

The Institutional Bias in Illinois:

Wasting Taxpayer Money and Denying Personal Freedoms

Despite the fact that over 20 years of scientific research conclusively shows that people with significant disabilities are better off in small, family-scale homes, the State of Illinois continues to spend hundreds of millions of dollars to keep these individuals in large, outdated, expensive institutions.

The State of Illinois ranks dead last in supporting people with significant disabilities in community settings. Rather, 70% of residences for people with disabilities are for 7 or more people.¹

In 2006, Illinois spent over \$626 million on institutions to operate 9 state facilities and approximately 250 private institutions. Over 2,700 individuals are housed in state facilities and 5,272 are placed in private institutions of 16 or more people. Total institutional population in Illinois is more than double the national average.²

How the Institutional Bias Wastes Taxpayers' Money

Institutional care costs more than twice as much as community-based care. In 2006, Illinois spent over \$130,000 a year for each of its 2,709 residents in state institutions.³ These individuals could be served on average in the community with 24-hour support for \$54,000 a year.⁴

There are federal funds available to states for community care through the Medicaid Home and Community Based Services "waiver" program (HCBS). The fundamental premise of the program is to use home and community-based services to reduce the need for institutional services. The HCBS program is recognized in all states as an important resource for providing community services. Illinois has not made good use of this resource and is ranked 47th in the nation in waiver spending.⁵

The Personal Costs of Institutionalization

Independent research has shown that everyone can benefit from community-based living, even those with the most severe mental and physical disabilities. Studies by well-respected universities conducted over 20 years show that people with significant disabilities are "better off in most ways when they leave large congregate care settings for community living in small, family-scale homes."⁶ Research also indicates that crime rates against people with disabilities are higher in institutions and other segregated facilities than in the community. Sobsey and Mansell concluded that the risk of being sexually abused is two to four times higher in an institutional setting than in community settings.⁷

¹ D. Braddock et al., (2008). *The State of the States in Developmental Disabilities: 2008*, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, The University of Colorado.

² D. Braddock et al., (2008). *The State of the States in Developmental Disabilities: 2008*, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, The University of Colorado.

³ D. Braddock et al., (2008). *The State of the States in Developmental Disabilities: 2008*, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, The University of Colorado.

⁴ This Figure includes \$44,000 for residential services and \$10,000 for day programs.

⁵ D. Braddock et al., (2008). *The State of the States in Developmental Disabilities: 2008*, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, The University of Colorado.

⁶ TASH Newsletter, Volume 24, Issue Number 3, March 1998

⁷ Sobsey, D. & Mansell, S. (1990). *The Prevention of sexual abuse of persons with developmental disabilities*. Developmental Disabilities Bulletin, 18, 51-65.

Since Illinois spends the majority of its disability resources on large congregate care facilities, thousands of people who desperately want to live independent lives have no choice but to suffer under inadequate, under funded community services. Many have no real choice but to give up their freedoms in order to receive the care they need.

Some people believe institutions are the best places for people with disabilities. But those who represent the best interests of those with significant disabilities in Illinois, including people with disabilities themselves and the vast majority of parents of children with disabilities who want take care of their loved ones at home, respectfully disagree.

Even when it's done for ostensibly good reasons, forcing people into isolation benefits no one. Institutions rob people with significant disabilities of their ability and responsibility of personal choice...the choice of who cares for them and the type of care and support services they need.

As a matter of principle, *all* Americans should be able to choose who cares for them and the type support services that best meet their specific needs, not those that are easiest to provide to a large number of people.

The rights of Life, Liberty, and the Pursuit of Happiness were extended to all in the Declaration of Independence. The U.S. Supreme Court upheld this principle of equality in its 1999 *Olmstead v. L.C.* ruling. The Court said that "...*Unjustified institutional isolation of persons with disabilities is a form of discrimination.*"

In essence the Court recognized that the very nature of institutionalization makes it extremely difficult to pursue a free life.

- You eat *when* other people tell you to eat.
- You eat *what* other people want to give you.
- You bathe when it is convenient for others.
- Your day is completely out of your control.
- Worse yet, you are isolated from potential friends, neighbors, and loved ones.

Effective supports and services *can* be provided to individuals with significant disabilities in community settings.

Nine states* have closed *all* of their state institutions and are serving more of their citizenry with *better* supports in a more *cost effective* manner.

* Alaska, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont, Washington D.C., and West Virginia

We believe the State of Illinois can, and should, do a better job providing supports in *real* homes that are part of *real* communities. People with disabilities in Illinois deserve and should demand no less.

Compiled by *The Campaign for Real Choice in Illinois*
www.realchoiceinillinois.org