



Deinstitutionalization Toolkit: **INSTITUTIONS** – in**BRIEF**

Institutional Settings

Most advocacy focuses on closing state-run institutions, but it is important to recognize a substantial number of people with intellectual disabilities and developmental disabilities (ID/DD) live in other institutional settings, including 26,695 in large (more than 16 residents) non-state DD facilities and 29,608 in nursing homes.

Large Institutions: Trends and Populations

The number of people with ID/DD residing in state-run institutions has declined from a peak of 194,650 in 1967 to 32,909 in 2009. The extent to which states continue to rely on institutions to house people with ID/DD varies significantly by state. Eleven states have closed all their state-run institutions, while others have resisted closing any.

Comparing your state with others can be a powerful advocacy tool. There are several metrics that you can use:

- Number of residents in large state institutions: This metric is useful for highlighting the number of people who could benefit from a deinstitutionalization effort, but makes no adjustments for the size of the state.
- Percentage of all out-of-home placements in large institutions: This metric shows how much the state relies on large public institutions to provide services, but it does not adjust for the proportion of the population with ID/DD that receives residential services.
- Residents of state institutions per 100,000 of the general population: This metric adjusts for the size of the state, which is a good proxy for the number of people with ID/DD in the state.
- Change in the average daily population: This metric illustrates the rate of depopulation.

State data and rankings are provided for each metric for 2009 in the detail section.



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Large Institutions: Population Characteristics

The residents of institutions range in age, level of intellectual disability, and other conditions and functional limitations. The same can be said of those who are served in the community.

Some people claim that the people currently being served in institutions are “more disabled” than those living in the community and cannot be supported safely in the community. The Supports Needs Index (SNI), a well-established metric, is used to compare the characteristics of people with ID/DD in order to compare the populations in large institutions with those in community-based settings.

For example, a study by the Human Service Research Institute used the SNI to compare the 156 people living at the Southeastern Virginia Training Center (SEVTC) with a sample of people receiving services under the Home Community-Based Services Waiver program. The study found that the people in SEVTC had a higher average score (111.96 compared with 101.74), but people in the community had a higher maximum level of support needs. In other words, many people in the community had needs equivalent to those at the SEVTC, and some had even more intensive needs (Fortune and Auerbach 2009).

As the population in institutions has declined, the proportion of people with profound impairments and additional conditions has increased. However, looking at the proportion distorts an important reality. The vast majority of people with ID/DD who have extensive needs for health and behavioral supports live in the community. Every person being served in an institution has a “twin” with the same functional needs living in the community. For additional data that support and explain this assertion, see the Deinstitutionalization Toolkit.

➤ INSTITUTIONS – in**DETAIL**

Comparison of Large Institutions by State

For the most up-to-date statistics, see the National Residential Information Systems Project Web site. You can access published reports at

<http://rtc.umn.edu/risp/reports/>



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or build a report using online data at

<http://rtc.umn.edu/risp/build/index.asp>.

United Cerebral Palsy uses the rate of institutionalization as one of several measures to develop a composite score chart of each state's ranking and progress in creating a quality, meaningful, and inclusive community life for people with ID/DD. Those rankings can be found in the annual "Case for Inclusion" report at

<http://medicaid.ucp.org/index.php>.

Several states have contracted with researchers to develop reports to compare their state with others. For one example, see *Closing the North Dakota Development Center: Issues Implications, Guidelines* by David Braddock in the Deinstitutionalization Toolkit.

➤ CLOSURES – in**DEPTH**

Cost of Large State Institutions

In 2009, the average annual cost of providing services in an institution was \$196,710. Adjusted for inflation, this is 60 percent more than the cost in 1990. Some of the stakeholders we interviewed believed that large state institutions are not sustainable with costs increasing so quickly.

The weighted per diem average of \$539 (\$196,710 per year) represents expenditures ranging from a low of \$285 per day (\$104,025 per year) in Arkansas to a high of \$1,030 (\$375,950 per year) in Tennessee.

See "INSTITUTIONS – in**DETAIL**" for a table (table 8) that ranks states by the average annual cost of state institutions. A number of factors account for the differences in cost among states, so a higher cost should not be construed as necessarily better or worse than a lower cost. However, you can use this information to illustrate how much is being spent per person. As an advocate, you can pose the question, "If you had \$196,710 [or whatever the relevant number is in your state] per year to spend on your loved one, would you choose institutional care?"



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For more information on institutions, see the subsequent parts of Section 3 of the Deinstitutionalization Toolkit.

- INSTITUTIONS – in**DETAIL**
- INSTITUTIONS – in**DEPTH**

References

Fortune, J., and K. J. Auerbach. (2009). Virginia SIS Comparisons for SEVTC and Comprehensive Community Waiver Populations. Human Services Research Institute, Information Brief. Accessed March 30, 2011. http://www.arcofva.org/docs/0910_sis_comp.pdf