

---

## Will it be different this time? Deinstitutionalization's Past: A Reason to Pause and Reconsider

In a frank and challenging article, "[The Past and Future of Deinstitutionalization Litigation](#),"<sup>1</sup> Samuel Bagenstos, former Principal Deputy Assistant Attorney General in the Obama Justice Department's Civil Rights Division and a key litigator in deinstitutionalization cases, disputes the generally-accepted view that deinstitutionalization of the mentally ill was a failure, admits that political expediency denied many people with mental illness and intellectual and developmental disabilities (I/DD) quality placements in the community, and calls for the creation of a new political alliance to achieve quality community placements.

### Quantity Not Quality: Success?

First, Bagenstos argues that one measure of the success of deinstitutionalization is the sheer numbers of people with I/DD who have been deinstitutionalized and the numbers of institutions that have been closed since 1967:

[D]einstitutionalization advocates have essentially won the old battles for the closing and downsizing of large state institutions for people with psychiatric and developmental disabilities . . . the population of state institutions now stands at approximately 16% of its peak, the population of state and local psychiatric hospitals stands at approximately 9% of its peak, and these numbers continue to decrease.<sup>2</sup>

Bagenstos goes on to admit, however, that the political alliance between deinstitutionalization advocates and fiscal conservatives meant certain failure for the advocates' second goal, "to develop an array of services and supports in the community to enable people with psychiatric disabilities or intellectual/developmental disabilities to flourish."<sup>3</sup>

It should not be surprising that the coalition of deinstitutionalization advocates and fiscal conservatives largely achieved their goal of closing and downsizing institutions and that deinstitutionalization advocates were less successful in achieving their goal of developing community services.<sup>4</sup>

Even if some deinstitutionalization advocates were initially unaware that they had entered into a "devil's bargain" with fiscal conservatives, unconscionably, closure efforts continued even after it became

---

<sup>1</sup> Samuel R. Bagenstos, *The Past and Future of Deinstitutionalization Litigation*, 34 *Cardoza L. Rev.* 1 (2012)

<sup>2</sup> *Id.* at 29; see also at 7: "Since that time, states have closed hundreds of their institutions, and they have downsized others."

<sup>3</sup> *Id.* at 15.

<sup>4</sup> *Id.* at 21.

apparent that widespread tragedies were befalling fragile individuals with I/DD developmental disabilities in inadequate community settings.<sup>5</sup>

### **Charting Deinstitutionalization's Future: Will it really be different this time?**

Bagenstos argues that new legal theories, which focus on alleged statutory discrimination under the Americans with Disabilities Act (ADA) instead of constitutional claims, and new advocacy alliances, will help correct for past mistakes and allow for deinstitutionalization *and* the development of a community system better prepared to accommodate all disabled people.

VOR is skeptical, and so, ultimately, is Bagenstos. After outlining his legal and political ideas, he concludes that “things will be different this time –though not necessarily better.”<sup>6</sup>

While an admission by a key player in deinstitutionalization efforts that the community is not utopia is refreshing, Bagenstos shows no willingness to take responsibility for the tragedies that he and the other advocates caused to these highly vulnerable individuals. Nor have past failures moved Bagenstos to take a more reasoned approach to deinstitutionalization efforts, one that insists on building quality, community placements and adequate oversight **before** displacing fragile individuals from ICFs/IID.

Instead, closure advocates are turning to new “battlefields” (private facilities, nursing homes and adult care homes),<sup>7</sup> without apparent concern for the hundreds of thousands of individuals on waiting lists for community services or the history of abuse, neglect and death that has befallen countless community-based individuals. Since 2009, the Justice Department, including while under Bagenstos' leadership, engaged in an unprecedented number of deinstitutionalization legal actions:

The Department has, at last count, filed, joined, or participated in *Olmstead* suits in twenty-one states [now more than 40] and obtained some significant far-reaching settlements.<sup>8</sup>

While Bagenstos professes support for developing community systems of care, and some Justice Department settlements during his tenure reflect this intent on paper, his and the Department's emphasis remains on first moving people (according to a certain timeline in DOJ settlements)<sup>9</sup> and then worrying about whether community services are sufficient:

‘The new paradigm is to ask, ‘Do all these people need to be in an institution?’ If not, provide them services in this community. Then look at wherever they are receiving services and make sure the services are sufficient.’<sup>10</sup>

---

<sup>5</sup> See, VOR, *Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities* (rev. October 2013)(1997- current bibliography of investigative media series, state audits and peer-reviewed research detailing detail systemic concerns with regard to quality of care in community-based settings across the country).

