



Deinstitutionalization Toolkit: **INSTITUTIONS** – in**DETAIL**

This section of the Deinstitutionalization Toolkit includes the supportive detail on the subject of Institutions. The research and detailed information are intended to provide background for the Deinstitutionalization Toolkit:

➤ **INSTITUTIONS** – in**DETAIL**

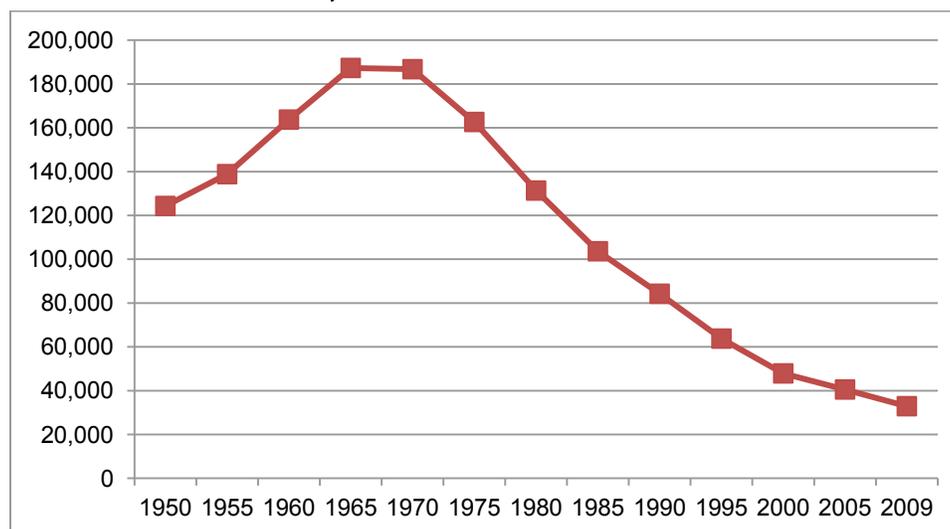
Large State Institutions

Large Institutions: Trends and Populations

The peak of institutionalization for people with Intellectual disabilities and developmental disabilities (ID/DD) was in 1967, when 194,650 people with ID/DD nationally were housed in large designated state institutions. Figure 1 shows that by 2008, this number had been reduced to 32,909 (Lakin et al., 2010).

An additional 33,850 people with ID/DD were housed in state psychiatric facilities in 1967, but by 2009, this number had been reduced to 765. When addressing the institutionalization of people with ID/DD, it is therefore reasonable to focus our research on large state and nonstate facilities for people with ID/DD.

Figure 1: Average Daily Census of People with ID/DD in Large State ID/DD Facilities, 1950–2009



Source: Data from Lakin et al., 2010



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Trends in the average daily census mask the dynamics of the movement to and from state institutions. New admissions have not stopped. Between 2008 and 2009, it is reported that 3,111 people were discharged and 870 had died. However, during the same period, reports indicate that 1,981 were admitted (Lakin et al., 2010). Thus, it is important to focus not only on moving people out of institutions but also on reducing new admissions.

Large Institutions: Population Characteristics

The population of people served in large (more than 16 residents) state institutions has changed since 1977, when the institutional population was more than four times what it is today. Table 1 shows the following information:

- The population has aged. The proportion of large state facility residents 21 years or younger declined dramatically between 1977 and 2008, from 36 percent to less than 5 percent. At the same time, the percentage of residents over 40 (ages 40 to 62 and 63 and older in table 1) increased dramatically, from 23 percent to 73 percent.
- The percentage of people with more significant levels of intellectual impairment has increased. Currently, 58 percent of institution residents have a profound intellectual impairment, compared with 46 percent in 1977.
- The type and level of assistance has changed. The percentage of residents with behavior disorders has increased substantially, and a higher percentage of residents need supervision with daily activities such as walking, eating, dressing, toileting, and communicating.



