PROFILE OF THE RHODE ISLAND BHDDH DEVELOPMENTAL DISABILITIES PROGRAM AND COMPARISON TO PROGRAMS IN OTHER STATES

FINAL REPORT

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Executive Summary

With the implementation of Project Sustainability, Rhode Island's Department of Behavioral Healthcare, Developmental Disabilities and Hospitals (BHDDH) has undertaken significant change in the way that it delivers and pays for services for individuals with intellectual and developmental disabilities (I/DD). This report is intended to show results of Project Sustainability efforts to date as well as to provide comparisons between Rhode Island's I/DD program and those in other states and against national norms.

Throughout this report, a distinction is made between institutional services and home- and community-based services (HCBS). *Institutional services* are defined as services delivered in aggregate settings where comprehensive residential and support services are offered to people who require a level of care beyond what is available in the community. These services are often referred to in the literature as ICF/MR, which stands for intermediate care facilities for the mentally retarded. Depending on the state, ICFs/MR can be state-run institutions or privately run. *HCB services* are provided to individuals at risk for institutional care but receive services in a family home or home-like setting that is always an integrated community setting. Most all of Rhode Island's services to individuals with I/DD are delivered in HCBS settings—for example, privately-run group homes, RICLAS group homes, independent living (like apartments), or living with natural family or host families (the Supported Living Program).

Rhode Island was a leader nationally in early adoption of the concept of deinstitutionalization. This is evidenced by the fact that many states, including some in the Northeast U.S. region, still have significant ICF/MR populations (e.g., New Jersey and Connecticut). Funding for HCBS provides significant cost savings to the state in the long-term. Based on a nationally-recognized report that tracks the trends in state I/DD program expenditures, BHDDH provided ICF/MR coverage to 1.1% of its total eligibles in 2009 while the national average was 13.8%. If Rhode Island had the same ratio of individuals in institutional care as the national average in 2009, BHDDH's budget requirement would have been $349 million instead of $254 million, a 37 percent increase.[1]

Early deinstitutionalization meant that per person HCBS expenditures were higher in Rhode Island than in other states because the community provided extensive services for many "hard to place" individuals that would be placed in an ICF/MR in other states. Nonetheless, BHDDH has managed to contain per person I/DD expenditures better than other states in the long term. As reported in Lakin et al.'s compendium of state I/DD expenditures, Rhode Island's per person expenditures decreased 29.5 percent between 1993 and 2009 while nationally the rate increased 17.8 percent. In neighboring states, Connecticut also decreased during this time period but not as much as Rhode Island (-16%) while Massachusetts increased (+28%). Rhode Island's I/DD program has continued to significantly decrease its per person expenditures, from $76,803 in State Fiscal Year (SFY) 2009 to $63,013[2] in SFY 2011, or 18 percent.

[1] Burns & Associates, Inc. calculations of information shown in Table 3.14 of *Residential Services for Persons with Developmental Disabilities: Status and Trends 2009*. Lakin, K. Charlie, Sheryl Larson, Patricia Salmi, and Amanda Webster.

[2] BHDDH calculations as reported to the OHHS for the Global Waiver quarterly reports.

This report includes other comparisons between Rhode Island's I/DD program and other states. Notable trends that were found include the following:

- *Enrollment*. The I/DD population served in Rhode Island's program grew 2.4 percent from 2006 to 2009, which placed the state seventh in enrollment growth among the ten Northeastern states (2009 latest year available for state comparisons).

- *Wait list policy.* Among the 44 states where data was available, Rhode Island is only one of nine stated that does not have a residential waiting list in its I/DD program. For comparison, Connecticut would have to increase its residential slots by 11 percent to accommodate its wait list.

- *Expenditures*. Rhode Island is one of only 14 states to report a reduction between 2007 and 2009 in per person I/DD expenditures (HCBS and ICF/MR services combined). Rhode Island's change of -4.0 percent compares favorably to the national average for this period of +5.6 percent. Looking further back to 1993 (Lakin et al.'s baseline period), Rhode Island is one of only 13 states to report a reduction from 1993 to 2009 (-29.5%) as compared to an increase in the national average (+17.8%).

- *Cost Containment.* BHDDH has adopted a policy that when 24-hour residential placement is necessary, Shared Living Arrangements (SLAs, or host families) are preferred to group home placements when clinically appropriate because the average SLA residential placement cost $39,309 in SFY 2011 versus the average group home placement (private agency) cost of $85,906. Since the beginning of SFY 2012 alone, the census of individuals in SLA settings has increased from 147 to 168 today.

- *State reform initiatives.* When comparing states responding to a recent survey about their I/DD programs, Rhode Island has implemented 12 out of 13 program reform efforts cited by other states.

