ESTABLISHING A TRADITION OF COMMITMENT: INTELLECTUAL AND DEVELOPMENTAL DISABILITIES SERVICES IN INDIANA

David Braddock, Ph.D. and Richard Hemp, M.A.

Prepared for the

Indiana Institute on Disability and Community, Indiana University
Indiana Governor's Council for People with Disabilities
Arc of Indiana
Indiana Association of Rehabilitation Facilities, Inc.

October 10, 2008

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Contents

Listing of Figures and Tables iii
Acknowledgments v
Executive Summary vi

I. INTRODUCTION TO THE STUDY 1

II. DECLINING UTILIZATION OF INSTITUTIONS 2
1. Trends in State-Operated Institutions in Indiana and the Comparison States 2
2. Closure of State Institutions 5
3. Utilization of Private Institutions in Indiana 7
4. Utilization of Nursing Facilities in Indiana 7
5. Summary: Institutions and Nursing Facilities in Indiana 9

III. GROWTH OF COMMUNITY SERVICES 10
1. Community Residential Services in the U.S. 10
2. Community Residential Services in Indiana 11
2.1 The Indiana 317 Plan 11
2.2 Quality Assurance and Quality Improvement 12
3. Out-of-Home Residents with I/DD in Indiana 13
4. Financing Community Services in Indiana 14
4.1 Family Support 16
4.2 Supported Employment 17
4.3 Supported Living 19
5. Fiscal Effort in Indiana 20

IV. MEDICAID FINANCING OF I/DD SERVICES 21
1. The Home and Community Based Services (HCBS) Waiver 22
2. HCBS Waiver Services in Indiana 23

V. COMMUNITY SERVICES IN THE COMPARISON STATES 26
1. Medicaid Financing in the Comparison States 26
2. Analysis of Services and Spending in Indiana and the Five Comparison States 27
2.1 Indiana 29
2.2 Illinois 30
2.3 Michigan 31
2.4 Minnesota 33
2.4 Ohio 35
2.4 Wisconsin 36
3. Summary of Comparison States 37

VI. AGING CAREGIVERS AND WAITING LISTS IN INDIANA 39

VII. CONCLUSION 42
Study Recommendations 45
The View Ahead 46

VIII. REFERENCES 49

Listing of Figures and Tables

Figure 1: Institutional utilization in Indiana, the U.S. and the five comparison states 3

Figure 2: Nursing facility utilization in Indiana, the U.S. and the five comparison states 9

Figure 3: Public and private 16+ institutional utilization in Indiana, the U.S., and the comparison states 9

Figure 4: Residents in settings for six or fewer persons in the U.S.: 1960-2006 10

Figure 5: Out-of-home residents with I/DD in Indiana and the comparison states, by setting: 2008 (Indiana) and 2006 14

Figure 6: Inflation-adjusted trends in I/DD spending in Indiana, 1977-2008 15

Figure 7: Family support utilization in Indiana, the comparison states and the U.S.: 1997-2008 15

Figure 8: Supported employment utilization in Indiana, the comparison states and the U.S.: 1997-2008 18

Figure 9: Supported living utilization in Indiana, the comparison states and the U.S.: 1997-2008 20

Figure 10: Total I/DD fiscal effort in Indiana and the U.S. 21

Figure 11: Public spending for I/DD services by revenue source in Indiana, 2008 22

Figure 12: Federal I/DD Medicaid revenue: U.S. 24

Figure 13: Federal I/DD Medicaid revenue in Indiana 25

Figure 14: Federal-state Waiver spending per capita, 2006 and 2008 (Indiana) 27

Figure 15: Trends in federal HCBS Waiver, ICF/MR, and related Medicaid spending in the comparison states: FY 1977-06 28

Figure 16: Indiana Trends in I/DD spending, 1977-06 29

Figure 17: Illinois Trends in I/DD spending, 1977-06 31

Figure 18: Michigan Trends in I/DD spending, 1977-06 32

Figure 19: Minnesota Trends in I/DD spending, 1977-06 34

Figure 20: Ohio Trends in I/DD spending, 1977-06 35

Figure 21: Wisconsin Trends in I/DD spending, 1977-06 36

Figure 22: Hourly wages in 2006 38

Figure 23: Indiana—Estimated distribution of individuals with I/DD by living arrangement, 2008 40

Figure 24: Indiana—Estimated number of individuals with I/DD by age group living with family caregivers, 2008 41

Figure 25: Annual percentage change in I/DD spending during 1999-2008: Indiana 44

Figure 26: Annual percentage change in inflation-adjusted state general fund spending: Indiana 47

Table 1: Average daily census of Indiana developmental centers state hospital I/DD units: FY 2008 4
Table 2: Completed, in-progress closures of public institutions since 2000 5
Table 3: States with family support cash subsidy programs in 2006 17

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John Dickerson and the Arc of Indiana played a key long term leadership role in this systemic change, along with Suellen Jackson-Boner, Director of the Indiana Governor's Council for People with Disabilities. Jim Hammond, President and CEO of the Indiana Association of Rehabilitation Facilities, and the late Costa Miller, former Executive Director of INARF, provided critical leadership through the Association toward this objective. This group of leaders, along with state DD agency leadership and staff, service providers, parents and advocates have also worked tirelessly and effectively to reform the service delivery system. In completing this 2008 study, we are indebted to conscientious and capable staff in the State of Indiana's Family and Social Services Administration (FSSA) and its constituent agency, the Division of Disability and Rehabilitative Services (DDRS). FSSA and DDRS provided data enabling updating of our longitudinal data files through FY 2008. We thank Randy Krieble in the DDRS Initiatives Unit for providing us with up-to-date financial and programmatic data on the State of Indiana's DD service delivery system. We also thank DDRS Director Peter Bisbecos and Deputy Director Adrienne Shields for their review of the data and support for the study. Kenneth Winslow's review as DDRS Controller was also most appreciated along with the reviews of data provided by Penny Shaffer in FSSA Budget and John B. Parks, the Chief Financial Officer of FSSA.

The State of Indiana has dramatically improved its DD data reporting capacities since we began our series of four special studies of the Indiana DD service delivery system in 1996. The FSSA and DDRS are to be commended for this improvement because it makes statewide program evaluation more feasible and enlightening, which in turn can lead to better public policies and services for people with developmental disabilities and their families in the State. As is the custom with studies of this type, however, the authors bear full and final responsibility for the accuracy of the data presented in this report, and for the conclusions and recommendations drawn therefrom.

ESTABLISHING A TRADITION OF COMMITMENT: INTELLECTUAL AND DEVELOPMENTAL DISABILITIES SERVICES IN INDIANA

Executive Summary

The purpose of this study was to a) describe the structure and funding of intellectual and developmental disabilities (I/DD) residential and community services in Indiana and the United States; b) analyze recent trends in service utilization and financing of I/DD services through fiscal year 2008; c) compare and contrast performance in Indiana to other states and to the U.S.; and d) present recommendations for the future direction of intellectual and developmental disabilities services in Indiana. This study focuses most specifically on I/DD activities during the 1999-2008 decade. It builds on our three previous analyses of Indiana services completed in 1996, 2000 and 2004 (Braddock & Hemp, 1996, 2000, 2004).

In the present study, five Midwestern states are compared to Indiana. The comparison states are Illinois, Michigan, Minnesota, Ohio, and Wisconsin. These states' experiences were analyzed comparatively with respect to community services development, utilization of institutional services, development of Home and Community Based Services (HCBS) Waiver options, and the provision of family support, supported employment, and supported living services. The study was designed to assist Indiana University's Institute on Disability and Community, The Indiana Governor's Council for People with Disabilities, The Arc of Indiana, the Indiana Association of Rehabilitation Facilities, Inc., and public officials, families, advocates, consumers and service providers to assess their state's progress in implementing services and supports for people with developmental disabilities during the past decade.

Growth of Community Services in the United States

The nation's census of persons with intellectual and developmental disabilities living in state-operated institutions has declined steadily from the peak of about 195,000 persons in 1967, to 38,299 today. Forty states have closed or scheduled the closure of one

or more of their institutions. Indiana, along with nine other states and D.C.--Alaska, Hawaii, Maine, Minnesota, New Hampshire, New Mexico, Rhode Island, Vermont, and West Virginia--now operate no state-operated I/DD institutions. Additionally, in 2006 there were only 127 I/DD institutional residents in Michigan and nine persons in a mental health center I/DD unit at Cambridge Mental Health Center in Minnesota. In Indiana, 147 persons resided in I/DD mental health units at the Logansport, Evansville, Madison and Richmond State Hospitals in 2008. Indiana is the most populated American state to have closed all of its free-standing state operated institutions exclusively serving people with I/DD.

States have closed institutions and reallocated substantial institutional funding to more individualized residential alternatives in community and family settings. Between 1980 and 2006, the number of individuals living in six-person or fewer community-based group homes and supervised living arrangements in the U.S. increased from 28,000 to approximately 373,000 persons. Individuals now living in community residential settings for six or fewer persons represent 70% of all persons with developmental disabilities residing in out-of-home residential settings in the United States.

Community Services Development in Indiana

In July, 1998, Indiana's "317 Task Force" of consumers, advocates, and state officials produced a report entitled *A Comprehensive Plan for the Design of Services for People with Developmental Disabilities.* The Plan addressed key issues including waiting lists for services, and the provision of necessary resources to support people with developmental disabilities in their homes and at work. The Plan's recommendations provided the framework for extensive program development activities by the Indiana Family and Social Services Administration.

Indiana has indeed made substantial progress in I/DD services development during the past decade. With the closure of New Castle, Northern Indiana, Muscatatuck, and Fort Wayne State Developmental Centers, Indiana's 2008 state-operated institutional utilization rate of two persons served per 100,000 individuals in the general population is substantially below the estimated 2008 U.S. rate of 10 persons per 100,000. *Indiana,*

however, has not fully reallocated the financial resources "saved" from the institutional facilities it closed to alternative community services, family support, supported employment and supported living. Although overall community services spending, adjusted for inflation, grew 93% in Indiana during 1999-2005, community services spending declined four percent during 2005-08 after the closures of Muscatatuck and Fort Wayne Developmental Centers. Indiana's HCBS Waiver spending declined four percent on an inflation-adjusted basis during the same period and the State's I/DD fiscal effort fell 10%. Total spending for I/DD services in Indiana, adjusted for inflation, fell by six percent in 2006, four percent in 2007; and by three percent in 2008. In nominal dollar terms (i.e., dollars as appropriated and not adjusted for inflation), total spending for I/DD services declined by 0.1% in 2006 and increased modestly by 0.4% and 2.9% in 2007 and 2008, respectively.

State government leadership, community providers and consumers in Indiana collaborated successfully during the past decade to develop HCBS Waiver services as the major federal financing component for community services. This was an important achievement. The Waiver underwrote 85% of adjusted community spending growth from 1999 to 2008. Moreover, the Daniels Administration is to be commended for several recent initiatives including: 1) mandating that all high school graduates with I/DD be enrolled in the Support Services Waiver; 2) assuring eligibility for appropriate services and supports for all family caregivers aged 80 and above and for persons with I/DD who lose shelter, lose a caregiver to death or illness, or age out of a children's program; 3) providing Waiver services for all nursing facility residents who wish to access community services; and 4) providing a commitment of $11 million in annual funding for 24-hour crisis intervention services for persons with I/DD and behavioral support needs.

Study Findings Summarized

Study findings are provided in two broad categories: those relating to the growth of community services and supports, and those pertinent to the utilization of institutional settings.

**Community Services Development
Grew Significantly**

1. A new Individual Community Living Budget (ICLB) process, initially implemented for individuals moving from Central State in 1994, helped assure that money follows individuals with disabilities receiving services;
2. The total number of persons served in residential settings increased four percent from 1999 to 2008. The proportion of individuals residing in settings for six or fewer persons increased from 42% of the system in 1999 to 63% in 2008. The 2008 rate, however, was still below the average U.S. state (70%);
3. We previously projected in 2000 that, if then current trends continued, HCBS Waiver revenue in Indiana would surpass ICF/MR revenue by 2006. This benchmark was actually attained two years earlier, in 2004. In 2008, Indiana HCBS Waiver spending exceeded ICF/MR spending by 38%;
4. Waiver spending per capita in 2008 places Indiana near the projected U.S. average, and above projected per capita spending levels in the comparison states of Illinois, Michigan and Ohio. Indiana, however, ranks below Minnesota and Wisconsin in the region; and
5. Community services spending in Indiana, adjusted for inflation, grew 85% during 1999-2008. Institutional spending declined by 81%. Community services spending, adjusted for inflation, declined by four percent during 2005-08. However, a new State of Indiana quarterly financial report projects non-adjusted increases of 10% and 6%, respectively, for the HCBS Waiver and for private ICFs/MR during 2008-09 (Indiana Family and Social Services Administration, 2008a).

**Utilization of Public and Private Institutions/
Nursing Facilities Declined Significantly**

6. Indiana has continued to reduce its reliance on state-operated institutions. New Castle and Northern Indiana closed in 1998/1999, Muscatatuck closed in 2005, and Fort Wayne closed in 2007. The 2008 institutional utilization rate of two persons per 100,000 of the general population in Indiana was well below the projected U.S. rate of 10 per 100,000;
7. In total, four developmental centers and six 16+ person private ICFs/MR closed between 1998 and 2007. This resulted in the combined public and private institutional census dropping 47% in the past 10 years (1999-2008);

Study Recommendations

Recommendations are provided in two broad categories: those relating to the growth of community services and supports, and those pertinent to the utilization of institutional settings.