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Table 1: Characteristics of Residents of Large State ID/DD Facilities, 1977 and 2008
(Data for 2009 are not available)

	1977	2008
	151,112	35,035
Gender-Male	57%	63%
Age		
0–21	36	5
22–39	41	23
40–62	19	61
63+	4	12
Level of Intellectual Disability		
Mild/No ID	10	14
Moderate	16	12
Severe	28	16
Profound	46	58
Additional Conditions		
Cerebral Palsy	19	23
Behavior Disorder	25	52
Psychiatric Disorder	NC	52
Needs Assistance or Supervision with:		
Walking	23	39
Eating	21	51
Dressing	56	53
Toileting	34	57
Communicating	44	58

Source: Lakin et al., 2009

Comparison of the “Severity of Disability” of People in an Institution and in the Community

The residents of institutions in the United States vary in age, level of intellectual disability, number of coexisting conditions, and functional limitations. Typically, they include people who have significant and complex medical needs, behavioral issues, and psychiatric disabilities, as well as people who have grown old in the institution.



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Research has revealed these two important facts about the population:

- More people with extensive support needs are served in the community than in institutions.
- A higher percentage of people in institutions have intensive support needs.

These facts about institutional populations present two important ideas about deinstitutionalization. The first indicates that people with extensive support needs can be served effectively in the community. The second affects the cost estimates for serving them. As discussed in the “Costs” topic area of the Deinstitutionalization Toolkit, costs are associated with a variety of factors, including level of need. For more information on this subject, see Section 6 of the Deinstitutionalization Toolkit.

- COSTS – in**BRIEF**
- COSTS – in**DETAIL**
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Opponents of deinstitutionalization claim that people in institutions are “more disabled” than those in the community, and thus the track record of success of community living does not apply to those still in institutions. They claim that people remaining in institutions have such significant complicating conditions that either they cannot be supported in the community or the cost of supporting them in the community exceeds the institutional cost.

Table 2 shows that the data substantiate the claim at this point in California institutions, where a higher proportion of people who remain in institutions are older, have more profound intellectual disabilities, have more complicating conditions, and require more assistance than those living in the community. As the number of people living in institutions has been reduced in the past 40 years, those with functional skills and fewer complicating factors generally were discharged first. As a result, the 32,909 people living in state institutions are, *on average*, “more disabled” than the 436,000 who are receiving state support and living in the community.



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Table 2: State of California Department of Developmental Services Characteristics of Clients in Developmental Center Compared with Clients in the Community, December 2007

Developmental Center Clients		Description	Community Clients	
n	Pct		n	Pct
1,082	41%	Have Cerebral Palsy	33,564	18%
349	13%	Have Autism	36,603	19%
1,334	50%	Have Epilepsy	36,553	19%
2,404	90%	Have Medical Problems	51,931	27%
480	18%	Are Technology Dependent	8,653	5%
1,198	45%	Take Behavior-Modifying Drugs	31,531	17%
541	20%	Have Severe Loss of Sight	15,357	8%
206	8%	Have Severe Hearing Loss	4,558	2%
991	37%	Have Severe Behavior Problem	13,189	7%
1,190	45%	Do Not Walk Well	36,217	19%
528	20%	Do Not Understand Spoken Word	5,872	3%
1,193	45%	Are Violent	21,811	11%
703	26%	Must Be Fed	14,679	8%
1,953	73%	Need Help Toileting	82,356	43%
2,040	76%	Need Special Health Care Item	44,659	23%
1,791	67%	Are Incontinent	62,713	33%
1,190	45%	Are Self-Injurious	24,954	13%
1,099	41%	Destroy Property	17,748	9%
1,533	57%	Have Unacceptable Social Behavior	43,263	23%
913	34%	Will Run Away	33,503	18%
Levels of Intellectual Impairment				
8	0%	Not MR	49,549	26%
449	17%	Mild	72,416	38%
238	9%	Moderate	32,152	17%
370	14%	Severe	14,614	8%
1,585	59%	Profound	9,256	5%
20	1%	Unknown	12,865	7%
Number of Special Conditions or Behaviors				
1,428	54%	None	174,647	92%
360	14%	One	9,685	5%
285	11%	Two	3,951	2%
597	22%	Three or More	2,569	1%