- *Service package*. Rhode Island's I/DD service package is also in line with what was reported by the majority of survey respondents, not more or less generous. One area where Rhode Island is different from other states is that every participant is authorized for transportation to and from a day activity, whether this is a traditional center-based program, a community-based program or supported employment.

- *Assessment and resource allocation tools*. Rhode Island is in the process of implementing a state-of-the-art resource allocation system informed by the Supports Intensity Scale (SIS) which is also used by seven other states. An additional ten states reported using tools like the SIS to set resource allocations for consumers.

- *Reimbursement*. Rhode Island's recent conversion to paying fee-for-service rather than as a monthly bundled service is in line with how 16 out of 18 states reported how they reimburse providers.

ENROLLMENT

Relative to states in its region, Rhode Island has maintained a slow rate of growth in its I/DD population. Among the ten Northeastern states, Rhode Island's population receiving HCBS services ranks eighth in percent growth from 2006 to 2009 (the most recent year available to compare to other states). The State's total I/DD population (including ICF/MR, HCBS and nursing home) ranks seventh in percent growth among the ten Northeastern states. In the years since 2009, BHDDH's count of individuals receiving services increased 2.5 percent in State Fiscal Year (SFY) 2010 and 1.0 percent in SFY 2011.

Exhibit 1
Comparison of Enrollment in Northeastern State I/DD Programs

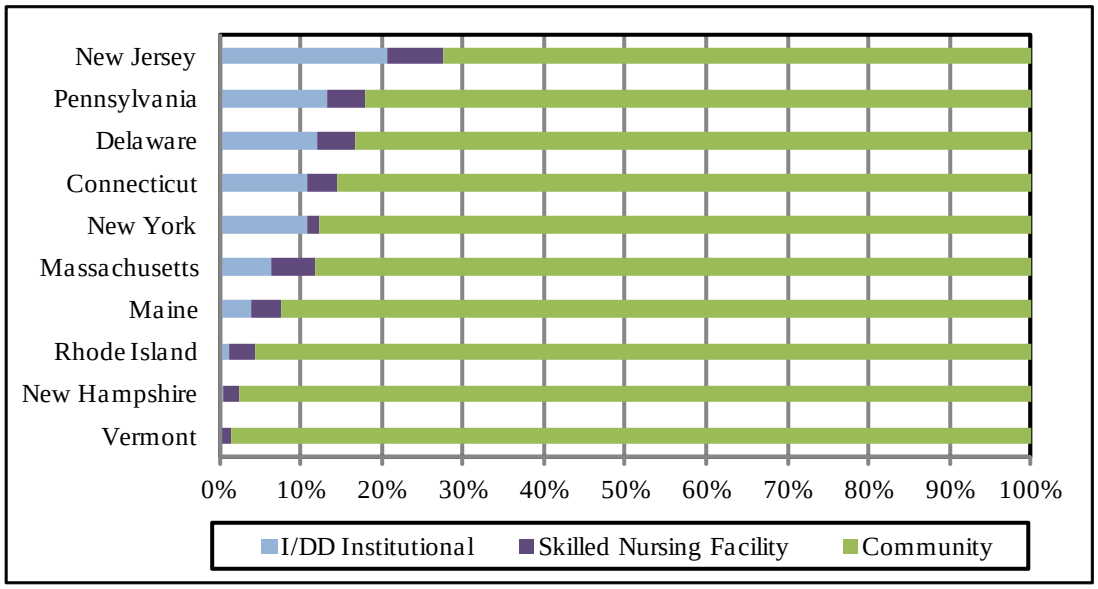
		HCBS Population Growth			
Rank	**State**	**2006**	**2009**	**% Change**	**Average Annual % Increase**
1	Maine	2,666	4,212	58.0%	16.5%
2	New Hampshire	3,254	4,108	26.2%	8.1%
3	Pennsylvania	25,643	30,393	18.5%	5.8%
4	Connecticut	7,232	8,519	17.8%	5.6%
5	New York	54,251	62,195	14.6%	4.7%
6	Vermont	2,102	2,372	12.8%	4.1%
7	Delaware	744	831	11.7%	3.8%
8	**Rhode Island**	**3,073**	**3,275**	**6.6%**	**2.1%**
9	New Jersey	9,611	10,081	4.9%	1.6%
10	Massachusetts	11,460	11,861	3.5%	1.2%

