastly and historically in support of parents. Although that includes the right to institutional care but it does not include the right to a specific facility. We are equally steadfast in the position that parents cannot refuse the right to 'active treatment,' the high federal standard advocated by the Plaintiffs on behalf of their son or daughter. "

Judge Neiman asked, "You said that your organization supports family choice; how would you respond to the objectors who are saying, 'We want to be able to decide to stay in this nursing facility'?"

Sarkissian responded, "**You'd basically freeze any evolution or advancement in developing community options. You'd freeze it in time.** This is what is happening in the Fernald situation." Sarkissian went on to describe his knowledge of families with children with medical needs and the outcomes many of them have seen in the community.

4. What is the connection between keeping institutional capacity status quo and growth of community services?

As we have detailed in The Arc community investment brochure, **Community Funding: A Priority**, ([click here](#))* over the past three years, the number of people served in the community system increased a total of 5%, while the number in the DMR institutions dropped a total of 11%. However, the pressure to increase funding to the state institutions continues, with a projected increase of \$22 million between 2006 and 2009 fiscal years. The same dynamic occurs with nursing homes. Since public dollars are limited, the additional institutional investment often prevents the growth of community alternatives. It is reported that Massachusetts decreased its investment in community alternatives during 2004-2006.**

Judge Nieman writes: “The court takes note that **many guardians and family members who initially opposed community placement under the original settlement agreement changed their minds when they learned more about community living, their role in the transition process, and the supports that were available.**”

Moving Forward

As a result of the testimony and briefs filed in this fairness hearing, the Court found that the Commonwealth will “create and fill **640 new community placement slots for class members over the next four fiscal years... as well as provide individualized transition services for class members awaiting community placements** Nothing in the agreement will force class members out of nursing homes against their will. Quite to the contrary, the evaluation process recognizes how difficult change may be for residents, their parents and guardians, and allows for both extensive input from family and clinical reviews.”

As The Arc’s Past President Don Stewart wrote in the *News Tribune* (June 2008) “**What really counts is the same for everyone else – personal safety, a sense of well being, a sense of belonging, and a fulfilling life, whatever your talents might be. On this score, community living wins hands down, as proven by hundreds of peer-reviewed articles ...over the past 30 years.**”

* Both informational brochures cited in this memo can be found at:

<http://www.arcmass.org/StateHousePolicy/RegulationandPolicyDebates/FernaldSchoolClosingandRICCIClass/CommunityInvestment/tabid/813/Default.aspx>)

**According to the 2008 “State of the State in Developmental Disabilities”, Braddock et al., page 8, community investment decreased when revenue is adjusted for inflation. Thank you to Marcia Boundy and Steve Schwartz of Center for Public Representation, and Judy Zacek for editorial comments.