by Charles D. Hammerman
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The Disability Housing Market in New England

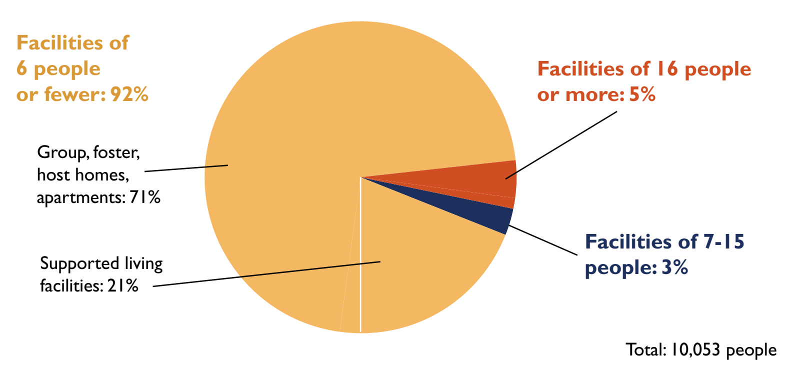
This year marks the 45th anniversary of the photographic essay *Christmas in Purgatory*, by Boston University Professor Burton Blatt.[1] Its 70-plus photographs depict the deplorable conditions that New York and Massachusetts state officials at that time considered "normal and acceptable" for their citizens with intellectual and development disorders (I/DD). And it galvanized public officials.

By 1973, U.S. legislators had passed the Vocational Rehabilitation Act to develop ways to empower people with disabilities who wanted to live independently. The Americans with Disabilities Act (ADA) and the Cranston-Gonzalez National Affordable Housing law were passed in 1990. But despite progress, a coherent public policy that addresses the housing needs of people with disabilities does not yet exist.[2]

Although New England states have been proactive in reducing or eliminating problematic state-run institutions, factors such as longer life expectancy, an aging baby boom population, and increased cases of Autism Spectrum Disorder present new challenges. The challenges need attention *now*. Current economic conditions and shortfalls in state budgets are threatening the successes of the last 45 years.

Out-of-Home Placements, 2009

Maine, New Hampshire, Rhode Island, Vermont



Source: D. Braddock, *State of the States in Developmental Disabilities* (Boulder, Colorado: Coleman Institute for Cognitive Disabilities, 2010, preliminary).

Regional Progress

Christmas in Purgatory launched a trend to allow Americans people with disabilities to live in their communities and receive any necessary services there. As of 2009, there were 586,932 individuals with intellectual and/or developmental disabilities (I/DD) in placements not their home throughout the United States.[3] Of those, 438,767, or 75 percent, were living in settings of six persons or fewer—in group homes, foster homes, host homes, and supported-living arrangements. Approximately 10 percent were living in facilities of seven to 15 residents. Fifteen percent were living in larger facilities, including nursing homes, private entities, and state institutions. But it remains a concern that 38 percent still reside in large, state-run institutions.

When compared with other regions, New England has been more progressive in deinstitutionalizing. As of 2009, there were 11 states with no state-operated I/DD institutions. Four are in New England (Maine, New Hampshire, Rhode Island, and Vermont). In fact, out of a population of 4.3 million people, those four states had barely 10,000 people with I/DD in any out-of-home placement. (See "Out-of-Home Placements, 2009.") More than 92 percent were residing in settings of six people or fewer. Less than 5 percent were living in nursing homes or private facilities of 16 or more people, much better than the nationwide average of 15 percent. For settings with seven to 15 people, the average rate in New England is 3.5 percent, whereas the U.S. average is 10 percent, Illinois 31 percent, New York 29 percent, North Dakota 22.4 percent, and South Dakota 22.3 percent.

Another barometer of how invested states are in addressing the needs of people with I/DD is the fiscal effort, a state's spending for I/DD services per $1,000 of total statewide personal income. As of this writing, Maine ranks first in fiscal effort, spending $8.30 per $1,000; Connecticut ranks third nationwide ($7.76); Rhode Island is tenth ($6.35).

Community-based housing is less expensive than institutional care.

In 1999, the U.S. Supreme Court handed down a decision citing the unlawful confinement of disabled persons as a violation of the ADA.[4] Not long after, the federal government increased its funding of the Home and Community Based Services (HCBS) Waiver Program from approximately $7.6 billion in 1999 to $14.8 billion in 2009—allowing HCBS to improve its support of Medicare and Medicaid services for people with disabilities. Meanwhile, the amount of spending on institutional settings decreased.