		Total Population Growth (ICF-MR + HCBS + Nursing Home)			
Rank	**State**	**2006**	**2009**	**% Change**	**Average Annual % Increase**
1	Maine	2,989	4,582	53.3%	15.3%
2	New Hampshire	3,375	4,208	24.7%	7.6%
3	Pennsylvania	29,386	35,367	20.4%	6.4%
4	New York	62,375	70,982	13.8%	4.4%
5	Connecticut	8,865	9,955	12.3%	3.9%
6	Vermont	2,146	2,405	12.1%	3.9%
7	**Rhode Island**	**3,191**	**3,423**	**7.3%**	**2.4%**
8	New Jersey	13,372	13,913	4.0%	1.3%
9	Delaware	969	997	2.9%	1.0%
10	Massachusetts	13,481	13,439	-0.3%	-0.1%

Source: Lakin, K. Charlie, Sheryl Larson, Patricia Salmi, and Amanda Webster. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2009* , Chapter 8

Rhode Island has a very small population still placed in institutional settings (4.3%, which includes ICF/MR and Skilled Nursing Facility combined). Among the states in the Northeastern U.S. region, only New Hampshire and Vermont are like Rhode Island in the virtual elimination of ICF/MR placements (refer to Exhibit 2 below). The rates in neighboring states are 11.7 percent institutional placement in Massachusetts and 14.4 percent in Connecticut.

Exhibit 2
Percent of State I/DD Population by Setting, 2009



Source: Lakin, K. Charlie, Sheryl Larson, Patricia Salmi, and Amanda Webster. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2009* , p. 136

Wait list Policies

Some states implement enrollment caps or maintain waitlists for I/DD services in order to manage their enrolled populations. Unlike other states, Rhode Island has been able to curtail its program expenditures without having to maintain a wait list. For example, for individuals receiving residential services in state I/DD programs, Connecticut would need to increase its program by 11 percent to remove all eligibles on their wait list (as of 2008). Massachusetts and Vermont are like Rhode Island in not maintaining a wait list. (Refer to Exhibit 3 on page 5.)

Another national survey examined state I/DD wait lists for residential services and stated that, among the 44 states where data was available, Rhode Island was one of only nine states that did not have a residential placement waiting list.[3] A separate tabulation was reported for individuals seeking HCBS services other than residential. Rhode Island is one of 23 states that do not have a waiting list for non-residential HCBS services. Among Northeastern states, five states have no wait list (Delaware, Massachusetts, New York, Rhode Island and Vermont). But other states have a large wait list. For example, Connecticut has 1,730 individuals on its wait list, or 21

[3] United Cerebral Palsy. *The Case for Inclusion 2011: An Analysis of Medicaid for Americans with Intellectual and Developmental Disabilities.*

percent of its current population receiving HCBS services. Pennsylvania's wait list represents 68 percent of its current population receiving services. Data was not available for New Jersey or New Hampshire.

Exhibit 3
Wait List for Residential Services in Northeastern State I/DD Programs
Individuals on Waitlist Shown as a Percent of Total Residential Placements

		Waiting List for Residential Services		
Rank (2009)*	**State**	**2007**	**2008**	**2009**
1	New Jersey	34%	40%	Not available
2	Delaware	23%	18%	16%
3	New Hampshire	15%	2%	12%
4	New York	9%	9%	9%
5	Pennsylvania	9%	8%	9%
6	Connecticut	11%	8%	7%
7	Maine	3%	2%	3%
8	**Rhode Island**	0%	0%	0%
8	Massachusetts	0%	0%	0%
8	Vermont	0%	0%	0%

* New Jersey assumed to be ranked #1 in 2009 based on prior year trend.

Source: Lakin, K. Charlie, Sheryl Larson, Patricia Salmi, and Amanda Webster. *Residential Services for Persons with Developmental Disabilities: Status and Trends (2007, 2008, 2009 editions) Table 2.5 in each edition*