Continue the Expansion of Community Services and Related Supports

1. ***Complete the reallocation of institutional services funding to community services***. Only a portion of the spending "saved" in the closures of Muscatatuck and Fort Wayne Developmental Centers has been reallocated to community services. That is hopefully temporary while funds from the closure of I/DD state institutions are being readied for deployment for additional community services. To date, however, total I/DD spending, adjusted for inflation, declined 13% during 2005-08 (a cumulative $95.2 million reduction). Indiana should reallocate **all** institutional funding previously "saved" to community services, family support and supported employment initiatives;
2. ***Expand HCBS Waiver services***. An estimated 13,935 persons with I/DD in Indiana await Waiver services. The need for such services and supports will grow rapidly in the future due to increases in the number of aging caregivers in the state;
3. ***Develop additional support programs for families***. The State should consider developing additional support programs for families, including implementation of a cash subsidy program similar to those in Illinois, Michigan, and Minnesota. Indiana ranked 40th nationally in 2006 in the number of families supported per capita and ranked 30th in family support spending per capita;
4. ***Expand supported employment services***. Indiana should seriously consider expanding supported employment services managed by the Bureau of Developmental Disabilities Services. Spending for this program declined in inflation-adjusted terms during 2006-08. Indiana ranked 28th in supported employment spending per capita; and,
5. ***Increase wages and benefits for direct support professionals***. Wages and benefits for community-based direct support staff should be increased significantly over the next several years to reduce staff turnover and improve service quality.

Continue to Reduce Reliance on Public and Private Institutions/Nursing Facilities

6. ***Reduce the number of persons with I/DD in nursing facilities***. Evaluate and relocate as appropriate to alternative community settings the 1,640 individuals with I/DD residing in nursing facilities in 2008. Indiana's nursing facility utilization rate is 27 per 100,000 of the state general population (2006 data). This was the fourth highest rate nationwide, and was substantially above both the U.S. rate (11) and the average rate of the five comparison states (12). Since the completion of our last study in 2004, Indiana reduced the average daily I/DD nursing facility population by only 78 persons. This is a reduction of less than 20 individuals per year. A class action lawsuit, *Kraus v. Hamilton*, was filed in St Joseph County Circuit Court several years ago on behalf of residents with I/DD in nursing facilities. A settlement agreement was reached in 2004 to facilitate community placements. This litigation is currently entering mediation (L. Frick, Indiana Attorney General's Office, personal communication, September 9, 2008); and,

7. ***Reduce I/DD mental health units and private ICFs/MR***. Continue to downsize the remaining four I/DD units at the Logansport, Evansville, Madison and Richmond State Hospitals, and the three remaining 16+ person private ICFs/MR. Allocate these resources to strengthen and develop additional community services programs and infrastructure.

The report that follows evaluates progress achieved by Indiana during the past decade and the challenges currently faced by the State.

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I. INTRODUCTION TO THE STUDY

The purpose of this study was 1) to analyze current trends in service utilization and financing of intellectual and developmental disabilities (I/DD) services in Indiana through 2008; 2) compare and contrast such trends in Indiana to the Midwestern states of Illinois, Michigan, Minnesota, Ohio and Wisconsin and to the United States; and 3) to present recommendations for the future direction of intellectual and developmental disabilities services in Indiana. In addressing these objectives, we focused our analysis primarily on progress in Indiana during the past 10 years, 1999-2008.

The five Great Lakes states selected for comparison with Indiana--Illinois, Michigan, Minnesota, Ohio, and Wisconsin--share much with Indiana in terms of demography, economics, and histories of I/DD services. Each state is made up of both urban and rural communities, their economies are based on the combined contributions of manufacturers, the service industry, and agriculture, and in each state there was an early history of relying on state-operated institutions as the primary model for I/DD services. These states' experiences in intellectual and developmental disabilities long-term care services and supports illustrate the policy choices that that have been made in the past and that continue to confront Indiana in 2008. Useful lessons from the comparison states include the conversion of institution-dominated I/DD service systems through the creative and cost-effective utilization of Medicaid Waivers; the expansion of family support, supported living, and supported employment programs; and the closure of state-operated institutions and large privately-operated ICF/MR facilities.

Comprehensive revenue, spending, and programmatic data for Indiana, Illinois, Michigan, Minnesota, Ohio, and Wisconsin were collected using standardized data collection instruments conforming to the definitions and data collection protocols established for the University of Colorado's State of the States in Developmental Disabilities Project (Braddock, Hemp, & Rizzolo, 2008). With excellent cooperation from Indiana agency staff, we collected new Indiana data for fiscal years 2007 and 2008.

We also revised and updated some of the data collected for our three previous Indiana studies (Braddock & Hemp, 2004, 2000, 1996).

II. DECLINING UTILIZATION OF INSTITUTIONS

Service delivery systems in the United States for persons with intellectual and developmental disabilities have undergone profound change in the past three decades. Indiana and the comparison states had strong historical precedents for utilizing the large state-operated institutions that at one time dominated State service systems. Indiana opened its first mental health institution, Central State Hospital, in 1848 and 31 years later, in 1879, the first "mental retardation" (hereafter I/DD) institution in Indiana opened in Fort Wayne (Braddock & Hemp, 2000). Beginning in the 1970s, class action litigation throughout the states targeted institutional reform and the need for community alternatives to institutions (Herr, 1992). Media exposés identified abysmal institutional conditions (Blatt & Kaplan, 1974). Indiana and other states began to address the need for community alternatives to state institutions and to initiate reforms in institutions as well.

Litigation helped stimulate the reduction in reliance on institutions and the development of community services. Three types of class-action lawsuits have been filed in recent years (Braddock et al., 2008). Litigation has sought to a) expand services to people with I/DD on waiting lists; b) meet the requirements of the community integration mandate of the Americans with Disabilities Act (ADA) and the *Olmstead* U.S. Supreme Court decision (1999); and c) provide Medicaid services for eligible individuals who were not receiving those services. In January 2008, waiting list lawsuits were active in 13 states and eight states had *Olmstead* lawsuits including three in Pennsylvania. Nine states had active Medicaid-access lawsuits, with two in Arkansas (Braddock et al., 2008).

1. Trends in State-Operated Institutions in Indiana and the Comparison States

The nation's institutional population peaked at 194,650 in 1967 and then declined steadily at the rate of four percent each year through 2006. The average daily institutional population in fiscal year 2006 was 38,299 (Braddock et al., 2008). From 1977 to 1988, the I/DD institutional population in Indiana declined by an average two percent per year,

half the national rate of decline. However, during 1999-2008 the I/DD institutional census decline rate in Indiana accelerated to 18% per year.

In terms of institutional utilization (per 100,000 of the general population) the Indiana trend approximates the declining reliance on institutions in the comparison states (***Figure 1***). Institutional utilization in Indiana was well below the U.S. average and the five comparison states in the aggregate during 1977-81, but briefly surpassed both the U.S. and the comparison states' rates during 1989-92. Indiana's institutional utilization rate again dropped below the rates in the comparison states and the U.S. during 2000-08. Indiana, Minnesota, Michigan, and Wisconsin were leaders in deinstitutionalization, with 2006 institutional utilization rates of 2.0, 0.2, 1.2, and 9.9 per 100,000, respectively. Institutional utilization rates were higher than the U.S. average in Ohio (14.1) and substantially higher in Illinois (21.3). In 2008, Minnesota operated only one I/DD unit in the Cambridge Mental Health Center for nine individuals. Michigan provided services for 127 individuals with I/DD at one state-operated facility, Mt. Pleasant.

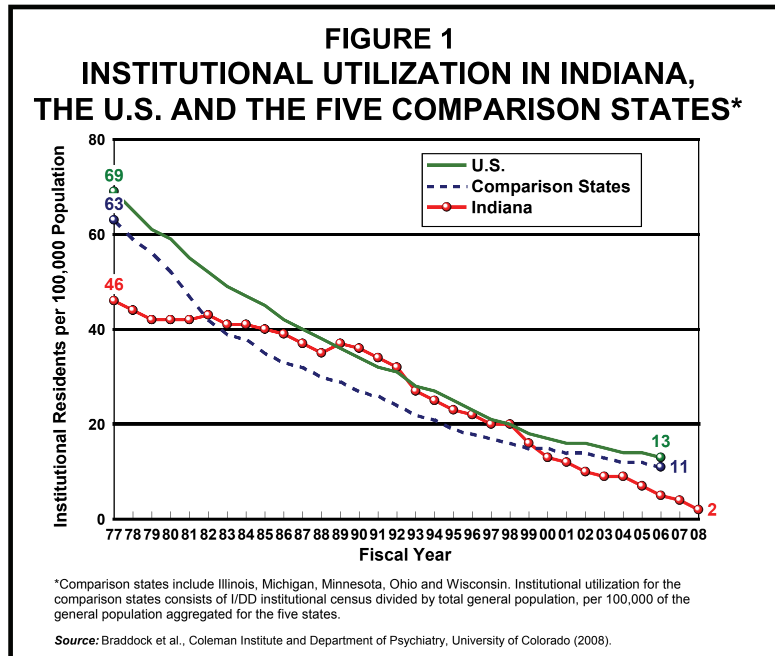


FIGURE 1
INSTITUTIONAL UTILIZATION IN INDIANA, THE U.S. AND THE FIVE COMPARISON STATES*

*Comparison states include Illinois, Michigan, Minnesota, Ohio and Wisconsin. Institutional utilization for the comparison states consists of I/DD institutional census divided by total general population, per 100,000 of the general population aggregated for the five states.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado (2008).

The Fort Wayne Developmental Center opened as the Asylum for Feeble Minded Children in 1879. New Castle State Developmental Center, originally the Indiana Village for Epileptics, was established in 1907. The Muscatatuck State Developmental Center was initially the Indiana Farm Colony for Feeble Minded Youth (1920) and Northern Indiana State Developmental Center opened in 1943 as the Northern Indiana Children's Hospital for children who had polio. Legislation in 1960 established Northern Indiana as

a facility for children with mental retardation and developmental disabilities. Two of the four original Indiana developmental centers, New Castle and Northern Indiana, closed in July 1998 and December 1998, respectively. Muscatatuck closed in 2005 and Fort Wayne closed in 2007.

The Indiana legislature authorized a "hospital for the insane" in 1827; the Indiana Hospital for the Insane opened 21 years later in 1848. The Hospital (subsequently re-named Central State Hospital) was constructed on the outskirts of Indianapolis. Additional public psychiatric facilities were then built after the turn of the century in Evansville, Logansport, Madison, and Richmond to relieve the overcrowding at Central State. Central State Hospital subsequently assumed responsibility for the mid-state district of 38 Indiana counties surrounding Indianapolis (Braddock & Hemp, 2000; Willever, 1996).

During the 1970's, Indiana established special I/DD units within Central State and at the Evansville, Logansport, and Madison state mental hospitals. All of these I/DD Units were certified as Intermediate Care Facilities/Mental Retardation (ICFs/MR). Central State Hospital and its I/DD Unit closed in June 1994. In fiscal year 2008 the four remaining intellectual and developmental disabilities units were in the Madison, Logansport, Evansville and Richmond state hospitals. The four units had an average daily population of 147 (***Table 1***).

TABLE 1
AVERAGE DAILY CENSUS OF INDIANA DEVELOPMENTAL CENTERS AND STATE HOSPITAL I/DD UNITS: FY 2008

Facility/Unit	Location	Opened	Closed	Census
Fort Wayne Developmental Ctr.	Fort Wayne	1879	2007	closed
Muscatatuck Developmental Ctr.	Muscatatuck	1920	2005	closed
New Castle Developmental Ctr.	New Castle	1907	1998	closed
Northern Indiana Developmental Ctr.	South Bend	1943	1998	closed
Central State Hospital (I/DD Unit)	Indianapolis	1848	1994	closed
Madison State Hospital (I/DD Unit)	Madison	1910		44
Logansport State Hospital (I/DD Unit)	Logansport	1888		46
Evansville State Hospital (I/DD Unit)	Evansville	1950		33
Richmond State Hospital (I/DD Unit)	Richmond	1973		24
TOTAL AVERAGE DAILY CENSUS				**147**

Sources: Braddock et al., 2008; state hospital units' data are from Bureau of Developmental Disabilities Services, 2008.

2. Closure of State Institutions

Since 1970, 40 states have closed or are scheduled to close 140 state-operated I/DD institutions (Braddock et al., 2008). Indiana, with the closure of Fort Wayne Developmental Center in 2007, joins Alaska, the District of Columbia, Hawaii, Maine, Minnesota, New Hampshire, New Mexico, Rhode Island, Vermont, and West Virginia. These jurisdictions now operate without state-operated I/DD institutions. ***Table 2*** summarizes information for the nation's 26 institutions that have closed since 2000, or are scheduled to close. Among the comparison states Illinois closed Lincoln in 2004, Fergus Falls in Minnesota closed in 2000, and Southgate Center in Michigan closed in 2001. In Ohio, Springview closed in 2004 and Apple Creek closed in 2005. Wisconsin's

TABLE 2
COMPLETED AND IN-PROGRESS CLOSURES OF U.S. PUBLIC INSTITUTIONS SINCE 2000

State	Institution	Year Built/ Became MR	Original Use	# Residents, Closure Announcement	Year of Closure	Alternate Use
Alabama	Brewer-Bayside	1984	MR Facility	67	2003	Corrections
Alabama	Tarwater	1976	MR Facility	74	2003	Corrections
Alabama	Wallace	1970	MR Facility	80	2003	Corrections
California	Agnews	1885/1966	MI Facility	411	2008	Undetermined
California	Napa	1875/1967	Asylum for MR/MI	30	2001	MI use only
Florida	Community of Landmark	1965	MR Facility	256	2005	Revert to Dade Cty.
Florida	Gulf Coast Center	1960	MR Facility	306	2010	Undetermined
Georgia	Bainbridge	1967	WW II Air Force Schoc	129	2001	Corrections
Georgia	Georgia Regional-Augusta			438	2003	Undetermined
Georgia	Gracewood School/Hospital			93	2003	Undetermined
Illinois	Lincoln	1877	MR Facility	153	2004	Vacant
Indiana	Ft. Wayne	1887	MR Facility	120	2007	To be demolished
Indiana	Muscatatuck	1920	MR Facility	287	2005	Military
Louisiana	Leesville	1913/1964	High School	20	2004	Undetermined
Louisiana	Columbia	1967	MR Facility	14	2004	Undetermined
Massachusetts	Paul A. Dever	1940/1946	P.O.W. Camp	294	2001	Higher Ed Ctr.
Michigan	Southgate	1977	MR Facility	55	2002	Undetermined
Minnesota	Fergus Falls	1888/1969	Asylum for MI	38	2000	Regional MH Center
Montana	Eastmont	1969/1979	Residential School	29	2003	Nursing facility
New York	Sunmount	1922/1965	TB Hospital	503	2003	OMRDD Specialty Units
North Carolina	Black Mountain Center	1883/1977	MI Facility	77	2005	Skilled nursing facility
Ohio	Apple Creek	1931	MR Facility	178	2005	Undetermined
Ohio	Springview	1910/1975	TB Hospital	86	2004	Undetermined
Oregon	Fairview	1907	MR Facility	327	2000	Commercial/housing
Pennsylvania	Altoona	1975	MR Facility	90	2008	Undetermined
Wisconsin	Northern Wisconsin Center	1897	MR Facility	173	2005	Short-term Dual Dx

Source : Braddock et al., 2008.