The New England region has embraced the HCBS Waiver Program. Of the top five states in the country with the most spending per capita of federal and state waiver dollars, three are in New England: Maine ranks first ($230 per capita); Rhode Island is third ($214); Vermont is fifth ($205). The average spending in the United States is $78 per capita, with three of the more populous states spending less than a quarter of those in New England (California, $52; Florida, $4; Texas, $28).

Today's Challenges

The coming decades will witness a tremendous increase in demand for residential services. Whether it is the baby boom population (an estimated 71 million over age 65 by 2030) or the number of Americans diagnosed with Autism Spectrum Disorder (currently more than 1 million), states will need to decide how to allocate funds.[5] And New England will have to reconcile the increased demand with the double-digit budget gaps seen in 2010.[6] The task is especially challenging given the likelihood of less federal support.

The time is right for new spending models. The Disability Opportunity Fund (DOF) offers one approach. It differs from most housing initiatives today, which tap an unintuitive patchwork of private and public entities. In 2007, the DOF became a community development financial institution (CDFI) and began to work with other CDFIs on pulling together finance, community outreach, and technical assistance to create affordable housing for people with disabilities.

Incorporating advocacy with lending has already achieved results in this previously overlooked market. Collaborations with existing CDFIs and mainstream financial institutions—as well as with government agencies at all levels—have made it possible to develop housing that meets the needs of both individuals and families.

An example is "The Cottage" in Darien, Connecticut (TCID). The families of the residents worked together for nine years to bring to fruition this six-bedroom, supportive-housing project. The creative collaboration included the Town of Darien (which offered to lease the land to TCID for $1/year for 80 years), the parents who incorporated TCID as a not-for-profit organization and proceeded to use outreach to the community to raise funds for the down payment, the State of Connecticut (which agreed to pay about $500,000 per year for support staff and operating expenses), and DOF and Leviticus Fund (both of them CDFIs), which offered flexible financing to build the home.

In early 2009, the lenders provided a five-year term, interest-only, balloon-payment construction loan of $685,000 with no prepayment penalty. Three exit strategies were weighed: (1) TCID would continue to raise funds and pay off the principal within the five-year period; (2) at the end of the five-year period DOF and Leviticus would roll the loan over into a new loan; or (3) the lenders would help TCID convince a mainstream financial institution to refinance the loan with longer terms. In May 2011, TCID closed on a 10-year mortgage with a conventional bank and repaid its loan to the two CDFIs—three full years ahead of schedule.

The most important public policy idea that the TCID experience highlights is that residents with disabilities can be the "owners" of their homes, rather than the State of Connecticut or a service provider. Although residents' names are legally not on the deed, they are owners in the sense that they control their fate. The service provider is a contractor paid to work in the house, much like the plumber or electrician. If providers do a great job, they stay. If not, they are fired and another service provider is brought in. The revolutionary concept upends the notion of having residents live in a bed owned by someone else. They live in their own home, in the community. The parent-driven, multifunded TCID project enables six residents to live alone, rather than with family or in adult foster care. It is one example of what can be done.

More is needed. Forty-five years after *Christmas in Purgatory*, challenges remain in providing safe, affordable, and accessible housing solutions for people with disabilities and their families. Forty-five years ago the country saw photographs of the wrong way to plan for the future. Since then we have recognized the benefits that community-based living has for everyone involved: for people with disabilities, who deserve to live with the rest of society; for their families, who need to know their family member will have good opportunities when they can no longer provide care; and for society in general since community-based housing is less expensive than institutional care. The Cottage in Darien is one of a number of excellent models from which to choose, but paying for new models requires ingenuity. All that should guide the future is choosing the just and humane path.

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Endnotes

[1] Burton Blatt and Fred Kaplan, *Christmas in Purgatory: A Photographic Essay on Mental Retardation* (Boston: Allyn and Bacon, 1966).

[2] David L. Braddock et al., *Opportunities for Community Development Finance in the Disability Market* (Boston: Federal Reserve Bank of Boston, 2010), http://www.bostonfed.org/commdev/cdevfin-disability-market/index.htm.

[3] David L. Braddock, *State of the States in Developmental Disabilities* (monograph, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, Boulder, Colorado, 2011).

[4] Olmstead v. L.C., 527 U.S. 581 (1999).

[5] Peter F. Gerhardt, *The Current State of Services for Adults with Autism* (New York: Organization for Autism Research, January 2009).

[6] Elizabeth McNichol, Phil Oliff, and Nicholas Johnson, "States Continue to Feel Recession's Impact" (white paper, Center on Budget and Policy Priorities, June 17, 2011), http://www.cbpp.org/cms/?fa=view&id=711.

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