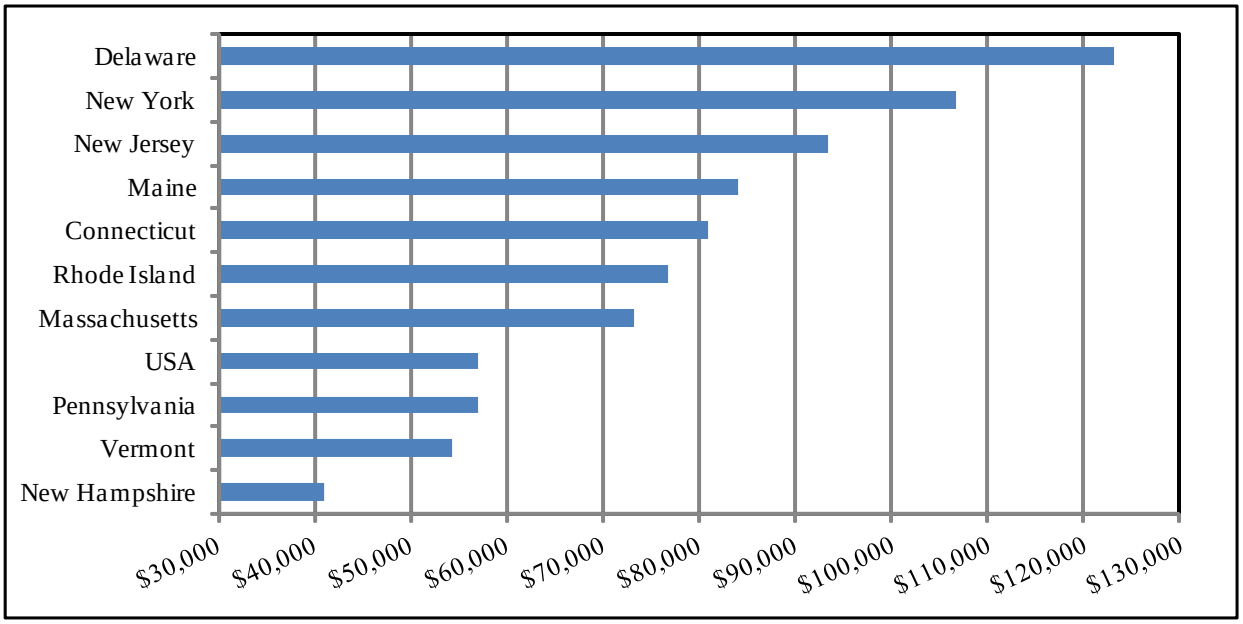
Burns & Associates (B&A) also conducted a survey of state I/DD programs in 2011 and asked questions related to wait lists. Of the 19 states that responded to the survey, 17 of them[4] (89%) maintain a wait list of some kind. Just over half of the states with a wait list also maintain more than one list which may be by waiver, by short- and long-term, or by residential and non-residential services. Thirteen states have priority categories on their wait lists, either according to level of assessed need or as priority status for individuals leaving state institutions.

[4] Alabama, Arkansas, Delaware, Georgia, Kansas, Maryland, Minnesota, Missouri, Montana, Nebraska, New Jersey, New York, Ohio, South Carolina, Texas, Vermont, and Wyoming.

EXPENDITURES

Expenditures for I/DD services vary greatly by state due to a number of factors, including economic, policy, demographic and political. Exhibit 4 shows average spending per I/DD consumer for 2009 in the ten Northeastern states. Rhode Island ranks 6th highest out of the ten ($76,803). The national average in 2009 was $57,126 (Lakin et al., 2009, Table 3.14). Many states report a low per person expenditure value if the state's HCBS program does not offer a 24-hour residential service or the service is limited (i.e., a large wait list). It is also interesting to note that among the ten states in 2009 with the highest per person HCBS expenditures, Rhode Island and Washington DC are the only jurisdictions with no residential wait list.[5]

Exhibit 4
Per Person Expenditures for I/DD Recipients for Northeastern States, 2009



Despite serving more complex individuals in the community and the ability to serve all eligibles without a wait list, Rhode Island's I/DD program has continued to decrease its per person expenditures, from $76,803 in SFY 2009 to $63,013[6] in SFY 2011, an 18 percent reduction.

When per person expenditures are examined for HCBS and ICF/MR services combined, Rhode Island is one of only 14 states to report a reduction between 2007 and 2009 (Rhode Island was 4.0 percent). For the period 1993 to 2009, Rhode Island's per person expenditures decreased 29.5 percent while nationally the rate increased 17.8 percent.[7] (Refer to Exhibits 5 and 6 on the following pages.)

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[5] United Cerebral Palsy. *The Case for Inclusion 2011: An Analysis of Medicaid for Americans with Intellectual and Developmental Disabilities.*

[6] BHDDH calculations as reported to the OHHS for the Global Waiver quarterly reports.

[7] Lakin, K. Charlie, Sheryl Larson, Patricia Salmi, and Amanda Webster. *Residential Services for Persons with Developmental Disabilities: Status and Trends (2007, 2008 and 2009 editions) Table 3.14 in each edition.*

Exhibit 5
Change in Per Person Expenditures for I/DD Recipients by State, 2007-2009