Northern Wisconsin Center closed in 2005.

The pathbreaking Indiana 317 Plan recommended redirecting funding away from large, congregate care settings. This was principally addressed through the State's closures of the Muscatatuck and Fort Wayne Developmental Centers (Bisbecos, 2007). Previously, during fiscal years 1998 and 1999, 164 persons relocated to the community from New Castle Developmental Center and 159 persons moved out of Northern Indiana State Developmental Center as the two facilities closed. Only one of the 323 individuals who moved from the two developmental centers required re-institutionalization in a state-operated facility (R. Krieble, Developmental Disabilities, Division of Disability, Aging, and Rehabilitative Services, personal communication, July 20, 2000). Seiders & Conroy (2000) conducted an assessment of outcomes after six months for the Developmental Center and private ICF/MR "movers" in Indiana. They found generally positive outcomes for both the private ICF/MR and Developmental Center groups in adaptive behavior, community integration, perceived improvement in quality of life, and reduced challenging behavior.

Researchers at Indiana University surveyed the overall satisfaction of individuals who moved from Muscatatuck State Developmental Center in 2001 and 2002 (Grossi, Mank, Migliori, Pitts, & Schaaf, 2003). Although respondents (individuals with disabilities, family members, guardians) were pleased with Muscatatuck services, they were more satisfied with life in the community after the move from the State Developmental Center. Respondents generally reported that they were well informed during the planning process and the moves, and across the two years there was an increase in respondents' general knowledge of the services offered by the Bureau of Quality Improvement Services (BQIS). The BQIS was a key component of improved quality assurance and quality improvement programs in Indiana (Cook, 2003).

In April 2008 the Indiana Family and Social Services Administration announced the dismissal of a consent agreement signed with the U.S. Department of Justice (DOJ) eight years earlier (*U.S. v. Indiana, S.D.*) (U.S. DOJ, 2006). The DOJ suit had alleged that conditions at Muscatatuck and Fort Wayne State Developmental Centers violated the provisions of the Civil Rights of Institutionalized Persons Act (CRIPA). According to the

National Association of State Directors of Developmental Disabilities Services (NASDDDS):

> Since the investigation began, Muscatatuck and Fort Wayne Centers have both been closed. Former residents are now working, volunteering, and being involved in a variety of community-based activities. In addition, DDRS implemented a number of wide-reaching changes to the system that have ensured quality assurance mechanisms to further protect individuals from abuse, neglect, and mistreatment, and provided improved community placements and services (NASDDDS, 2008, p. 8).

3. Utilization of Private Institutions in Indiana

"Institutional settings" in Indiana also include private facilities serving 16 or more persons per facility certified as ICFs/MR. In addition to the state facility closures in Indiana, three private institutional ICFs/MR in Sullivan, Angola, and Fort Wayne closed during fiscal year 1999 (Seiders & Conroy, 2000). During 2001-03 seven of the State's 10 remaining privately operated (16+) ICFs/MR closed. Three facilities (KCARC, 45 beds; New Horizon, 154 beds; and Miller Merry Manor Care, 38 beds) closed April 2001, December 2001, and June 2002, respectively. In addition, three facilities (Normal Life Sheridan, 50 beds; Riverbend, 93 beds; and Oak Meadows, 73 beds) closed during November and December 2003. The Holy Cross facility (38 beds) closed in 2004 (S. Cook, personal communication, January 10, 2004).

The average daily census of 16+ person private ICFs/MR in Indiana declined 63%, from 835 in fiscal year 1999 to 313 in fiscal year 2008. The remaining three facilities are Arcadia (60 beds), North Willow (208 beds) and Hickory Creek of Gaston (75 beds). In the United States, the number of residents in private ICF/MR facilities for 16 or more persons declined by an estimated 23% between 1999 and 2008, from 26,460 to an estimated 20,488 persons. ***The rate of reduction in the utilization of 16+ person privately operated facilities in Indiana was nearly three times the U.S. rate during the past 10 years.***

4. Utilization of Nursing Facilities in Indiana

Congress enacted the Nursing Home Reform Act of 1987 (Public Law 100-203) in response to the fact that most individuals with I/DD living in nursing facilities in the

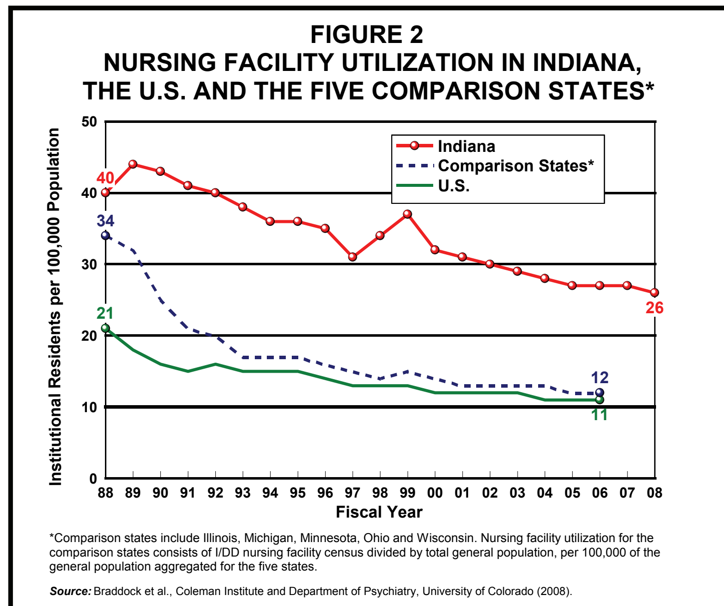
U.S. had been placed there inappropriately. Several studies have shown that 75-90% of individuals with I/DD living in nursing facilities were appropriate candidates for alternative living arrangements in community settings (Mitchell & Braddock, 1990).

The nursing facility reform legislation required that all states: a) assure that individuals with I/DD be admitted to a nursing facility only if the individual was in need of services made available in the particular facility; b) assess all nursing home residents with intellectual disabilities to determine any need for "active treatment"; c) for those assessed to be in need of active treatment, provide treatment in the nursing facility or obtain a more appropriate community placement; and, d) assure that individuals residing in nursing facilities for more than 30 months be given the option of moving or staying. As a result of states' efforts in response to Public Law 100-203, the number of individuals with I/DD in nursing facilities in the United States declined from 54,202 in 1988 to 33,885 in 2006 (Braddock et al., 2008).

Since the completion of our last Indiana study in 2004, Indiana reduced the average daily I/DD nursing facility population by only 78 persons. This is a reduction of less than 20 individuals per year. A class action lawsuit, *Kraus v. Hamilton*, was filed in St Joseph County Circuit Court several years ago on behalf of residents with I/DD in nursing facilities. A settlement agreement between the litigating parties was reached in 2004 to facilitate community placements. This litigation is currently entering mediation (L. Frick, Indiana Attorney General's Office, personal communication, September 9, 2008).

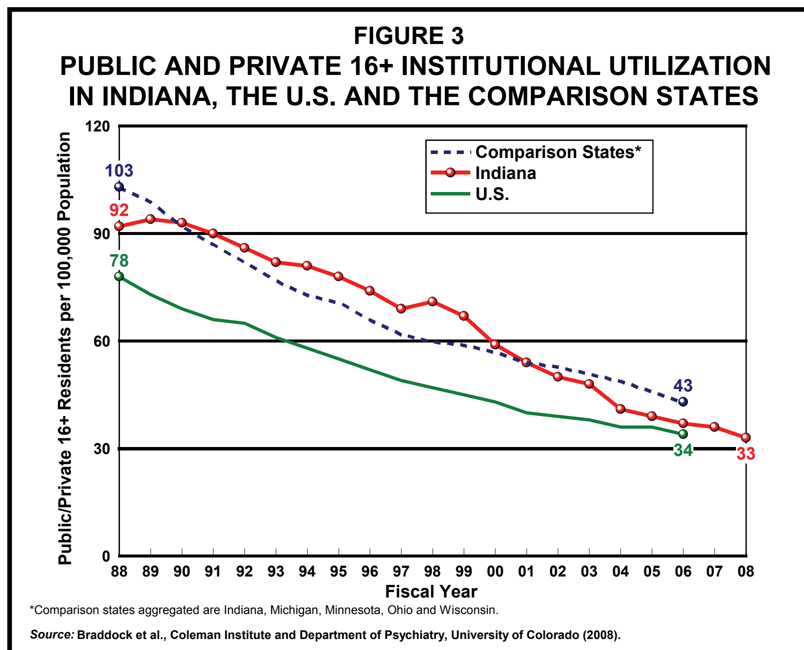
Indiana's Nursing Facility Trends. Indiana recently amended its Medicaid State Plan to provide that persons with I/DD residing in nursing facilities who wish to move to community settings may do so under the HCBS Waiver (Indiana Family and Social Services Administration, 2008). Non-specialized nursing facilities in Indiana served 1,640 individuals with I/DD in 2008. Expressed in terms of nursing facility utilization per 100,000 of the state's general population, Indiana's rate of 26 in 2008 (27 in 2006) was the nation's fourth highest. Indiana was well above the U.S. rate (11) and the consolidated nursing facility utilization rate for the five comparison states (12) (***Figure 2***). In 2006, nursing facility utilization rates were seven per 100,000 persons in the

general population in Minnesota, eight in Michigan, nine in Wisconsin, 12 in Illinois, and 20 in Ohio. The nursing facility utilization rate in Indiana would match the rate in Minnesota (seven per 100,000) if 1,201 or 73% of the 1,640 Indiana nursing facility residents were relocated to community alternatives. The rate in Indiana would match the U.S. rate (11 per 100,000) if 951 persons or 58% were relocated from such settings.



5. Summary: Institutions and Nursing Facilities in Indiana

Indiana has substantially reduced its reliance on public and private institutions, but not nursing facilities. This is reflected in the recent closures of all remaining state developmental centers and all but three private ICFs/MRs for 16+ persons. ***Figure 3*** depicts the combined utilization rate for nursing facilities, private 16+ person facilities, and developmental centers including I/DD units in state hospitals. The utilization rates displayed are for Indiana, the five

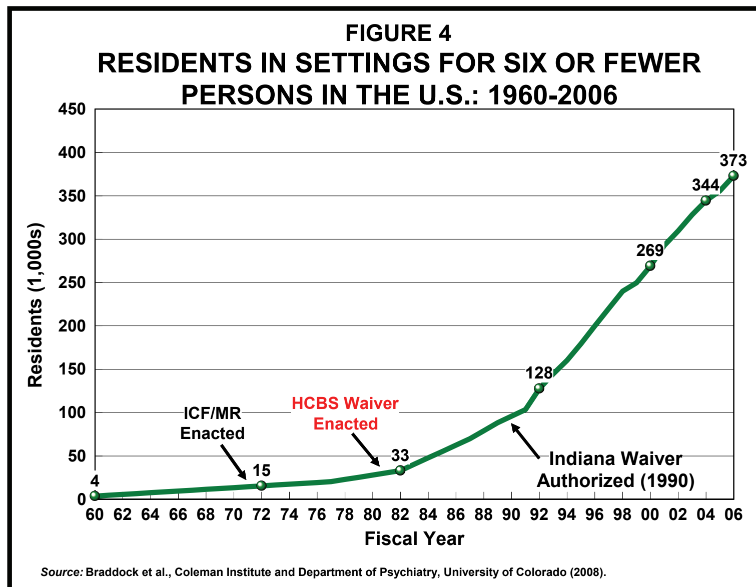


comparison states aggregated, and the U.S. During 1991-2000, the public/ private institutional utilization rate in Indiana exceeded the rate for both the U.S. and for the comparison states. However, during 1998-2008, Indiana's public and private institutional utilization rate declined rapidly, falling well below the comparison states. Public/private 16+ person facility utilization rates in 2006 for the comparison states were: Michigan (17 per 100,000), Minnesota (19), Wisconsin (43), Ohio (59), and Illinois (63). Indiana's rate was 33 per 100,000 persons in 2008. The average daily population of all public and private institutions (including nursing facilities) in Indiana declined from 4,177 in 1998 to 2,100 in 2008. This was a decline of 50% over that 11-year period, and compared to a decline of 26% in the U.S. during 1996-2006 (from 137,076 to 101,416).

III. GROWTH OF COMMUNITY SERVICES

1. Community Residential Services in the U.S.

The growing number of persons with I/DD served in community residential settings for six or fewer persons in the U.S. is illustrated in ***Figure 4.*** The expanding system of six person or fewer community residences includes group homes, supervised apartments, and supported living settings. The number of individuals served grew from 4,000 in 1960 to 373,000 in 2006. In the 1970s, the predominant community residential settings were state-funded group homes. With the authorization of the ICF/MR program in 1972 (and the provision for ICF/MR funding for settings for 15 or fewer persons in 1974), many states including Indiana greatly expanded 15 or fewer person ICFs/MR. Since 1981, the Medicaid Home and Community Based



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado (2008).

Services (HCBS) Waiver Program has emerged as the principal funding source for the development of smaller, more individualized community settings including supported living.

2. Community Residential Services in Indiana

The first community residential services in Indiana included a family boarding home program established in 1955, followed by group homes developed by local Associations for Retarded Citizens in the 1960s (Indiana Legislative Services Agency, 1991). In 1978, the Indiana Legislature's Select Committee on Residential Care for the Mentally Retarded and Developmentally Disabled reviewed developmental disabilities services needs, funding, and program development issues. Lobbying efforts by the Indiana Association for Retarded Citizens, Indiana Association of Rehabilitation Facilities, and other advocacy organizations, coupled with the impact of the Select Committee's report, led to the passage of Public Law 126 in 1978 (Indiana Legislative Services Agency, 1990). This legislation authorized the first Community Residential Facilities/Developmental Disabilities (CRFs/DD) in Indiana, which were subsequently certified as ICFs/MR for eight persons per facility.