Source: State of California, Quarterly Client Characteristics Report, December 2007.

http://www.dds.ca.gov/FactsStats/docs/Dec07_QRTTBLS.pdf



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The proportions can distort an important reality. The California data indicate that vastly larger numbers of people with ID/DD and extensive needs for health or behavioral support are living in the community rather than in institutions. For example, although 59 percent of an institution's residents have profound intellectual impairment compared with 5 percent of community residents, there are only 1,585 people with profound intellectual impairment in institutions compared to 9,256 in the community.

A Human Service Research Institute (HSRI) study confirms these findings. Utilizing the Support Needs Index (SNI), a well-established metric for needs assessment, researchers compared the 156 individuals living at the Southeastern Virginia Training Center (SEVTC) with a sample of people receiving services under the Home Community-Based Services (HCBS) Waiver program. They 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).

Table 3 compares the minimum, maximum, and average scores of the total SNI and of each of its component parts, and Figure 2 compares the distribution of SNI scores.

Table 3: Comparison of Support Needs of HCBS Waiver Clients and SEVTC Residents, 2009

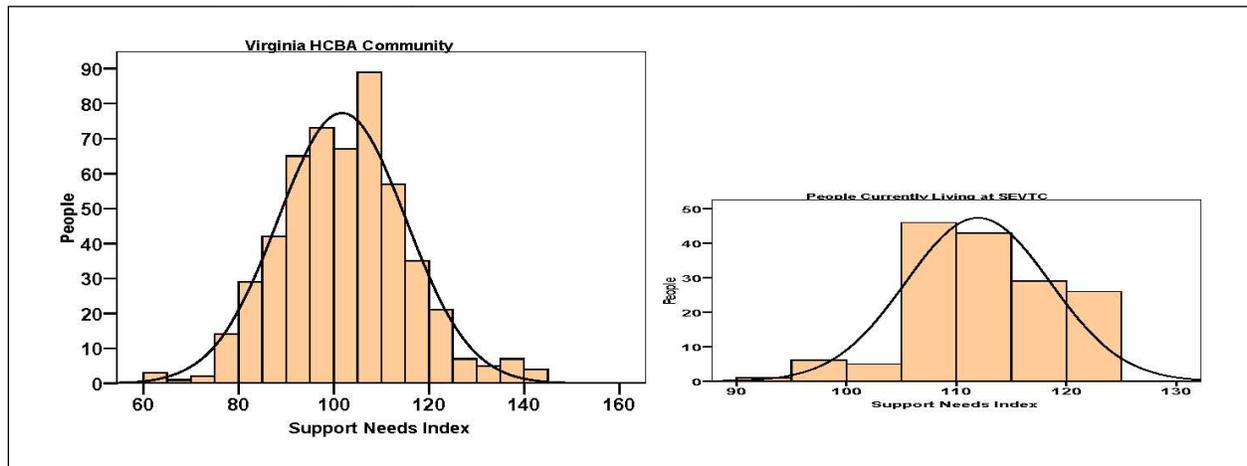
	HCBS Waiver Clients (n=521)			SEVTC Residents (n=156)		
	min	max	avg	min	max	avg
Home Living Activities, Community Living Activities, Health and Safety Activities)	12	52	30.56	27	42	35.37
Medical Problems	0	22	2.43	0	22	6.32
Behavioral Problems	0	20	4.77	0	20	5.55
Total Support Needs Index*	60	143	101.74	90	124	111.96

Source: Fortune and Auerbach, 2009.