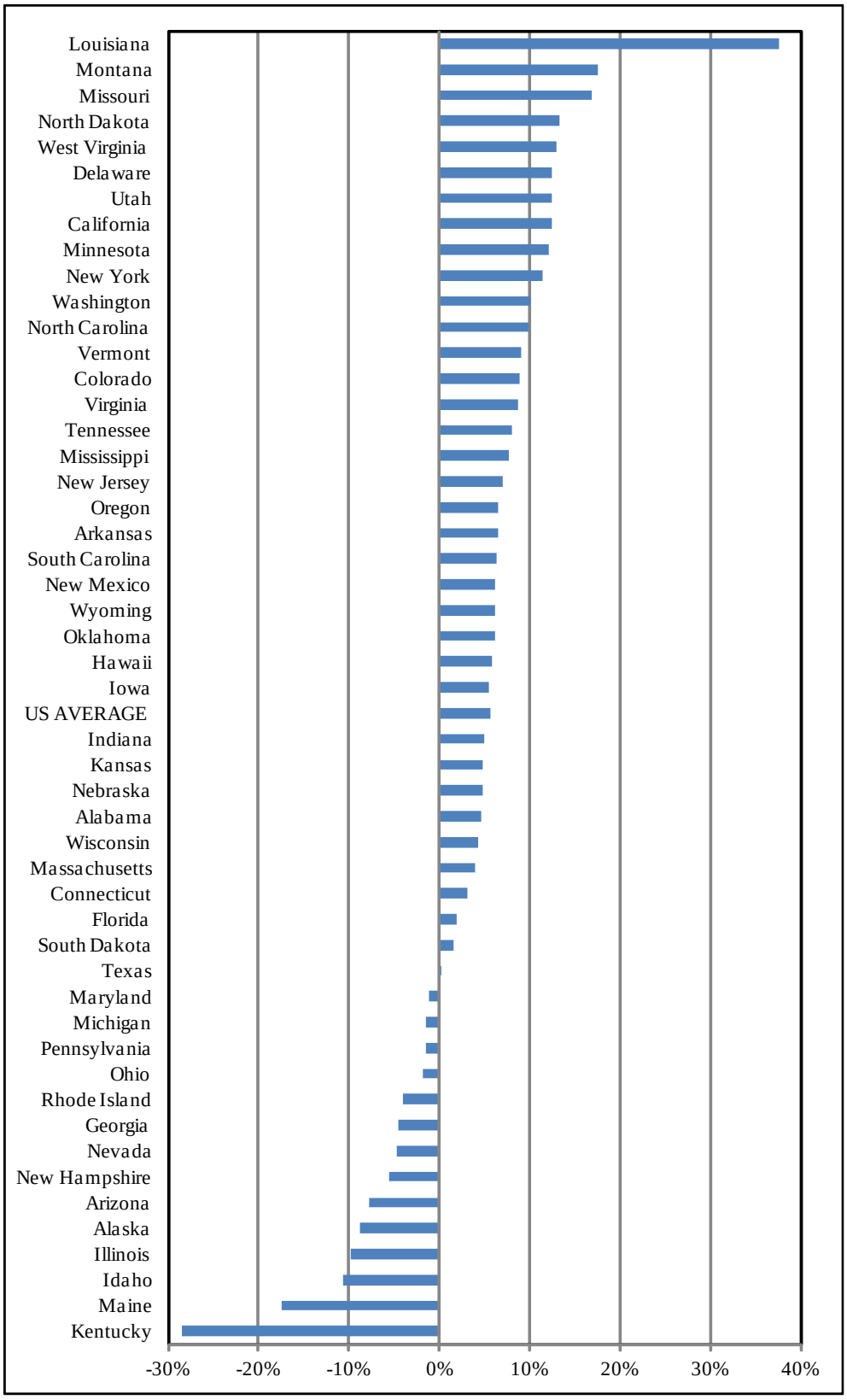
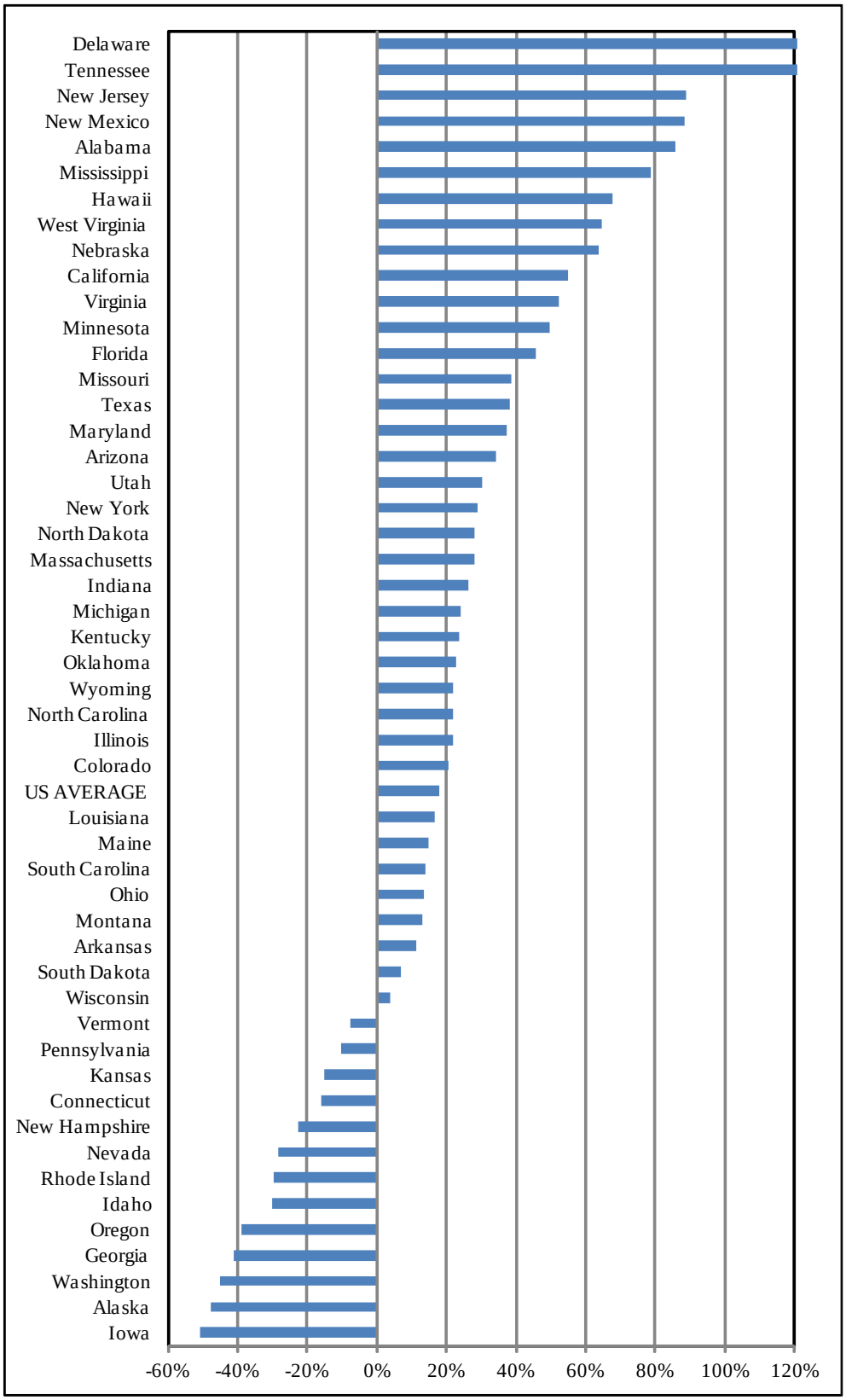