<sup>6</sup> *Id.* at 5.

<sup>7</sup> *Id.* at 29, 48.

<sup>8</sup> *Id.* at 5.

<sup>9</sup> Bagenstos, *supra* note 10, at 34.

<sup>10</sup> Janine Bertram Kemp, *Olmstead Ruling Enforcer Winning Over Advocates, Independence Today* (December 2010) (quoting Bagenstos) at [http://www.itodaynews.com/december2010/8IT\\_News\\_26\\_JBK\\_Olmstead.htm](http://www.itodaynews.com/december2010/8IT_News_26_JBK_Olmstead.htm).

In actions initiated by the Justice Department and settled with states, the Department and the states have set downsizing quotas alongside "extensive and detailed provisions governing the types of services states must provide in the community to those who have been institutionalized or are at risk of institutionalization."<sup>11</sup> Yet, it is unknown what the Justice Department will opt to enforce first, quotas or quality, when states are inevitably unable to finance a community system capable of providing high quality, highly specialized care to individuals with significant needs. This problem is exacerbated by the fact that proper community care is no less costly than licensed facility homes (ICFs/IID) care. VOR has been documenting this fact for years and Bagenstos finally admits it in his article:

[A]dvocates have increasingly focused on the creation of high-quality, ever-more integrated services in the community, [and thus] fiscal concerns have become more of an obstacle to their efforts.<sup>12</sup>

\* \* \* \* \*

Although studies of deinstitutionalization have found that people who move from institutions to the community can achieve better outcomes at lower cost, it is reasonable to expect that the cost gap will shrink [or reverse] as people in the community receive more services. This may be especially true because a significant part of the cost gap reflects differences in the wages paid to workers in institutional and community settings.<sup>13</sup>

Although Bagenstos argues that the *Olmstead* doctrine equips advocates with a sword to challenge cuts to community services, and presumably community expansion to meet growing needs caused by long waiting lists and deinstitutionalized individuals, no amount of sword wielding will increase a finite funding pie. To this point, Bagenstos hints that states could opt to drop out of the Medicaid program if pushed too hard,<sup>14</sup> a real risk if faced with relentless lawsuits and impossible settlements.

### **A hope for new alliances?**

Having played such a major role in the elimination of quality living arrangements for people with I/DD, Bagenstos has the gall to suggest that the families of current and former ICF/IID residents, and unions, now join with deinstitutionalization advocates in support of even more closure lawsuits:

[W]hat that wave of litigation can do is ensure that, when large state institutions close, there are adequate and appropriate community-based services for people who would formerly have been housed there. The sooner deinstitutionalization advocates, parent organizations, and employee groups recognize that fact – and that it means they share far more interests than disagreements – the better will be the position in which they will be fighting the politics of fiscal retrenchment.<sup>15</sup>

---

<sup>11</sup> Bagenstos, supra note 8, at 33.

<sup>12</sup> *Id.* at 39.

<sup>13</sup> *Id.* at 43; compare, Kevin Walsh, et al, *Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research*, *Mental Retardation*, Vol. 41, No. 2: 103-122 (April 2003) (“Findings do not support the unqualified position that community settings are less expensive than are institutions and suggest that staffing issues play a major role in any cost differences that are identified”).

<sup>14</sup> *Id.* at 36.

<sup>15</sup> *Id.* at 47-48.

Despite the temerity of Bagenstos, VOR has and will continue to work for quality community options. In fact, VOR just this year launched a “quality in the community initiative” in an effort to secure uniform quality standards across all care settings. Yet here, even where deinstitutionalization advocates and VOR members agree, on quality community placements, Bagenstos’ proposed alliance would be highly unlikely to overcome the opposition of fiscal conservatives. This is particularly true in a time of tight state budgets and rising state Medicaid costs.

What, VOR will **not** do is abandon its support for a continuum of service options. Our members are willing to work toward the common goal of quality in the community, but not at the expense of an equally necessary and integrated (see below) service option – ICFs/IID. Federal law, including the ADA and *Olmstead*,<sup>16</sup> also recognizes the need for a range of service options to ensure individualized care and, appropriately, puts the right of choice in the hands of individuals and, where necessary, their families and legal guardians. Although often ignored as an apparent inconvenience by deinstitutionalization advocates, the right of individual choice is secure in federal law.