By 1979, ICF/MR reimbursement was established for Indiana's CRFs/DD. In 1981, P.L. 137 augmented Medicaid reimbursement, and rapid CRF/DD expansion commenced four years later in 1985. By 1987, CRFs/DD federal Medicaid reimbursement surpassed federal Title XX revenues to become the primary federal community services funding source in Indiana (Braddock & Hemp, 2000).

2.1 The Indiana 317 Plan

In 1997, Governor Frank O'Bannon signed Senate Enrolled Act 317. The law established a bipartisan task force of consumers, advocates, and state officials that was charged with conducting a study of services for people with developmental disabilities. In its July 1998 report, *A Comprehensive Plan for the Design of Services for People with Developmental Disabilities*, the 317 Task Force identified over 6,000 people with developmental disabilities awaiting home and community based services. The *Plan's* series of recommendations included a) accessing financial support outside of the Bureau

of Developmental Disabilities Services (BDDS) for children aging out of residential services; b) emergency funding for caregivers not able to provide care; c) services for over 1,300 persons who had been on waiting lists for an extended period of time; d) resources to prevent family crisis situations; and e) maintenance of existing services to keep people at home and at work (Braddock & Hemp, 2004).

As a result of the work of the 317 Task Force, the Indiana 2000/2001 biennial budget bill included new funding of $39.3 million for services for people with developmental disabilities. The late Costa N. Miller, CAE, formerly Executive Director of the Association of Rehabilitation Facilities of Indiana, for purposes of governmental affairs activities relating to the 317 Task Force's resources and legislation, had stressed the importance of including Senate Republican leadership in supporting the recommendations of the 317 Task Force (J. Hammond, INARF, personal communication, September 5, 2008). The FY 2001 budget targeted services for an additional 1,300 persons by the end of fiscal year 2001 (The Arc of Indiana, 2000). The 317 Plan resulted in $157 million in new funding from state fiscal year 2000 through 2003, addressing maintenance of services and the needs of those on waiting lists (Cook, 2003, p.5).

Three of the five Indiana 317 Plan recommendations addressed supported living and/or person centered planning. The precedent for the Indiana Individual Community Living Budget (ICLB) was individualized planning for persons moving from Central State Hospital in 1994, and for the first time money followed the individual rather than the service provider agency. Rule 460 IAC 7, promulgated in May 2003, mandated the use of the person centered planning process for all individuals receiving services authorized by the Bureau of Developmental Disabilities Services (BDDS), including supported living, group home services, and private 16+ person ICFs/MR.

2.2 Quality Assurance and Quality Improvement

Indiana 317 Plan recommendations one, two and four addressed person centered planning and funding, and redirecting funding from congregate settings to integrated community residential, day and employment settings. Quality assurance and quality improvement was the subject of the Plan's third recommendation: "Assure and improve the quality of services delivered to individuals with developmental disabilities." The

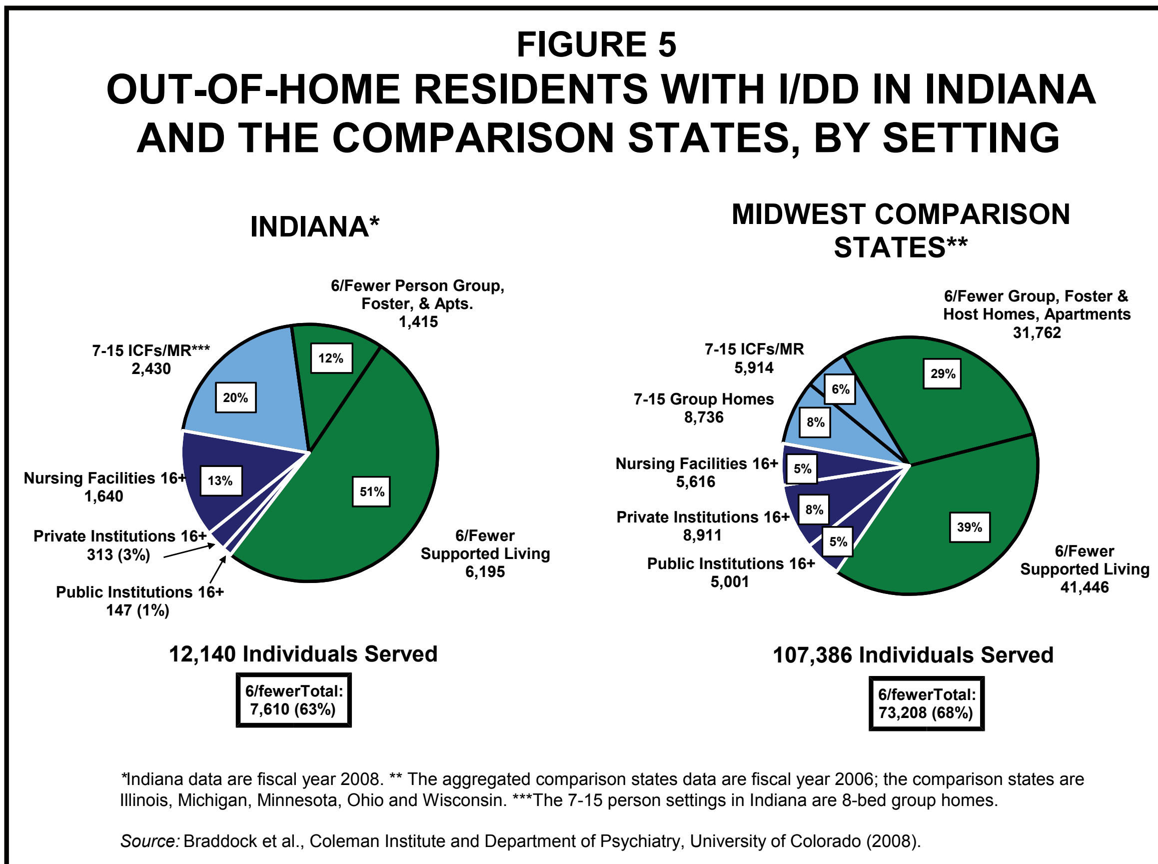
Bureau of Quality Improvement Services (BQIS) was established in January 2000, with the responsibility to develop and implement quality assurance and quality improvement systems through DDARS. Funding was made available with Indiana 317 Plan funds as well as funds from the closure of New Castle State Developmental Center and the downsizing of Muscatatuck.

Quality assurance and quality improvement in Indiana included a complaint process, an incident reporting policy and procedure, a risk management committee, and a mortality review committee. Indiana joined the National Core Indicators Project in 1997 (a joint effort of the National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute), scoring at or above the national average in most areas (Cook, 2003, pp. 3, 4). As of February 2008, Indiana's quality assurance responsibility was contracted to a private company, Liberty Health Care. Early reports from state officials are that this has been a successful transition and that key mortality and other data are being tracked effectively (R. Krieble, DDRS, personal communication, June 19, 2008).

3. Out-of-Home Residents with I/DD in Indiana

Indiana is roughly comparable to the aggregated comparison states in the proportion of persons with I/DD residing in six person or fewer settings. In 2008, 51% of individuals with I/DD in Indiana participated in supported living and 12% resided in other six person or fewer settings including foster homes, apartments, or group homes. In total, 63% of individuals with I/DD in Indiana resided in settings for six or fewer persons. This compared to 68% in the five comparison states (***Figure 5***) and 70% in the United States. In 2006, the proportion of placements in settings for six or fewer persons was higher in four of the five comparison states than in Indiana in 2008. Minnesota provided services in settings for six or fewer persons to 90% of the State's total of persons with I/DD residing in out-of-home settings. The proportions in the other comparison states were: Michigan (82%), Wisconsin (74%), Ohio (69%), and Illinois, the "outlier," (30%).

If Illinois, the regional outlier, were removed from the comparison states, the proportion in six person or fewer settings for the Midwest comparison states would be 77%, consisting of 45% of persons with I/DD in supported living and 32% in other six



person or fewer settings. Indiana, however, significantly exceeds the comparison states in the proportion of persons with I/DD residing in 7-15 person settings (20% vs. 14%). Indiana's share in 16 + person settings including nursing facilities, private ICFs/MR and state institutions was 17%, slightly below the 18% share for the five comparison states. (If Illinois is removed from the comparison states, that group's percentage in 16+ settings declines to 13%.) It should be noted that Indiana's 7-15 person settings, certified as ICFs/MR and termed CRFsDD, are *eight-person* group homes (Prouty et al., 2007).

4. Financing Community Services in Indiana

Spending for community services in Indiana first surpassed institutional spending in 1990, and institutional spending began to decline in 1993. In 2008, 84% of total I/DD resources in Indiana was allocated for community services; 16% supported persons with I/DD in state mental health centers and 16+ private ICF/MR settings. There have been five distinct periods of developmental disabilities spending growth in Indiana during the past three decades (***Figure 6***). First, during fiscal years 1977-1983, inflation-adjusted

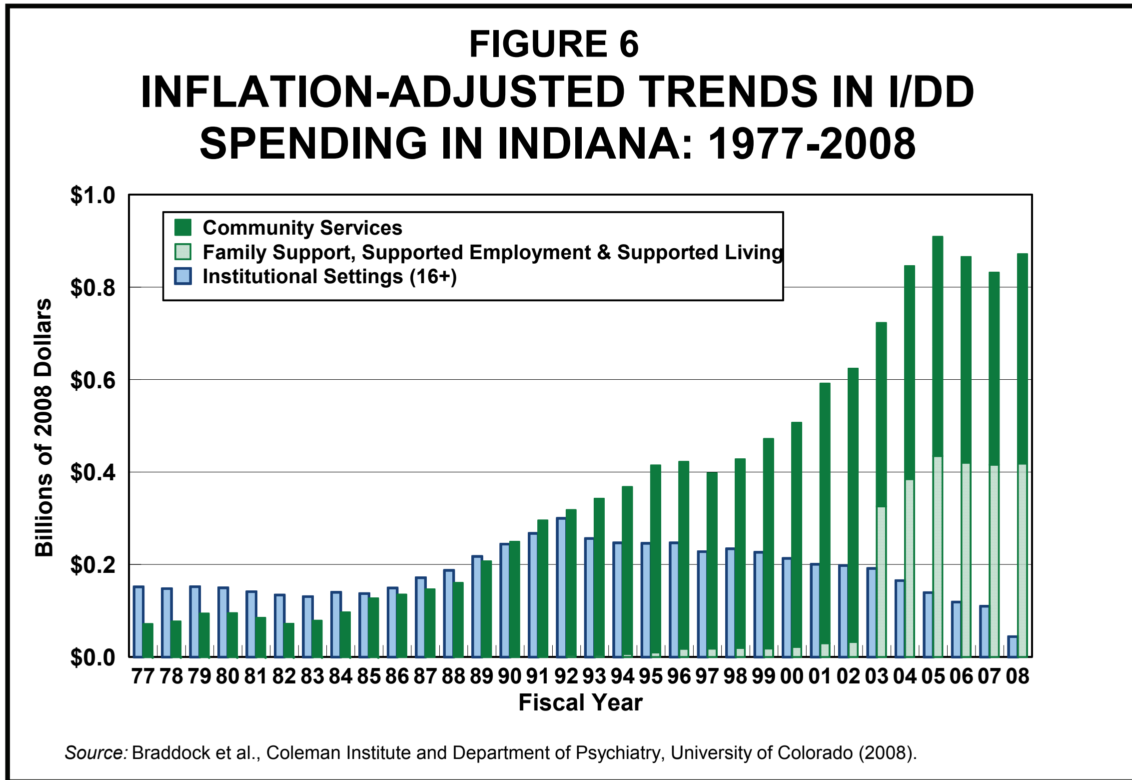


FIGURE 6
INFLATION-ADJUSTED TRENDS IN I/DD SPENDING IN INDIANA: 1977-2008

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado (2008).

public and private institutional spending declined and community services spending was flat (no growth). Total I/DD spending declined by 6% during 1977-1983. In the second period, 1983-1992, there was sustained growth in both the institutional and community sectors, and total spending nearly tripled. In the third period, 1992-1997, total adjusted spending advanced by only one percent, public and private institutional spending declined by 24%, and community spending advanced by 25%. However, community spending declined by 6% in the last year of that period, from 1996 to 1997.

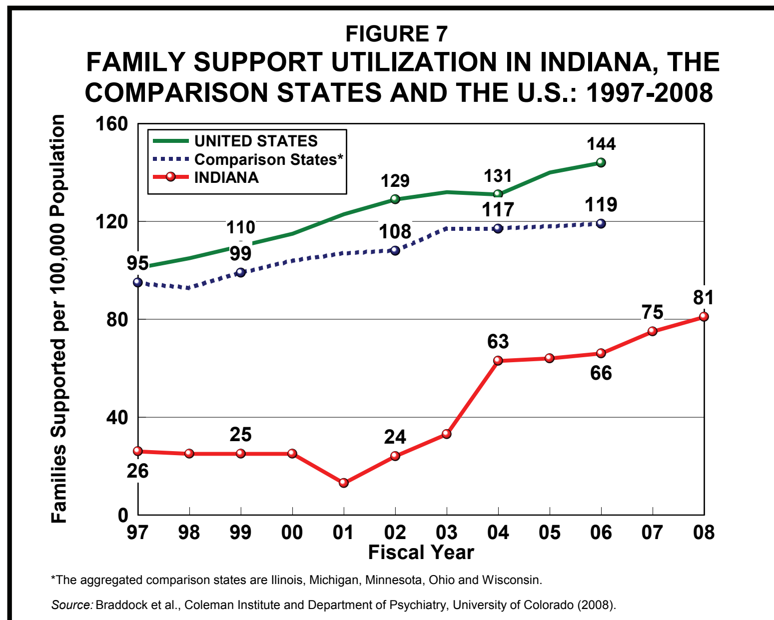
In the fourth distinct period in the financing of I/DD services, 1997-2005, combined institutional and community spending in real terms advanced 68% to a total adjusted spending level of $1.048 billion in 2005. During 1997-2005, community spending grew 129% and institutional spending plummeted by 39% as the New Castle and Northern Indiana State Developmental Centers and large private ICFs/MR were closed. In the final distinct period of I/DD spending in Indiana, 2005-08, total I/DD spending in Indiana actually declined 13% in real terms. The institutional component of total I/DD spending declined 68% in real terms during 2005-08 as Muscatatuck and Fort Wayne Developmental Centers closed. Community services spending also dropped four

percent in real economic terms during 2005-08. Significant expansion of the revenue base for community services in 2009 and beyond is needed to continue to address waiting lists for such services. There is reason to believe that the State of Indiana is likely to significantly increase its resource allocation for community services now that the state-operated institutions have been closed. The next few years will be critically important for community services development as Indiana moves closer to an "institution-free" I/DD service delivery system.