Exhibit 6
Change in Per Person Expenditures for I/DD Recipients by State, 1993-2009



When examined on a per capita basis, in 2009 Rhode Island's average of $241.64 was similar to Connecticut's 220.88 (Lakin et al. 2009 edition, Tables 3.4 and 3.14). When computing the state share only, however, the states are almost the same—Rhode Island at $114.56 and Connecticut at $110.44 (does not include temporary enhanced federal assistance due to the federal stimulus package in either state's figure).

Rhode Island is also the second lowest state in the Northeast Region when measuring the state's total I/DD budget as a percentage of the state's Medicaid budget. In 2009, Rhode Island's I/DD budget (ICF-MR and HCBS combined) was 14.6, the lowest of any state other than Massachusetts (refer to Exhibit 7 below).

Exhibit 7
State I/DD Spending as a Percentage of Total Medicaid Spending, 2009

Rank	State	Total Medicaid Spending 2009 (millions)	I/DD Spending 2009 (millions)	I/DD Spending as Percent of Medicaid
1	Connecticut	$6,035	$1,510.0	25.0%
2	New York	$49,369	$9,260.0	18.8%
3	Pennsylvania	$17,232	$2,890.0	16.8%
4	New Jersey	$9,667	$1,590.0	16.4%
5	New Hampshire	$1,327	$215.3	16.2%
6	Maine	$2,518	$399.9	15.9%
7	Vermont	$974	$150.6	15.5%
8	Delaware	$1,212	$177.9	14.7%
9	**Rhode Island**	**$1,893**	**$275.5**	**14.6%**
10	Massachusetts	$12,481	$1,560.0	12.5%

Source: www.statehealthfacts.org, year 2009

In addition to the annual Lakin report that measures state I/DD expenditures, David Braddock et al. at the University of Colorado release similar statistics on I/DD programs once every three to four years. In their 2011 edition, Braddock et al. reported on state's fiscal effort, described as "a ratio that can be utilized to rank states according to the proportion of their total statewide personal income devoted to the financing of developmental disabilities services"[8] This is different from the per capita calculations since it factors in each state's personal income.