*The SNI is normed to represent support needs with average of 100 and a standard deviation of 15. For more information about the scale, see Fortune and Auerbach, 2009.



Figure 2: Comparison of the Distribution of Scores of the SNI between a Sample of Virginia's HCBS Waiver Community and SEVTC Residents, 2009



Source: Fortune and Auerbach, 2009

The University of Minnesota Research and Training Center on Community Living further confirms this finding. Using data from the National Core Indicators in six states in 2006, Lakin et al. (2006) found that “HCBS Waiver finances services for people with a full range of disabilities and support needs, but ICF/DD beneficiaries on average on a number of measures exhibited substantially greater levels of impairment than HCBS recipients. Because of the greater total number of HCBS recipients on most of the same measures there were more HCBS than ICF/DD recipients with substantial impairments.” Table 4 shows the following examples:

- Fifteen percent of HCBS Waiver recipients were reported to have profound ID, compared with 39 percent of ICF/DD recipients, but of the combined HCBS and ICF/DD samples, 60 percent of the respondents with profound ID were HCBS Waiver recipients (Lakin et al., 2006).
- In addition, 11 percent of HCBS Waiver recipients were reported to be nonambulatory, compared with 20 percent of ICF/DD recipients, but of the combined HCBS and ICF/DD samples, 70 percent of those who were nonambulatory were HCBS Waiver recipients (Lakin et al., 2006).
- HCBS and ICF/DD recipients were *not* statistically different in the proportions with visual impairments, cerebral palsy, autism, monthly or more frequent seizures, or dual diagnoses of intellectual and psychiatric disabilities; or in the



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prescription of medication for mood, anxiety, or behavior disorders (Lakin et al., 2006).

Table 4: Selected Characteristics of Adults (18 and Older) with ID/DD Receiving Medicaid HCBS and ICF/DD Waiver Services in Six States

Characteristics	HCBS		ICF/DD		Total	
	N	%	N	%	N	%
Age						
Average Age		42.25		45.38		43.77
18 to 54	1,947	83.4	445	77.5	2,392	82.3
55 and older	387	16.6	129	22.5	516	17.7
Total	2,334	80.3	574	22.6	2,908	100.0
Level of ID						
Mild	955	40.6	149	25.6	1,104	37.7
Moderate	603	25.7	87	14.9	690	23.5
Severe	352	15.0	110	18.9	462	15.8
Profound	334	14.2	221	38.0	555	18.9
None	48	2.0	4	0.7	52	1.8
(Not Reported)	(58	2.5)	(11	1.9)	(69	2.4)
Reported Total	2,350	80.2	582	19.8	2,932	100.0
Psychiatric Diagnosis						
No	1,576	69.4	387	66.7	1,963	68.9
Yes	695	30.6	193	33.3	888	31.1
% of Total	2,271	79.7	580	20.3	2,851	100.0
Autism						
No	2,107	93.8	514	93.8	2,648	93.8
Yes	140	6.2	36	6.2	176	6.2
% of Total	2,247	79.3	577	20.4	2,824	100.0
Cerebral Palsy						
No	1,939	86.0	472	81.9	2,411	85.2
Yes	315	14.0	104	18.1	419	14.8
% of Total	2,254	79.6	576	20.4	2,830	100.0
Seizure or Neurological Disorder						
Disorder reported	735	33.0	240	41.9	975	34.8
1 or more seizures/month	228	10.0	50	9.0	278	9.8



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Table 4: Selected Characteristics of Adults (18 and Older) with ID/DD Receiving Medicaid HCBS and ICF/DD Waiver Services in Six States (continued)