4.1 Family Support

The number of families supported in Indiana remained constant at 1,500 during 1991-98, then increased steadily to 5,125 in 2008. On a per capita basis, per 100,000 of the state general population, the number of families supported in Indiana increased from 63 per capita in 2004 to 81 per capita in 2008 (***Figure*** *7*). The number of families supported per capita in Indiana in 2006 (66), however, remained 54% below the average state's per capita level (144), and 45% below the five aggregated comparison states (119). In 2006, Indiana ranked 40th nationwide in the number of families supported per capita. The comparison states' rankings were Wisconsin (16th), Minnesota (20th), Michigan (29th), Ohio (30th) and Illinois (35th).

Financial commitments for family support activities in Indiana consisted of respite care spending of $500,000 annually from 1991-1998. Spending increased slightly to $875,000 in 1999 and 2000, $6.5 million in 2001, $8.0 million in 2002 and $26.0 million in 2003. Family support spending peaked at $28.5 million in



2006, then fell to $24.2 million in 2008. In 2006, Indiana ranked 30th in family support *spending* per capita of the general population. Michigan ranked 26th, Illinois (29th), Wisconsin (31st) and Ohio (44th). Minnesota ranked second nationwide in family support spending per capita.

Legislation in Indiana (PL 126 in 1979) had previously created a "family cash subsidy program" designed to fund support services allowing persons to remain with their natural families. However, only limited funding accompanied this legislative initiative (Indiana Legislative Services Agency, 1991, p. 40). Indiana does not now operate a cash subsidy program for families.

TABLE 3
STATES WITH FAMILY SUPPORT CASH SUBSIDY PROGRAMS IN 2006

STATE	SPENDING	FAMILIES	SUBSIDY PER FAMILY
Alaska	$4,548,000	1,516	$3,000
Arizona	$1,046,224	573	$1,826
Arkansas	$143,052	92	$1,555
Connecticut	$3,280,095	3,525	$931
Delaware	$233,854	126	$1,856
Florida	$473,600	210	$2,255
Illinois	$36,071,886	2,611	$13,815
Iowa	$1,602,523	378	$4,239
Kansas	$3,415,962	1,418	$2,409
Louisiana	$4,634,670	1,705	$2,718
Maine	$600,000	545	$1,101
Michigan	$17,614,656	6,722	$2,620
Minnesota	$13,392,880	2,346	$5,709
Nevada	$1,877,750	454	$4,136
New Jersey	$12,005,157	7,851	$1,529
New Mexico	$568,752	164	$3,468
North Dakota	$607,599	142	$4,272
Oklahoma	$4,972,075	2,077	$2,394
Rhode Island	$170,116	50	$3,402
South Carolina	$3,233,432	1,151	$2,809
Tennessee	$3,897,900	2,018	$1,932
Texas	$5,000,000	2,674	$1,870
Utah	$15,907	5	$3,181
Washington	$5,073,735	2,513	$2,019
UNITED STATES	**$124,479,825**	**40,866**	**$3,046**

Source: Braddock et al. (2008).

In 2006, 24 states financed cash subsidy programs, including the comparison states Illinois, Michigan, and Minnesota (***Table 3***).

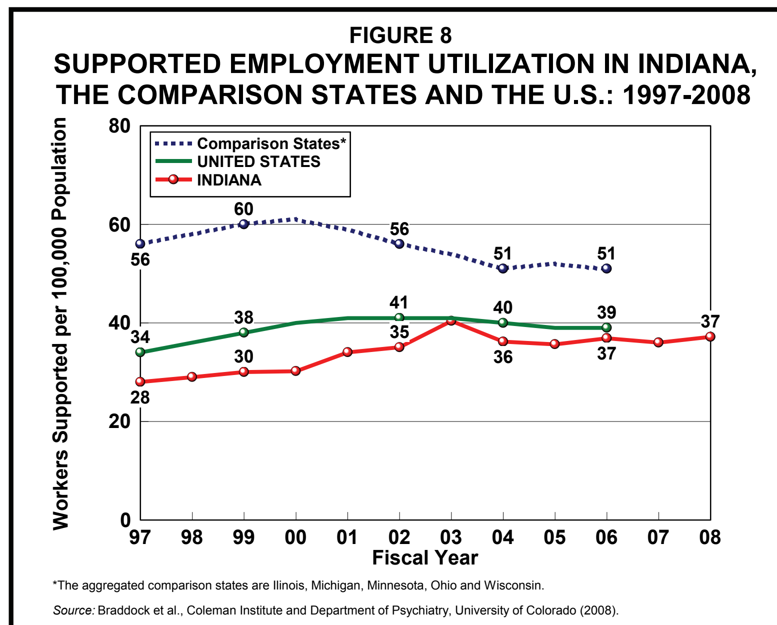
4.2 Supported Employment

Supported employment data from 1999-2008 were reported by BDDS officials, based on surveys from the Indiana Institute on Disability and Community. The Institute researchers produced reports on day and employment services outcomes during 2002-07 (Grossi and Mank, 2006, 2007). In 2007, 11,217 individuals with disabilities were receiving day and employment services from 55 of the 65 programs in Indiana. Of 10,688 persons responding about where they spend their day including recreation, day, and employment services, 30% were in individual jobs, earning an average $6.68 per hour

(wage data for May 2004). The BDDS utilized the Institute's data, adjusting the annual totals during 2002-08 by 71%-77%, to estimate the proportion that persons with I/DD ("MR/DD," autism and cerebral palsy) constituted of all persons with disabilities in the State's day/work programs.

However, Supported Employment Follow-Along (SEFA) funding managed by the Bureau of Developmental Disabilities Services declined 10% in inflation-adjusted terms during 2006-08, from $14.5 million (adjusted) to $13.0 million. During 2006-08, the number of supported and competitive workers increased from 2,320 to 2,371. On a per capita basis, the number of Indiana workers in 2008 was well below the five Midwestern comparison states in the aggregate in 2006 but comparable to the U.S. per capita (***Figure 8***).

The number of supported employment workers nationally plateaued at 118,000 during 2002-06 (Braddock et al., 2008), and this is manifest in the declining per capita levels displayed in ***Figure 8***. A declining per capita is evident for the five aggregated comparison states as well, from 56 in 2002 to 51 in 2006. In 2006 Indiana ranked 25th in supported employment workers per capita of the general population. The comparison state per capita ranks were: Ohio (7th), Minnesota (16th), Wisconsin (19th), Michigan (22nd) and Illinois (32nd).



In 2006, Indiana ranked 28th in supported employment *spending* per capita of the general population ($2.09). The U.S. average was $2.39 and the comparison state spending per capita levels were: Illinois ($1.55), Michigan ($2.45), Minnesota ($2.53), Ohio ($2.86),

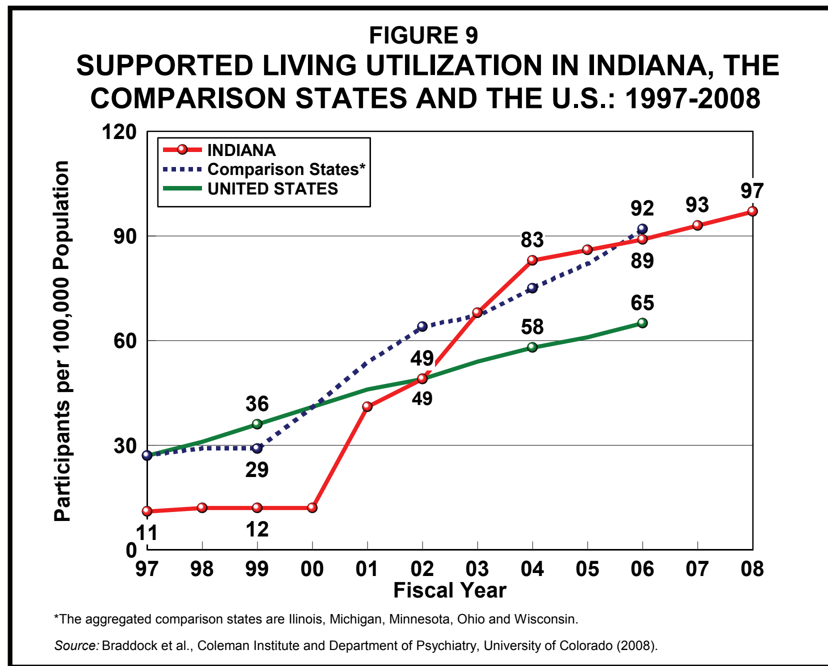
and Wisconsin ($2.95). These supported employment spending per capita levels for the five comparison states ranked 35th, 24th, 22nd, 20th, and 19th, respectively. Indiana's spending per capita ranking exceeded only Illinois among the comparison states.

Nationwide, supported employment workers constituted 21% of all day/work program participants in 2006. Total day/work consisted of supported and competitive workers, sheltered workshop and work activity center participants, and day training and day habilitation program participants. In 2008, supported workers in Indiana constituted 22% of the total, just above the U.S. average in 2006 (21%), greater than all but Michigan and Ohio of the comparison states, and ranking 24th nationally. The supported employment share and rankings for the comparison states were: Illinois (13%, ranked 42nd), Minnesota (15%, ranked 36th), Wisconsin (16%, ranked 32nd), Ohio (22%, ranked 23rd) and Michigan (24%, ranked 21st). The Balanced Budget Act of 1997 afforded the states an opportunity to greatly expand HCBS Waiver funding for supported employment. In Indiana Waiver funding constituted 56% of supported employment spending in 2008.

4.3 Supported Living

There are three essential components of supported living: a) supported individuals choose where and with whom they live; b) the housing is owned by the individual, the family, or a housing cooperative or landlord; and c) individualized support planning recognizes and meets individuals' changing needs over time. In 2006, 49 state I/DD agencies funded initiatives in supported living and/or personal assistance that were consistent with the stated criteria. Supported living spending in 2006 totaled $4.90 billion nationally for 188,616 participants (Braddock et al., 2008).

Supported living spending in Indiana totaled $385.1 million for 6,195 participants in 2008. Supported living participants in Indiana on a per capita basis substantially exceeded the projected U.S. average in 2008 and was comparable to the comparison states in 2006 (***Figure 9***). Indiana ranked 16th nationally in 2006 in supported living participants per capita, and 6th in supported living spending per capita. Supported living participant per capita rankings in the comparison states were: Ohio (5th), Michigan (7th), Wisconsin (11th), Minnesota (42nd) and Illinois (42nd). The comparison states' supported



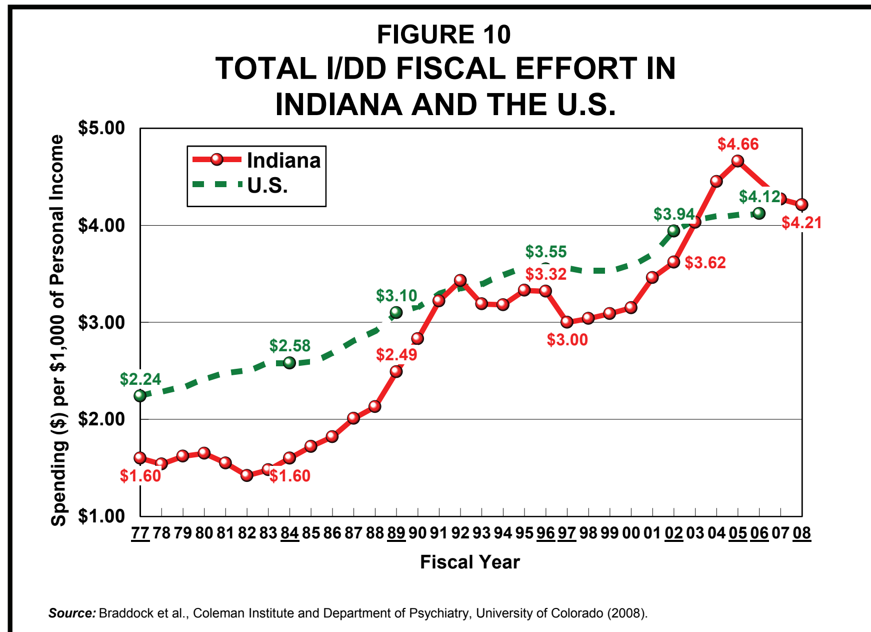
living *spending* per capita ranks in 2006 were Ohio (5th), Michigan (17th), Minnesota (22nd), Wisconsin (24th), and Illinois (42nd).

The HCBS Waiver has become the principal financial source for individual and family support spending in the U.S. and in Indiana (Rizzolo, Hemp, & Braddock, 2006). In the nation as a whole, federal-state Waiver spending in 2006 constituted 54% of supported employment spending, 70% of family support spending, and 86% of spending for supported living and personal assistance. In 2008, HCBS Waiver funding in Indiana constituted 98% of family support spending, 97% of supported living spending, and 56% of the State's spending for supported employment services. Indiana's Support Services Waiver is dedicated entirely to financing family support services, contributing $23.8 million in federal-state Medicaid funding in 2008.

5. Fiscal Effort in Indiana

"Fiscal effort" is a ratio utilized to compare states according to the proportion of their total statewide personal income devoted to I/DD services. Fiscal effort is expressed in terms of I/DD spending per $1,000 of statewide aggregate personal income (Braddock & Fujiura, 1991).