Exhibit 8 on the next page shows that, overall, Rhode Island's fiscal effort has been decreasing since 2003. When considering HCBS spending among the I/DD population, Rhode Island ranks in the middle among the ten Northeastern states but is the only state to see a decrease in fiscal effort between 2003 and 2009.

[8] Braddock, D., Hemp, R & Rizzolo, M.C. (2011). *The state of the states in developmental disabilities: 2011*. Washington, DC: American Association on Intellectual and Developmental Disabilities, page 58.

Exhibit 8
State Fiscal Effort for I/DD Services in the Community Setting Among Northeastern States

		Fiscal Effort for HCBS Services			
Rank (2009)	**State**	**2003**	**2006**	**2009**	**Change 2003-2009**
1	New York	$7.81	$8.64	$9.18	17.5%
2	Maine	$7.61	$7.86	$8.20	7.8%
3	Connecticut	$5.73	$5.98	$6.31	10.1%
4	Vermont	$5.30	$5.69	$6.21	17.2%
5	**Rhode Island**	**$7.06**	**$7.08**	**$6.16**	**-12.7%**
6	Pennsylvania	$4.20	$4.46	$4.68	11.4%
7	Massachusetts	$4.00	$4.08	$4.24	6.0%
8	Delaware	$3.40	$3.64	$4.12	21.2%
9	New Hampshire	$3.56	$3.54	$3.74	5.1%
10	New Jersey	$2.12	$2.28	$2.39	12.7%

Source: Braddock, D., Hemp, R & Rizzolo, M.C. (2011). *The state of the states in developmental disabilities: 2011* . Washington, DC: American Association on Intellectual and Developmental Disabilities

Budget Containment in Project Sustainability

BHDDH has been able to curtail expenditures in its private HCBS program through a number of initiatives. Between SFY 2011 and SFY 2012:

- BHDDH has changed its method of paying private providers from a monthly bundled payment per recipient to a fee-for-service basis. As such, providers bill only when services are delivered.

- Authorizations to deliver services are now given on a quarterly instead of an annual basis. In doing this, BHDDH is able to more quickly adapt to changes in available funding, both upward and downward.

- Group home residential placements have remained essentially flat. The number of individuals residing in privately-operated group homes in June 2010 was 1,311; today, that number is 1,302.[9]

- BHDDH has adopted a policy that when 24-hour residential placement is necessary, Shared Living Arrangements (SLAs, or host families) are always the first option when clinically appropriate. In addition to the benefit of a more integrated setting, SLAs are a less costly alternative to group home placement. The average SLA residential placement cost $39,309 in SFY 2011 versus the average group home placement (private agency) cost of $85,906. Since the beginning of SFY 2012 alone, the census of individuals in SLA settings has increased from 147 to 168 today.[10]

[9] June 2010 census provided by BHDDH as reported to the OHHS for the Global Waiver quarterly reports. Current census tabulated from B&A's work with BHDDH in developing Q4 authorizations for SFY 2012.
[10] Ibid.

PROGRAM CHARACTERISTICS

This section highlights other features of BHDDH's Project Sustainability initiatives and how these initiatives compare to what is occurring in other state I/DD programs. B&A made comparisons based on our working knowledge of Rhode Island's programs as well as other states. Additionally, we conducted a survey in 2011 (under subcontract to Cyndy Johnson and Associates) for the Center for Health Care Strategies that reviewed programmatic features of I/DD programs at the states. All states were invited to participate and we received responses from 19 states.

Reform-related Initiatives

B&A found that Rhode Island is conducting all but one of the 12 reform-related initiatives in Project Sustainability that were cited by other states (one initiative, reducing wait lists, is not applicable to Rhode Island). Exhibit 9 shows the survey responses.

Exhibit 9
State I/DD Reform Efforts Undertaken by States in 2008-2010

Reform Effort	Number of States (out of 16)	Occurring in Rhode Island?
Transportation Delivery or Payment Reform	15	Yes
Improving Technology Use	13	Yes
Expand Supported Employment	13	Yes
Reform Case Planning	12	Yes
Service Package Innovations	11	Yes
Service Delivery Innovations	11	Yes
Integrating Behavioral Health and Physical Health	11	Yes
Reduce Waiting Lists	11	Not applicable
Reform Reimbursement Methods	9	Yes
Changing Oversight of the Program	8	Yes
Outcomes/Cost Effectiveness Measures	8	Yes
Expand Independent Living	6	Yes
Resource Allocation/Individual Budgeting	4	Yes
Performance Incentives	3	No

Source: Burns & Associates, Inc. tabulation of results from the Center for Health Care Strategies' *Survey of the Status Quo and Innovations in Service Delivery and Reimbursement for Persons with Intellectual and Developmental Disabilities* , 2011

Northeast region states responding to the survey (Delaware, New Jersey, New York and Vermont) were each working on seven or eight of the examples cited above.