### **Pursuing Integration, Not Isolation: Ignoring the Reality of the Depth of Disability of ICF Residents**

Deinstitutionalization advocates have long contended that community placements are integrated and facility placements are isolated. This argument, which Bagenstos assumes to be true, ignores the fact that all people with I/DD are not the same. While there are many people in the community with disabilities comparable to those of ICF/IID residents, the people who now reside in ICFs/IID, as a whole, are among the most disabled and fragile members of our society. For these citizens, their cognitive, medical, physical and behavioral disabilities are so profound and complex, that quality of care means compassionate, highly skilled care, life-sustaining care. Quality of life is also not lacking, for despite their complex disabilities, many ICFs/IID residents attend community events and have many visit the ICF/IID home.<sup>17</sup> In sharp contrast, some community homes are so lacking in resources that people with I/DD live in isolation. Consider the living experiences of Mark and Brian:

Mark has multiple disabilities, including autism, is prone to wandering out of his home but has little sense of danger and is prone to outbursts. His mother keeps buzzers around her home to keep Mark safe. ‘If he goes out of the door, then we and God and everyone else can hear it because it is so loud,’ she said. ‘But it is exhausting. It is intensely stressful and it’s very exhausting.’

---

<sup>16</sup> See, *Olmstead v. L.C.*, 527 U.S. 581, 587 (1999)(community placement is not required if opposed by the individual); *Heller v. Doe*, 509 U.S. 312, 328-29 (1993) (“close relatives and guardians, both of whom likely have intimate knowledge of a mentally retarded person’s abilities and experiences, have valuable insights which should be considered during the involuntary commitment process”); and the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. 15001(c)(3)(1993) (*Findings, Purposes and Policies*) (“Individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families”).

<sup>17</sup> The Glenwood, Iowa School District, for example, serving school children from pre-school through high school, shares the same campus as Glenwood Resource Center, a state-operated ICFs/IID. There is also a workforce development center, a domestic violence shelter, offices for the Department of Natural Resources Conservation and Forestry, a variety of University training and research programs, and other programs on the Glenwood campus.

Brian, age 42, experiences dangerous behaviors. When living in his family home, he injured every family member and they replaced hundreds of windows. Brian was expelled from four community homes in two states before receiving appropriate care in a state-operated Medicaid-certified facility (ICF/IID).<sup>18</sup>

In these real-life examples, DOJ and other federal agencies would find Mark to be integrated and Brian to be isolated, solely due to where they live and who they live with.<sup>19</sup> Brian's home is under attack by deinstitutionalization advocates who found a friend in a fiscally-conservative governor. Sound familiar?

## Conclusion

Ideologically-motivated deinstitutionalization has resulted in the forced removal of thousands of individuals with intellectual, developmental and other disabilities from true communities and into isolation. This point is lost on Bagenstos and other deinstitutionalization advocates, which is to the disabled citizen's peril and makes future alliances nearly impossible.

Alliances are only possible if all stakeholders are willing to accept that "Individuals with disabilities" describes a widely diverse group of people, ranging from people with mild physical and/or intellectual disabilities to those with profound or other severe intellectual disabilities, along with medical or behavioral disabilities, who will have different care needs. Support for full community integration of most individuals with disabilities should not be interpreted to deprive individuals with profound intellectual and developmental disabilities (I/DD) or other serious I/DD and medical and/or behavioral disabilities from assurances of proper care of their health and safety needs, and individuals with disabilities should not be forced to accept services or participate in activities they do not wish to accept. As Justice Ginsburg wrote in the *Olmstead* decision, "Each disabled person is entitled to treatment in the most integrated setting possible for that person – recognizing that, **on a case by case basis**, that setting may be in an institution."<sup>20</sup>

---

<sup>18</sup> VOR, *Integration or Isolation? Defining "Community" Beyond Bricks and Mortar* (June 10, 2013).

<sup>19</sup> For federal enforcers, integration is often defined by arbitrary criteria that lead to absurd definitions of "community" and "integration." In a recent case, the U.S. Department of Housing and Urban development has alleged that a housing complex for hearing impaired seniors is in violation of the ADA's integration mandate because too many disabled residents are living one location. In response, the National Association for the Deaf criticized HUD's "ideological vision of forced integration" that will, in actuality, lead to "forced isolation." (April 25, 2013).

<sup>20</sup> *Olmstead*, supra note 16 at 605 (*emphasis added*)