Fiscal effort in Indiana grew by 55% between 1997 and 2005 (from $3.00 to $4.66 per $1,000 of aggregate statewide personal income). *During 2005 to 2008, however, Indiana's fiscal effort fell--by 10% from $4.66 to $4.21 per $1,000* (***Figure 10***). This degree of decline is unusual. In 2006, Indiana ranked 23rd in I/DD fiscal effort and

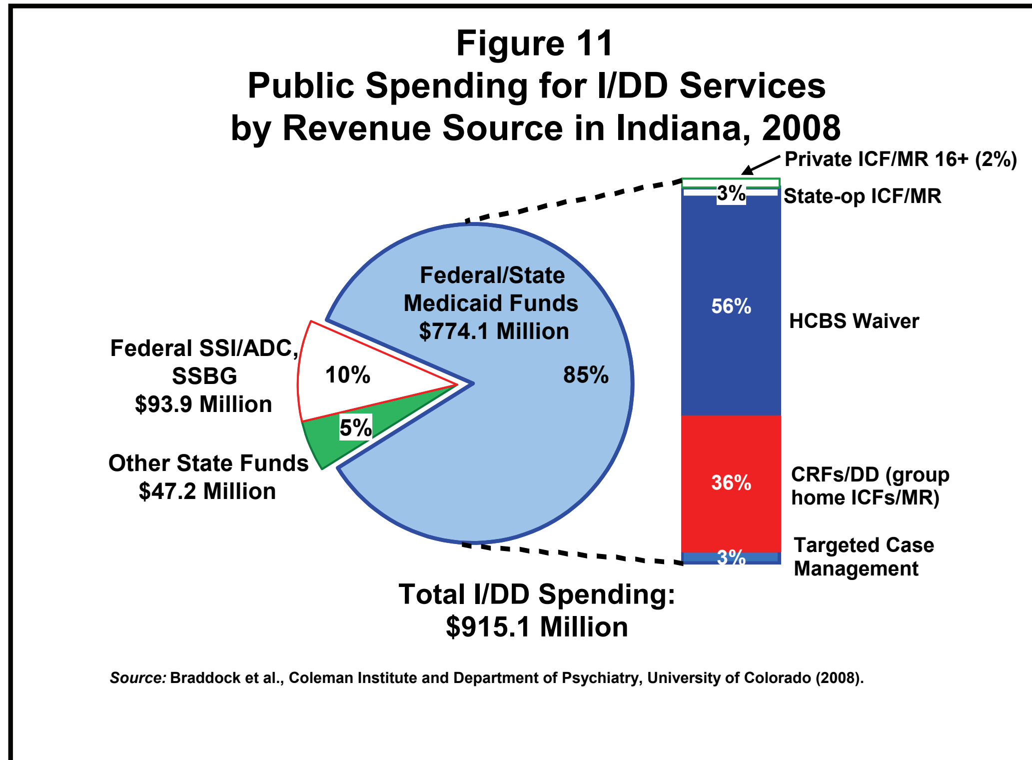


25th based on our national estimates for 2008. The comparison states' fiscal effort rankings in 2006 were Minnesota (6th), Ohio (9th), Wisconsin (17th), Michigan (36th), and Illinois (40th). Indiana's fiscal effort in 2005 exceeded the U.S. effort level, but the Indiana effort level in 2008 is just below the projected U.S. fiscal effort level ($4.25).

Community fiscal effort in Indiana also advanced rapidly from 1999 to 2005, posting a 93% increase from $2.09 to $4.04. In 2008, the Indiana community fiscal effort ($4.01) is above the projected average U.S. community fiscal effort level ($3.66). Indiana ranked 21st in 2006 in community fiscal effort. The five comparison states' community fiscal effort rankings in 2006 were: Minnesota (4th), Ohio (10th), Wisconsin (19th), Michigan (28th), and Illinois (43rd).

IV. MEDICAID FINANCING OF I/DD SERVICES

Medicaid financing is essential to intellectual and developmental disabilities long-term care. Nationwide federal and state Medicaid funding in 2006 constituted 78% of total spending of $43.8 billion for I/DD long-term care services. There are two primary sources of Medicaid financing for I/DD long-term care: the ICF/MR program, and the Home and Community Based Services (HCBS) Waiver. Other optional community Medicaid services include personal care, targeted case management, and rehabilitative and clinic services. In Indiana, federal and state Medicaid spending was $774.1 million in 2008 and constituted 85% of total spending of $915.1 million (***Figure 11***). "Other federal



funds" in the figure consisted primarily of Waiver participants' Social Security benefits ($80.8 million), and the Social Services Block Grant ($13.1 million).

Spending for private CRFs/DD serving 15 or fewer persons, certified as ICFs/MR, constituted 36% of total federal-state Medicaid of $774.1 million in Indiana. The HCBS Waiver constituted 56%, state mental hospital I/DD units certified as ICFs/MR constituted three percent, Medicaid spending for targeted case management constituted three percent, and the balance (2%) consisted of Medicaid spending for three private ICFs/MR serving 16 or more persons.

1. The Home and Community Based Services (HCBS) Waiver

In 1981, the Federal government was concerned about rising Intermediate Care Facility/Mentally Retarded (ICF/MR) costs. State officials and advocates were also concerned that the ICF/MR program's "institutional bias" promoted the institutionalization of people with I/DD. The HCBS Waiver program was enacted in Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (Public Law 97-35), authorizing federal reimbursement for a wide array of community services and supports.

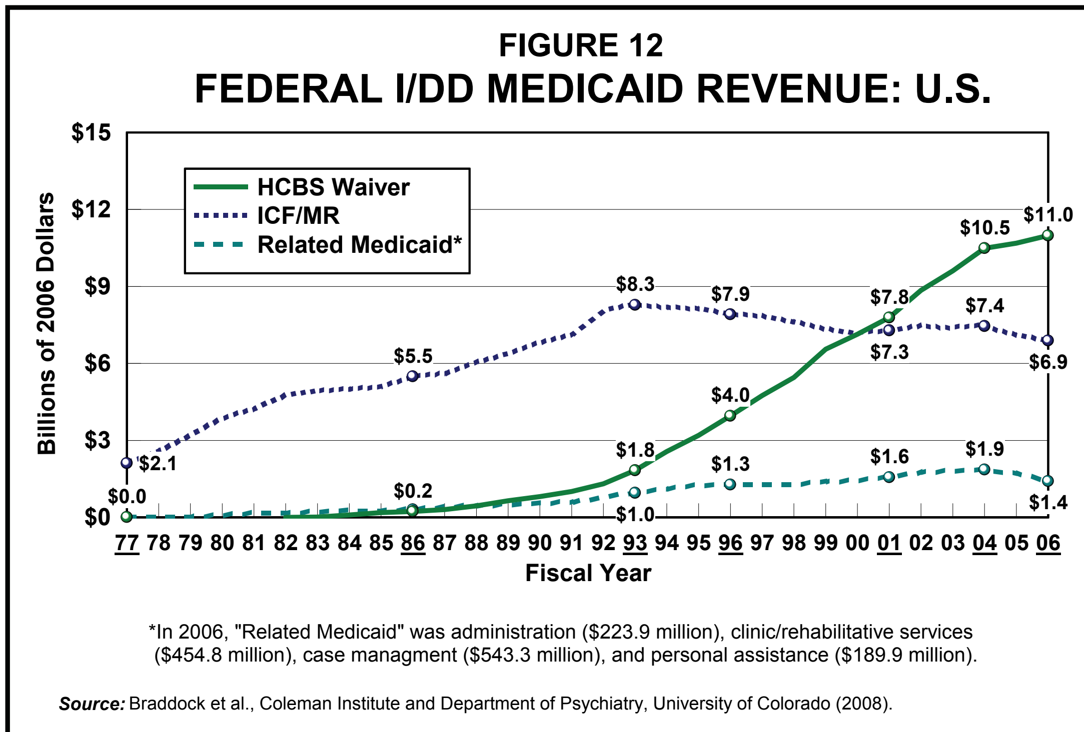
Services that are reimbursed under the Waiver include supported employment, habilitation training, respite care and other family supports, case management, supported living, assistive technology, personal assistance, physical, occupational, and speech therapies, and behavior management. The HCBS Waiver finances individuals in community residential settings, including apartments, small homes, and the family's home. Nationwide, there were 489,384 Waiver participants in 2006, nearly five times the 102,300 residents in public and private ICFs/MR of all sizes (Braddock et al., 2008). All fifty states and the District of Columbia are now participating in the HCBS Waiver. Indiana's Waiver was implemented in 1990; however, Indiana was one of the last 12 states to finance HCBS Waiver services.

An important collateral benefit of the HCBS Waiver to state governments, it should be noted, is the $637 per month in federal income maintenance benefits which Waiver participants receive in the form of Supplemental Security Income (SSI) payments or other social security benefits consisting mostly of Adults Disabled in Childhood (ADC) benefits under Title II of the Social Security Act. These federal SSI/ADC funds pay room and board and other costs. The residents of public and private ICFs/MR of all sizes receive $30-$60 per month in personal allowance from SSI/ADC. Waiver participants' SSI/ADC funds totaled $3.5 billion nationwide in 2006 ($637 per month), in addition to the $19.6 billion in federal/state Medicaid Waiver funding. In Indiana, $80.8 million in federal SSI/ADC funding was generated for the State's 10,570 Waiver participants in 2008.

The rapid growth of federal HCBS Waiver spending nationally is illustrated in ***Figure 12***. After the peak of $8.3 billion (adjusted) in 1993, federal ICF/MR spending in the U.S. declined 17% to $6.9 billion in 2006. Inflation-adjusted federal Medicaid spending for the HCBS Waiver grew 17% per year from 1993 (the peak in ICF/MR spending) to 2006. In 2006, federal Waiver spending in the U.S. was 59% more than federal ICF/MR spending.

2. HCBS Waiver Services in Indiana

As noted, Indiana established its Waiver program in 1990, and in 2008 financed services for 10,570 Waiver participants. In 1991, community provider organizations and



*In 2006, "Related Medicaid" was administration ($223.9 million), clinic/rehabilitative services ($454.8 million), case managment ($543.3 million), and personal assistance ($189.9 million).

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado (2008).

state advocacy associations had collaborated with Indiana state officials to expand HCBS Waiver services in the State (Indiana Conference of Executives of Associations for Retarded Citizens, 1994). Providers agreed to curtail growth in CRFs/DD and work with the State to expand funding and services under the Waiver (Braddock & Hemp, 1996).

The impact of reduced ICF/MR spending and increased Waiver spending in Indiana is illustrated in ***Figure 13***. Indiana ICF/MR spending peaked in 1996 at $332.3 million (adjusted). Inflation-adjusted federal ICF/MR spending in Indiana has declined 41% during 1996-2008, more than double the national decline of 17% from the peak in 1993 through 2006. Inflation-adjusted Waiver spending in Indiana grew 171% during 2002-05, *but then declined $10.7 million from 2005 to 2008, a decline of 4%.*

In a previous report (Braddock & Hemp, 2000) we projected that "if Indiana maintains the rate of Waiver spending growth and ICF/MR spending decline that was established during 1997-2000, Indiana's HCBS Waiver revenue will surpass ICF/MR revenue in the State in five years (by 2006)" (p. 23). In fact, that target was reached in 2004. In 2008, Indiana Waiver spending exceeded ICF/MR spending by 38%.

There are three HCBS Waivers for persons with developmental disabilities in Indiana. The ICF/MR Waiver, established in 1992, was replaced in 2001 by the Developmental Disabilities (DD) Waiver. The Autism Waiver was established in 1990

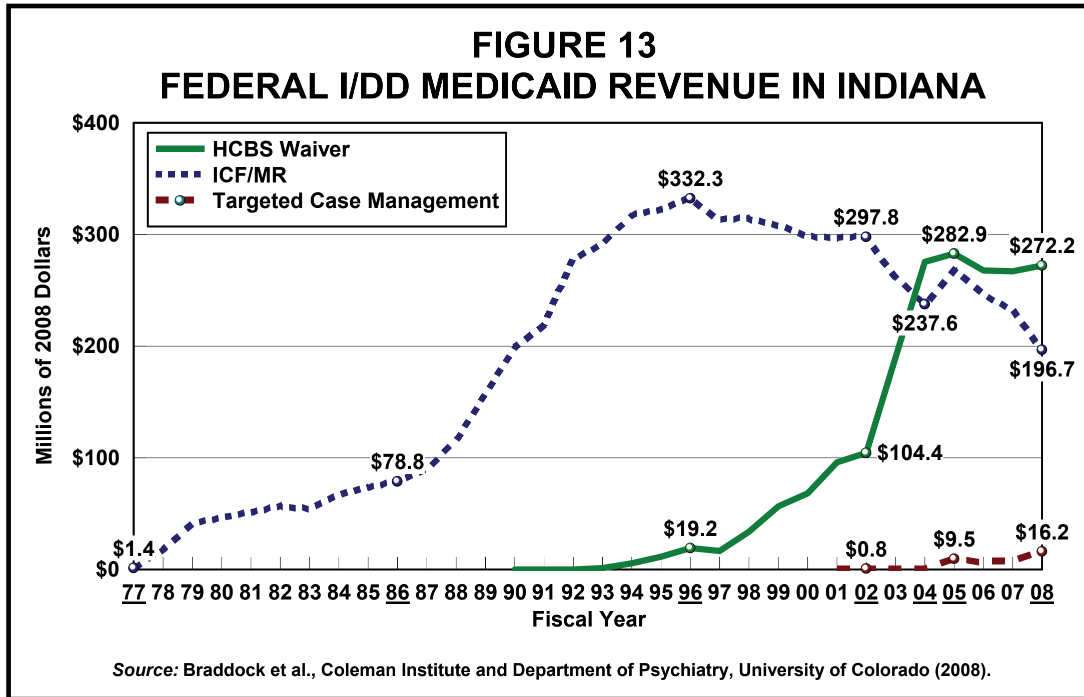


FIGURE 13
FEDERAL I/DD MEDICAID REVENUE IN INDIANA

Source: **Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado (2008).**

and the Support Services Waiver was established in 2002. All three Waivers have an over-all spending cap (i.e., spending levels can vary for individual participants as long as the Waiver cost per participant overall meets cost neutrality requirements). In addition, the Support Services Waiver has an individual participant cap of $13,500 per year, which may include up to $2,000 per year in respite care.