Characteristics	HCBS		ICF/DD		Total	
	N	%	N	%	N	%
Self-Injury						
No	1,868	82.1	461	69.2	2,329	79.2
Yes	406	17.9	205	30.8	611	20.8
At least monthly	241	61.6	111	55.0	352	59.4
At least weekly	98	25.1	64	31.7	162	27.3
At least daily	45	11.5	23	11.4	68	11.5
At least hourly	7	1.8	4	2.0	11	1.9
% of Total	391	65.9	202	34.1	593	100.0
Disruptive Behavior						
No	1,488	65.6	361	54.2	1,849	62.9
Yes	782	34.4	305	45.8	1,087	37.0
At least monthly	438	56.6	150	49.3	588	54.5
At least weekly	223	28.8	119	39.1	342	31.7
At least daily	101	13.0	29	9.5	130	12.1
At least hourly	12	1.6	6	2.0	18	1.7
% of Total	774	71.8	304	28.2	1,078	100.0
Uncooperative Behavior						
No	1,477	65.2	401	60.2	1,878	64.1
Yes	788	34.8	265	39.8	1,053	35.9
At least monthly	402	51.3	135	51.1	537	51.3
At least weekly	260	33.2	86	32.6	346	33.0
At least daily	113	14.4	38	14.4	151	14.4
At least hourly	8	1.0	5	1.9	13	1.2
% of Total	783	74.8	264	25.2	1,047	100.0



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Comparison of States' Use of Large State Institutions

States have reduced the number of residents in state institutions to varying degrees. As of 2008, 86 percent of the nation's institutional population resided in 18 states, with Texas housing almost one in seven (14%) of all institutional residents (table 5).

Table 5: Distribution of Residents in Large State Institutions as of June 30, 2009

State	Population (as of June 30, 2009)	Percentage of Total	Cumulative Percentage
1. Texas	4,541	14%	14%
2. New Jersey	2,785	8%	22%
3. Illinois	2,254	7%	29%
4. California	2,252	7%	36%
5. New York	2,056	6%	42%
6. North Carolina	1,593	5%	47%
7. Ohio	1,429	4%	51%
8. Mississippi	1,336	4%	55%
9. Virginia	1,259	4%	59%
10. Pennsylvania	1,230	4%	63%
11. Louisiana	1,165	4%	67%
12. Florida	1,094	3%	70%
13. Arkansas	1,078	3%	73%
14. Washington	926	3%	76%
15. Massachusetts	893	3%	79%
16. Georgia	849	3%	81%
17. South Carolina	810	2%	84%
18. Connecticut	723	2%	86%



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Table 6 presents data on the number of residents of large state institutions and the percentage of all residential service recipients who are served in large public 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 ID/DD population that receives residential services. For example, states that have relatively few people in institutions but provide little residential care will rank high on this metric. However, the issue is not that these states are using institutions more than other states, but rather that they provide less care overall.

Table 6: States Ranked by Public Institution Residents as a Percentage of Total Residential Service Recipients, 2009

State	Total Residential Service Recipients	Residents in ID/DD Settings with 16+		Public Institution Residents as a Percentage of Total Residential Service Recipients	
	Number	Number	Rank	Percentage	Rank
Alaska	1,062	0	1	0.0	1
District of Columbia	1,280	0	1	0.0	1
Hawaii	1,114	0	1	0.0	1
Maine	2,910	0	1	0.0	1
Michigan	14,607	0	1	0.0	1
New Hampshire	1,795	0	1	0.0	1
New Mexico	2,158	0	1	0.0	1
Rhode Island	2,237	0	1	0.0	1
Vermont	1,554	0	1	0.0	1
West Virginia	1,947	0	1	0.0	1
Oregon	5,664	0	1	0.0	1
Minnesota	14,157	22	12	0.2	12
Idaho	43,731	74	16	0.2	13
Indiana	9,257	134	22	1.4	14
Maryland	7,438	129	21	1.7	15
Colorado	5,227	103	18	2.0	16
Arizona	4,111	123	20	3.0	17
Nevada	1,544	47	13	3.0	18
Montana	1,893	64	14	3.4	19
Wisconsin	11,341	441	31	3.9	20
California	55,436	2,252	48	4.1	21
Kentucky	4,097	170	24	4.1	22