Service Package

Rhode Island's I/DD service package resembles that in most reported by the majority of the survey respondents. It is not more or less generous than most (see Exhibit 10 below).

Exhibit 10
State I/DD Program Services Offered

	Percent of States Responding Yes (out of 19)	Offered by Rhode Island?
Case management	68%	Yes
Residential Services		
Residential group home	79%	Yes
Host Home	47%	Yes
Residential habilitation	68%	Yes
Respite	95%	Yes
Day Programs		
Day habilitation	84%	Yes
Supported employment	95%	Yes
Adult day health	16%	No
Prevocational services	68%	Yes
Transportation	68%	Yes
In Home and Other Personal Services		
Personal care	79%	Yes
Homemaker	26%	Yes
Home health aide	11%	Yes
Behavioral supports	63%	Yes
Nursing	58%	Yes
Therapies	58%	Yes
In-home intensive supports	47%	Yes
In-home skill building	47%	
Crisis services	42%	Yes
Live-in caregiver	42%	No
Family/care giver training	37%	Yes
Supports for Self Direction		
Financial management	37%	Yes
Participant-directed goods and services	47%	Yes
Supports brokering for self-directed	58%	Yes
Mentorship	11%	No
Peer supports	11%	No
Rehabilitation		
Psychosocial rehabilitation	5%	No
Rehabilitation	5%	No
Clinic services	5%	No
Equipment		
Assistive technology equipment and supplies	95%	Yes
Home modifications	89%	Yes
Vehicular modifications	79%	Yes
Other		
Community transition from ICF-MR into HCBS services	42%	Yes
Community integration from group home into the community	37%	No

Source: Burns & Associates, Inc. tabulation of results from the Center for Health Care Strategies' *Survey of the Status Quo and Innovations in Service Delivery and Reimbursement for Persons with Intellectual and Developmental Disabilities* , 2011

Residential Service Characteristics

Exhibit 11 shows the percentage of consumers who receive I/DD residential in each Northeast Region state by size of residential setting. Rhode Island ranks fourth among the states for the percentage of consumers receiving residential services in the least restrictive setting (up to 6 people). At 84 percent, this is much higher than the neighboring states of Connecticut and Massachusetts. Settings of greater than six people typically mean an institutional-based setting as opposed to a community-based group home.

Exhibit 11
Size of Setting for I/DD Individuals Receiving Residential Services

State	Up to 6 People	7-15 People	16+ People
Vermont	98%	0%	2%
New Hampshire	94%	1%	5%
Maine	87%	6%	7%
Rhode Island	**84%**	**7%**	**8%**
Delaware	82%	0%	18%
Massachusetts	79%	6%	15%
Connecticut	68%	8%	24%
Pennsylvania	67%	3%	30%
New Jersey	58%	6%	36%
New York	41%	46%	13%

Source: Braddock, D., Hemp, R & Rizzolo, M.C. (2011). *The state of the states in developmental disabilities: 2011* . Washington, DC: American Association on Intellectual and Developmental Disabilities

Assessment and Resource Allocation Tools and Practices

States use a number of different assessment tools for service planning and resource allocation purposes. Rhode Island is moving forward on a state-of-the-art resource allocation system informed by the Supports Intensity Scale (SIS). Ultimately, all consumers receiving I/DD services from BHDDH will be assessed and their resources will be determined based on a formula set to match the services for individuals with similar needs. Of the 18 states that responded to the CHCS survey questions about assessment tools, 10 were using assessment tools for service planning purposes and 11 were using tools for resource allocation purposes. From our knowledge of the industry, we are aware that other states are also using the SIS for resource allocations or are in the planning stages to do so. This includes Colorado, Georgia, Louisiana, New Mexico, North Carolina, North Dakota and Oregon.

Reimbursement

Through Project Sustainability, Rhode Island changed its method to reimburse providers from a global per person per month to a fee-for-service model. Among the 18 states that responded to the CHCS survey of I/DD agencies:

- Sixteen states used a direct fee-for-service payment arrangement (some states used this in combination with other methods);
- Five states use an administrative service organization (like a lead agency) to pay providers for services under a fee-for-service arrangement;
- Two states were using capitated arrangements (like Rhode Island's former method); and
- Three states were using cost reimbursement systems with interim payments, meaning that each provider was paid a temporary rate during the year and then a cost settlement process was completed at the end of the year that reconciled the payments with the provider's costs (although this does not necessarily mean that 100 percent of costs were covered).