The Support Services Waiver's array of services consisted of adult day services, respite care, behavior management, case management, crisis intervention, day services, family and caregiver training, OT, PT and music, psychological, speech and language and recreational therapies, personal emergency response systems (PERS), specialized medical equipment, and vehicle modification. The DD and Autism Waivers' services consisted of all of those services included in the Support Services Waiver and, in addition, adult foster care, community transition services, environmental modifications, rent and food for unrelated live-in caregiver, and residential habilitation and support. Effective 11/1/05, "day services" (in all three Waivers) combined the previously separate services community habilitation and participation, prevocational services, supported employment follow along, and transportation. "Residential habilitation and support" in the DD and Autism Waivers combined the previously separate services residential habilitation and support, community habilitation and participation, and health care coordination (Indiana

Family and Social Services Administration, 2008b).

Initiatives in smart home technology for individuals with I/DD in Indiana are being provided by Madison, Wisconsin-based Night Owl Support Systems, LLC, and by Lafayette, Indiana-based Rest Assured, LLC. Night Owl Support Systems uses telephone line connections to sensors in consumers' homes, with professional back-up at a central call response center. Rest Assured, affiliated with ResCare, Inc., is a collaborative effort of Wabash Center Arc and Engineering Projects in Community Service (EPIC) at Purdue University College of Engineering. In 2008, Rest Assured served 118 consumers at 52 sites (personal communication, J. Darling, President, Rest Assured, LLC, March 4, 2008). It utilizes *Telecare* wireless technology with a secure broadband Internet connection and a central video monitoring center. In Indiana, Night Owl Support Systems and Rest Assured are state funded. However, the State is working with the Centers for Medicare and Medicaid Services (CMS) to amend the Indiana Waiver's Personal Emergency Response System (PERS) service to include coverage for the "electronic monitoring" provided by smart home services like Night Owl and Rest Assured.

V. COMMUNITY SERVICES IN THE COMPARISON STATES

This section addresses in more detail the community services development activities of the five comparison states. The discussion begins with these states' HCBS Waiver utilization compared to ICF/MR utilization. A discussion of 1977-2006 trends in spending for institutional services and community services follows.

1. Medicaid Financing in the Comparison States

In 2006, three of the five comparison states utilized the HCBS Waiver more extensively than Indiana. Minnesota, Wisconsin, Michigan, Ohio, and Illinois ranked 3rd, 16th, 25th, 32nd, and 47th, respectively, in federal-state Waiver spending per capita of the general population. Indiana ranked 31st. Per capita Waiver spending in Indiana in 2008 was slightly above the U.S. average for 2006 (***Figure 14***). Waiver utilization in Minnesota provides an example for Indiana. Minnesota relied heavily on federal ICF/MR financing of private ICFs/MR for 15 or fewer persons until 1994, when HCBS Waiver

growth accelerated in the state. By 2006, Waiver spending in Minnesota constituted 71% of Medicaid spending for I/DD long-term care services in the state, and as noted Minnesota ranked 3rd (behind New York and Rhode Island) in federal-state HCBS Waiver spending per capita.

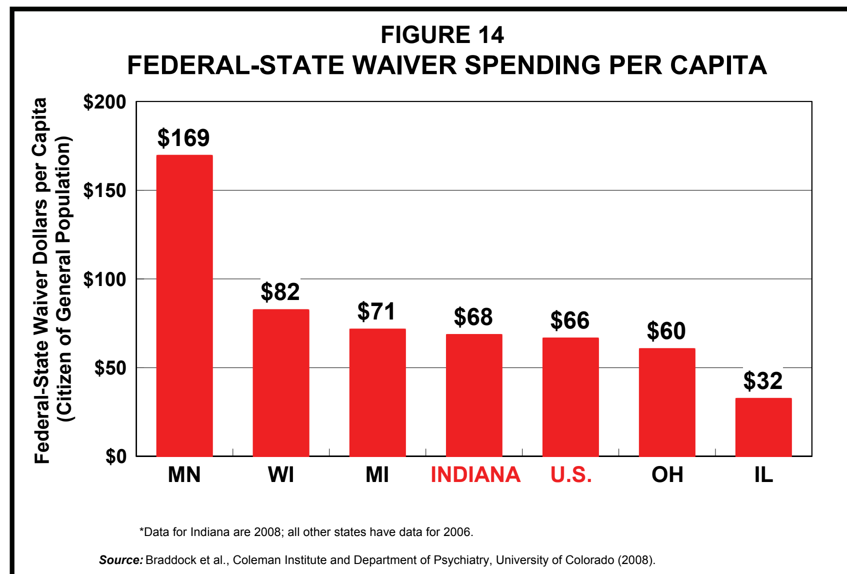
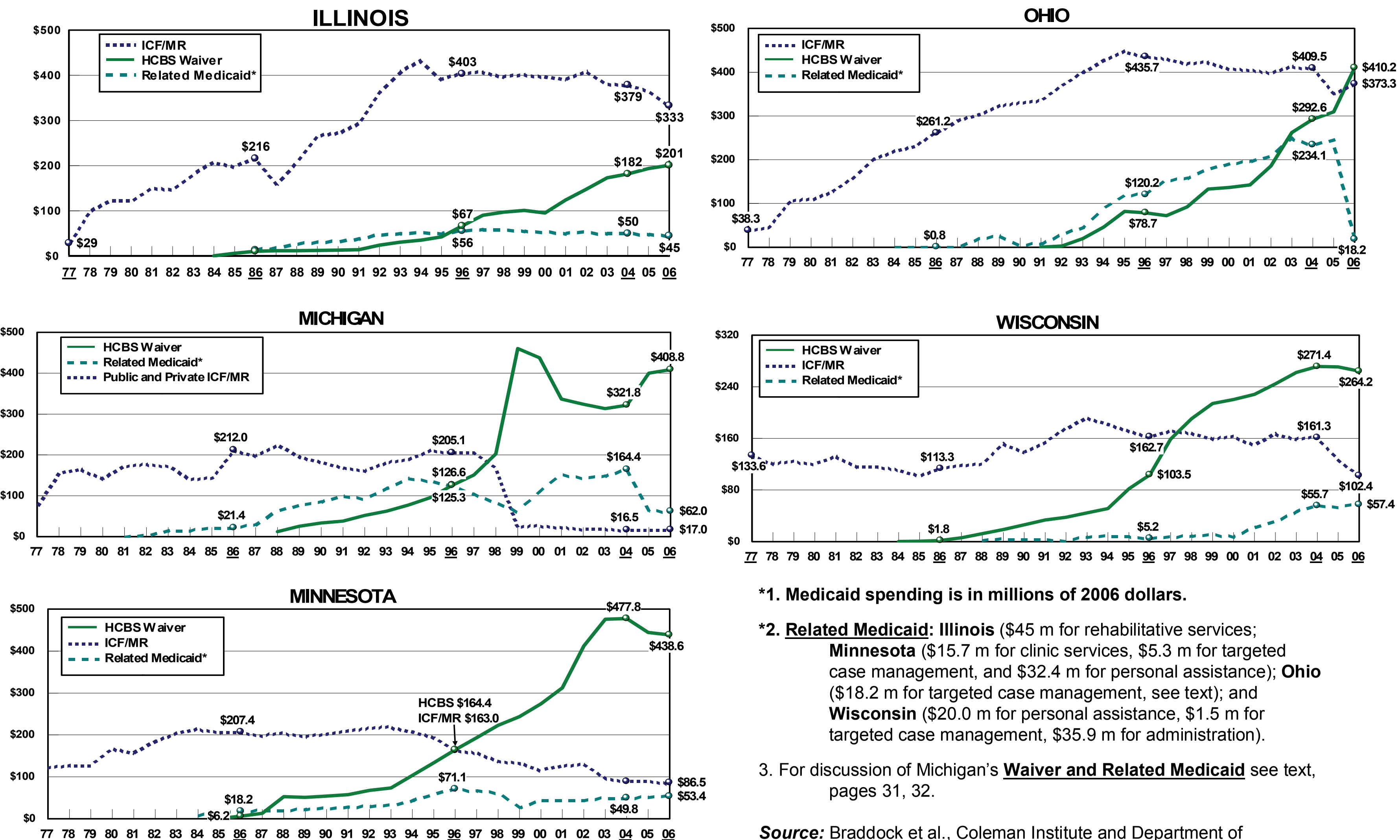


Figure 15 presents ICF/MR and Waiver spending trends for each of the five comparison states. Minnesota began spending more for HCBS Waiver services than for combined public and private ICF/MR services in 1996 and Michigan and Wisconsin did so in 1998, and in 2006 Ohio began spending more for the HCBS Waiver than for ICF/MR services. Illinois continues to receive substantially more ICF/MR reimbursement than HCBS Waiver reimbursement. Each comparison state and Indiana has begun to reduce ICF/MR spending. The reduction of ICF/MR spending commenced in 1993 in Minnesota and Wisconsin, 1994 in Illinois, 1995 in Ohio, and 1997 in Michigan. As previously discussed, Indiana began to substantially reduce its commitment to financing public and private ICFs/MR beginning in 1997 (***Figure 13***, p. 25).

2. Analysis of Services and Spending in Indiana and the Five Comparison States

Illinois, Michigan, Minnesota, Ohio and Wisconsin were compared to Indiana along several dimensions of their developmental disabilities spending profiles, including: a) the year in which "parity" between community spending and public/private institutional care spending was achieved; b) the extent to which funds have been reallocated to community services; and, c) the types of residential programs and indi-

FIGURE 15
TRENDS IN FEDERAL HCBS WAIVER, ICF/MR AND RELATED MEDICAID SPENDING IN THE COMPARISON STATES: FY 1977-2006*



***1. Medicaid spending is in millions of 2006 dollars.**

***2. <u>Related Medicaid</u>: Illinois** ($45 m for rehabilitative services; **Minnesota** ($15.7 m for clinic services, $5.3 m for targeted case management, and $32.4 m for personal assistance); **Ohio** ($18.2 m for targeted case management, see text); and **Wisconsin** ($20.0 m for personal assistance, $1.5 m for targeted case management, $35.9 m for administration).

3. For discussion of Michigan's **Waiver and Related Medicaid** see text, pages 31, 32.

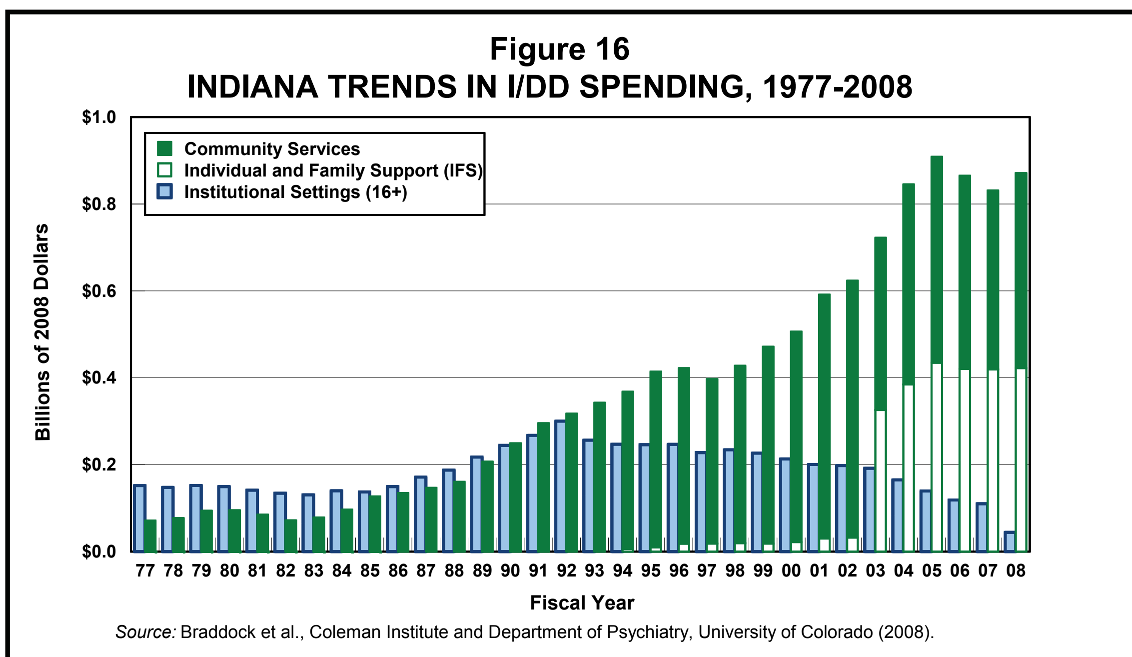
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado (2008).

vidual and family support utilized in community services development (Braddock et al., 2008).

2.1 Indiana

As discussed earlier (p. 14) I/DD spending for institutional and community services in Indiana underwent substantial changes during 1977-2008. During 1977 through 2005 there were continuous annual reductions in inflation-adjusted institutional spending. This was in contrast to annual inflation-adjusted increases in community spending for every year during 1977-2005 except during 1981-82 and in 1997. During 2005-08, total I/DD spending in Indiana dropped 13% in real terms and institutional spending declined 68% as the Muscatatuck and Fort Wayne Developmental Centers were closed. *Most notable, however, during 2005-08, was the four percent inflation-adjusted decline in community spending* (***Figure 16***).

Prior to 1993, Indiana's competing growth in community and institutional spending was similar to neighboring Illinois. The Lincoln State School and Colony in Illinois and the Asylum for Feeble Minded Children in Fort Wayne in Indiana were two of the nation's first I/DD institutions, established in 1877 and 1879, respectively. Both states relied heavily on state-operated developmental centers well into the 1990s and Illinois continues to do so today. Both states developed large numbers of private



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado (2008).