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Table 6: States Ranked by Public Institution Residents as a Percentage of Total Residential Service Recipients, 2009 (continued)

State	Total Residential Service Recipients	Residents in ID/DD Settings with 16+		Public Institution Residents as a Percentage of Total Residential Service Recipients	
	Number	Number	Rank	Percentage	Rank
New York	46,568	2,056	47	4.4	23
Pennsylvania	24,095	1,230	42	5.1	24
Alabama	3,549	192	26	5.4	25
Iowa	8,994	528	32	5.9	26
North Dakota	2,062	123	19	6.0	27
Nebraska	3,013	184	15	6.1	28
Kansas	5,761	353	29	6.1	29
South Dakota	2,307	146	23	6.3	30
Ohio	22,521	1,429	45	6.3	31
Wyoming	1,271	82	17	6.5	32
Oklahoma	4,404	289	28	6.6	33
Utah	3,303	222	27	6.7	34
Delaware	1,028	72	15	7.0	35
Florida	15,339	1,094	40	7.1	36
Massachusetts	12,235	893	37	7.3	37
Tennessee	5,370	421	30	7.8	38
Connecticut	7,001	723	34	10.3	39
Illinois	21,311	2,254	49	10.6	40
Missouri	6,511	695	33	10.7	41
Washington	7,168	926	38	12.9	42
North Carolina	12,261	1,593	46	13.0	43
Georgia	5,961	849	36	14.2	44
Louisiana	7,332	1,165	41	15.9	45
South Carolina	4,885	810	35	16.6	46
Virginia	7,411	1,259	43	17.0	47
Texas	25,640	4,541	51	17.7	48
New Jersey	13,389	2,785	50	20.8	49
Arkansas	3,863	1,078	39	27.9	50
Mississippi	3,379	1,336	44	39.5	51
U.S. Total	443,134	32,909			

Source: Lakin et al., 2010



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Table 7 presents the number of institution residents per 100,000 people in the state. 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.

Table 7: States Ranked by the Number of Institution Residents per 100,000 Total Population

State	Institution Residents per 100,000 population		Percentage Change in Average Daily Population, 1980–2009	
	Number	Rank	Percentage Change	Rank
Alaska	0	1	-100	1
District of Columbia	0	1	-100	1
Hawaii	0	1	-100	1
Maine	0	1	-100	1
Michigan	0	1	-100	1
New Hampshire	0	1	-100	1
New Mexico	0	1	-100	1
Rhode Island	0	1	-100	1
Vermont	0	1	-100	1
West Virginia	0	1	-100	1
Oregon	0	1	-100	1
Minnesota	0.4	12	-98.8	12
Nevada	1.8	13	-67.6	39
Arizona	1.9	14	-81.4	23
Colorado	2	15	-92.4	15
Indiana	2.1	16	-94.6	13
Maryland	2.31	17	-93	14
Kentucky	3.9	18	-81	24
Alabama	4.1	19	-88.3	17
Idaho	4.8	20	-79.2	27
Florida	5.9	21	-72.3	35
California	6.1	22	-72.9	33
Montana	6.6	23	-79.7	26
Tennessee	6.7	24	-76.7	30
Wisconsin	7.8	25	-79.2	28
Oklahoma	7.8	26	-84.1	20
Utah	8	27	-72	36
Delaware	8.1	28	-85.9	19



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Table 7: States Ranked by the Number of Institution Residents per 100,000 Total Population (continued)

State	Institution Residents per 100,000 Population		Percentage Change in Average Daily Population, 1980–2009	
	Number	Rank	Percentage change	Rank
Georgia	8.6	29	-63.9	42
Pennsylvania	9.8	30	-83	21
Nebraska	10.2	31	-68.3	38
New York	10.5	32	-86.2	18
US Total	10.7		-74.4	
Missouri	11.6	33	-63.8	43
Ohio	12.4	34	-71.2	37
Kansas	12.5	35	-73.4	32
Massachusetts	13.5	36	-80.1	25
Washington	13.9	37	-58	46
Wyoming	15.1	38	-82.2	22
Virginia	16	39	-64.3	41
North Carolina	17	40	-47.5	49
Illinois	17.5	41	-64.4	40
Iowa	17.6	42	-56.1	47
South Carolina	17.8	43	-72.9	34
South Dakota	18	44	-77.4	29
Texas	18.32	45	-55.1	48
North Dakota	19	46	-88.4	16
Connecticut	20.5	47	-74.8	31
Louisiana	25.9	48	-63	44
New Jersey	32	49	-60.9	45
Arkansas	37.3	50	-30.1	50
Mississippi	45.3	51	-20.3	51

Source: Lakin et al., 2010

Cost of Institutional Care

The average daily expenditures per resident in fiscal year 2008 for public residential settings with 16 or more residents varied significantly across states. The weighted per diem average of \$539 (\$196,710 per year) represents expenditures ranging from a low



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of \$285 per day (104,025 per year) in Arkansas to a high of \$1,030 (\$375,950 per year) in Tennessee (Lakin et al., 2010). Adjusted for inflation, these costs have nearly doubled since 1988, owing in large part to the decreasing numbers of residents sharing the fixed costs of maintaining the institutions (Lakin et al., 2010).

Table 8 presents data on the average cost of care in large state institutions. Many factors account for the variation in costs, so a higher cost should not be construed as necessarily indicating better or worse care than a lower cost.

Table 8: States Ranked by Average Cost of Care in Large State Institutions

State	Average Cost per Day	Average Cost Per Year
Arkansas	\$285	\$104,025
South Carolina	\$310	\$113,150
Mississippi	\$318	\$116,070
Illinois	\$395	\$144,175
Texas	\$398	\$145,270
Florida	\$404	\$147,460
Kansas	\$408	\$148,920
Arizona	\$416	\$151,840
Ohio	\$419	\$152,935
Missouri	\$437	\$159,505
South Dakota	\$458	\$167,170
Utah	\$463	\$168,995
Maryland	\$466	\$170,090
Georgia	\$472	\$172,280
Louisiana	\$473	\$172,645
North Carolina	\$481	\$175,565
Virginia	\$496	\$181,040
Nevada	\$501	\$182,865
North Dakota	\$514	\$187,610
Oklahoma	\$525	\$191,625
Alabama	\$535	\$195,275
Indiana	\$538	\$196,370
Washington	\$569	\$207,685
Colorado	\$580	\$211,700



Table 8: States Ranked by Average Cost of Care in Large State Institutions (continued)

State	Average Cost per Day	Average Cost Per Year
Iowa	\$595	\$217,175
Pennsylvania	\$603	\$220,095
Nebraska	\$608	\$221,920
Wyoming	\$645	\$235,425
Massachusetts	\$675	\$246,375
New Jersey	\$685	\$250,025
Kentucky	\$687	\$250,755
Montana	\$690	\$251,850
California	\$701	\$255,865
Wisconsin	\$701	\$255,865
Idaho	\$802	\$292,730
Delaware	\$853	\$311,345
Minnesota	\$906	\$330,690
Connecticut	\$922	\$336,530
New York	\$925	\$337,625
Tennessee	\$1,030	\$375,950

Source: Lakin et al., 2010. States with no large state institutions are not included in the table.

For a comparison of the costs of institutional and community-based care, see Section 6 of the Deinstitutionalization Toolkit.

- COSTS – in**BRIEF**
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Additional resources are available in the Institutions topic area in the Deinstitutionalization Toolkit. These external documents may be accessed for a more “inDepth” review of the topic area.

- INSTITUTIONS – in**DEPTH**



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