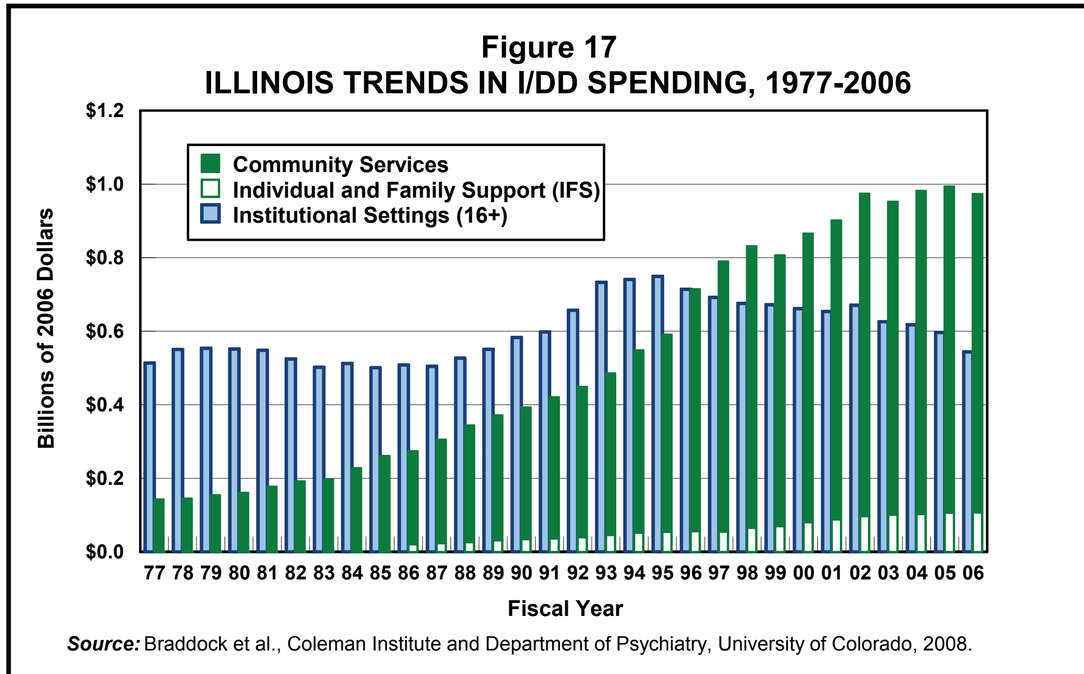
ICFs/MR serving 16 or more persons, and ICFs/MR for 15 or fewer persons. In Indiana, these were termed CRFs/DD and consist of eight-bed facilities. Indiana and Illinois were relatively late in establishing the HCBS Waiver as a significant funding source for community services. In 2008, however, the Indiana HCBS Waiver was twice the size of the Illinois Waiver on a per capita basis.

Waiver expansion, the development of six person or fewer community residences and supported living, and the substantial increases in community spending have been the hallmarks of Indiana's development of services and supports during 1999-2008. When Indiana closed Fort Wayne in 2007, it joined nine other states and DC that no longer have state-operated institutions for individuals with I/DD. In 2008, Indiana committed 88% of total I/DD resources to community services. This figure compares to 97% in Minnesota, 94% in Michigan, 82% in Ohio, 71% in Wisconsin and only 64% in Illinois.

2.2 Illinois

Illinois, like Indiana, was relatively late in establishing the HCBS Waiver as a primary funding source for community services. But unlike Indiana's strong HCBS Waiver spending growth during 1999-2008 and a per capita ranking of 31st in 2006, Illinois ranked 47th in Waiver spending per capita. Illinois' family support programs continue to serve as somewhat of a model for Indiana. Illinois in 1991 was one of the first states to pass legislation initiating family support cash subsidies. In 2006, Illinois' cash subsidy program of $36.1 million served 2,611 families and total family support spending in the state was $62.5 million for over 11,000 families. Illinois expended more for cash subsidies than any other state and was fifth behind Connecticut, Michigan, New Jersey and Texas in the number of families receiving cash subsidies.

During 1977-2008 there were four major periods in financing I/DD services in Illinois. During 1977-84, institutional spending was essentially flat, community spending advanced 59% and total I/DD spending advanced 13% (***Figure 17***). During 1984-95, total spending increased 81%, consisting of strong growth both in institutional spending (46%) and in community spending (160%). During the third period, 1995-2002, there was a steady decline in institutional spending of 10%, except for a slight increase in 2002. Community spending advanced 65% and there was 23% inflation-adjusted growth



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2008.

in total I/DD spending during the same period. Illinois' community spending first surpassed institutional spending in 1997. During 2002-06, total adjusted Illinois I/DD spending declined 8%, institutional spending dropped 19%, and community spending was flat (-0.1%).

In 2006, Illinois committed 64% of total I/DD resources to community services, compared to 88% in Indiana. That year, real institutional spending in Illinois declined nine percent. Despite this reduced institutional spending, Illinois community spending dropped two percent during 2005-06 and consequently total I/DD spending in real terms declined five percent (Braddock & Hemp, 2008). Illinois, like Indiana, has failed to reallocate savings from reduced institutional spending to the financing of community services. Unlike Indiana, however, Illinois continues to have a substantial financial investment in state-operated institutions and 16+ person private ICFs/MR.

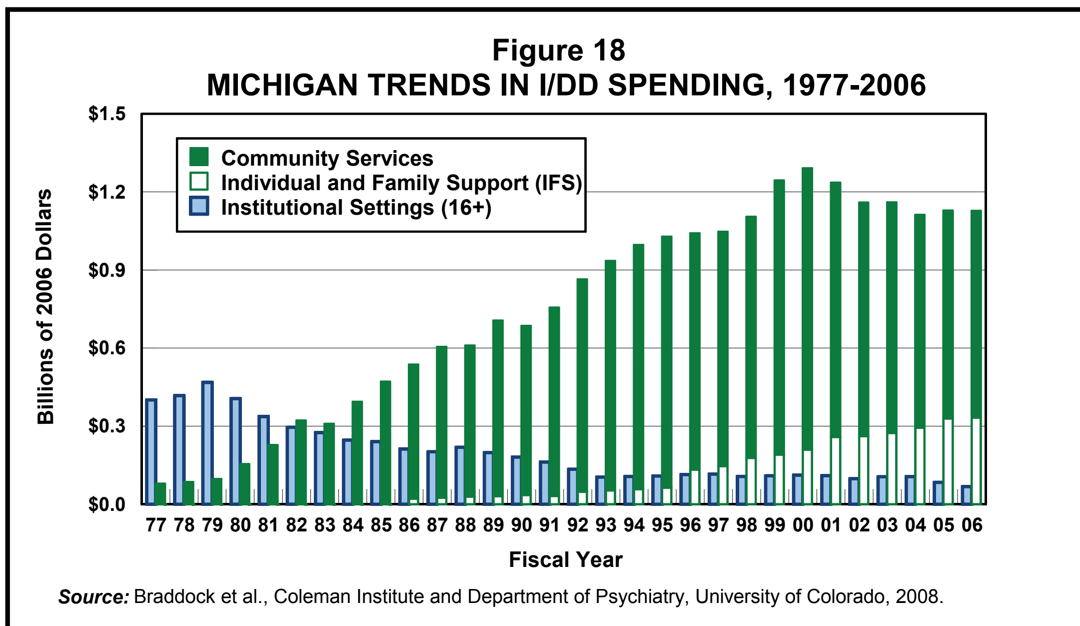
2.3 Michigan

Michigan has been one of the national leaders since the early 1980s in reducing reliance on public and private institutions and in the development of family support. The Michigan family support cash subsidy program, established in 1984, was a notable achievement and served as a model for Illinois' 1991 family support cash subsidy legislation. In 1981 and 1982, Alaska, Michigan and Colorado were the first three states

to spend more for community services than for institutional services, and by 2006 Michigan spent 94% of total resources of $1.20 billion on community services for six or fewer persons (***Figure 18***). The initial foundation for community services in Michigan was "alternative intermediate services/mentally retarded" (AIS/MR) settings that were certified as private ICFs/MR for 15 or fewer persons. Beginning in 1995 Michigan greatly expanded use of the HCBS Waiver to finance community services and family support in the state. In 2006, 82% of individuals with I/DD who were served in out-of-home settings in Michigan resided in settings for six or fewer individuals.

The allocation of I/DD resources in Michigan was driven by the *Michigan ARC v. Smith* (1979) lawsuit, the State's collaborative efforts with county boards, its institutional closures, and adoption of a strong program of family support. Institutional spending began to decline steadily in the state in 1980. In subsequent years, as several institutions closed, institutional spending declined rapidly and funds were reallocated to finance community residential alternatives and family support. In 2006, the cash subsidy family support program in Michigan, in combination with approximately $7,200 annually in federal Supplemental Security Income (SSI) payments, provided in-home support for 6,722 individuals with I/DD and their families. Annual cost per person in Michigan's one remaining state facility, Mt. Pleasant, is $325,671. This is 75 times a typical combined cash subsidy and SSI payment, which is approximately $4,340. The cash subsidy and SSI payment is also only 10% of the cost of a typical group home placement in Michigan.

Figure 18
MICHIGAN TRENDS IN I/DD SPENDING, 1977-2006



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2008.

Illinois and Minnesota, in part, have modeled their cash subsidy programs on Michigan's example.

The Michigan Medicaid program is unique, consisting of a "Section 1915(b)/(c) Combination Waiver" and Medicaid state plan personal care funding for community I/DD programs. Medicaid funding for the state's 1915b/c Waiver and for "B-3 Community Living Services" (CLS) is included in the HCBS Waiver line in ***Figure 15***. Federal Medicaid funding for these two programs ranged from $14.1 million in 1998 to $201.9 million in 2006. The marked changes in Waiver spending and in "related Medicaid" (personal care) during 1998-2006 were due in part to growth in person-centered planning and the B-3 Waiver, and in part to poor data quality during the transfer from fee-for-service to managed care in 1998.

In 1997, Michigan proposed to the Centers for Medicare and Medicaid Services (CMS) the development of a comprehensive, prepaid, capitated managed care network that would be administered by local government Community Mental Health Services Programs (CMHSPs). The CMHSPs are the 51 county-based public Community Mental Health agencies that have traditionally provided long-term care to people with I/DD in Michigan's 83 counties. Michigan's "Combination 1915(b)/(c) Medicaid Prepaid Specialty Services and Supports for Persons with Developmental Disabilities" waiver was approved in June 1998 (CMS, 2003). Person-centered planning amendments in Michigan's 1995 Mental Health Code became an integral part of the Medicaid managed care plan. The Michigan Waiver affords a uniform package of benefits for people with I/DD, allowing the state to remove the artificial distinctions between Medicaid state plan benefits and Medicaid HCBS Waiver benefits. Michigan's PHP contracts affirmatively require CMHSPs to ensure that individuals with I/DD can choose among service providers, and that consumer service plans are developed using person-centered planning principles (Smith, O'Keeffe, et al. 2000).

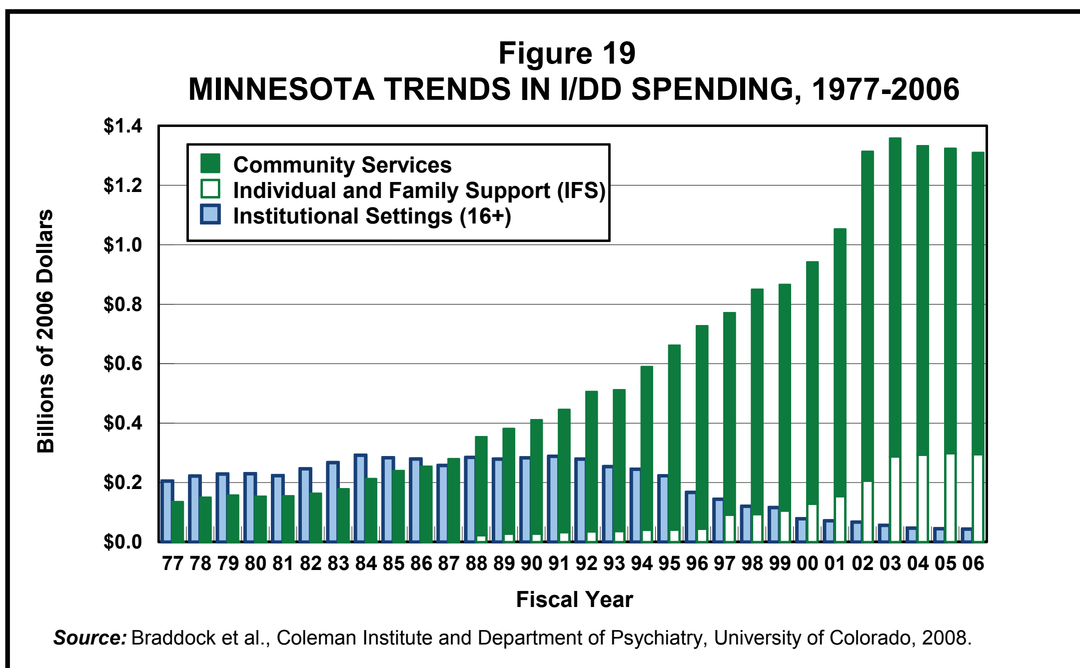
2.4 Minnesota

Minnesota, like Michigan, heavily utilized Intermediate Care Facility/Mental Retardation (ICF/MR) funding for settings for 15 or fewer persons as the foundation of community services development in the 1980s. Like Michigan, Minnesota began in the

mid-1990s to shift from ICF/MR funding to greatly expanded use of the HCBS Waiver (***Figure 15***). Inflation-adjusted federal Waiver spending during 1998-2004 advanced over 114% and in 2006 Minnesota ranked third among all states in federal-state Waiver spending per capita of the general population.

Minnesota first expended more resources for community services than public and private institutional services in 1987, and institutional spending began to decline rapidly in 1992 (***Figure 19***). By 2006, 97% of Minnesota's total developmental disabilities resources financed community services, family support, supported employment, and supported living. In October 2000, Minnesota closed its sole remaining state I/DD institution, Fergus Falls. The only remaining state-operated institutional setting is the Minnesota Extended Treatment Options (METO) program, a unit for persons with I/DD at the Cambridge Mental Health Center that served nine individuals during fiscal year 2006. Minnesota's nursing facility census in 2006, 383 persons, was 64% below the level in 1996. As noted, the number of nursing facility residents per capita (7) in Minnesota was the lowest among the comparison states and was well below the nursing facility utilization rate in Indiana (27).

Figure 19
MINNESOTA TRENDS IN I/DD SPENDING, 1977-2006

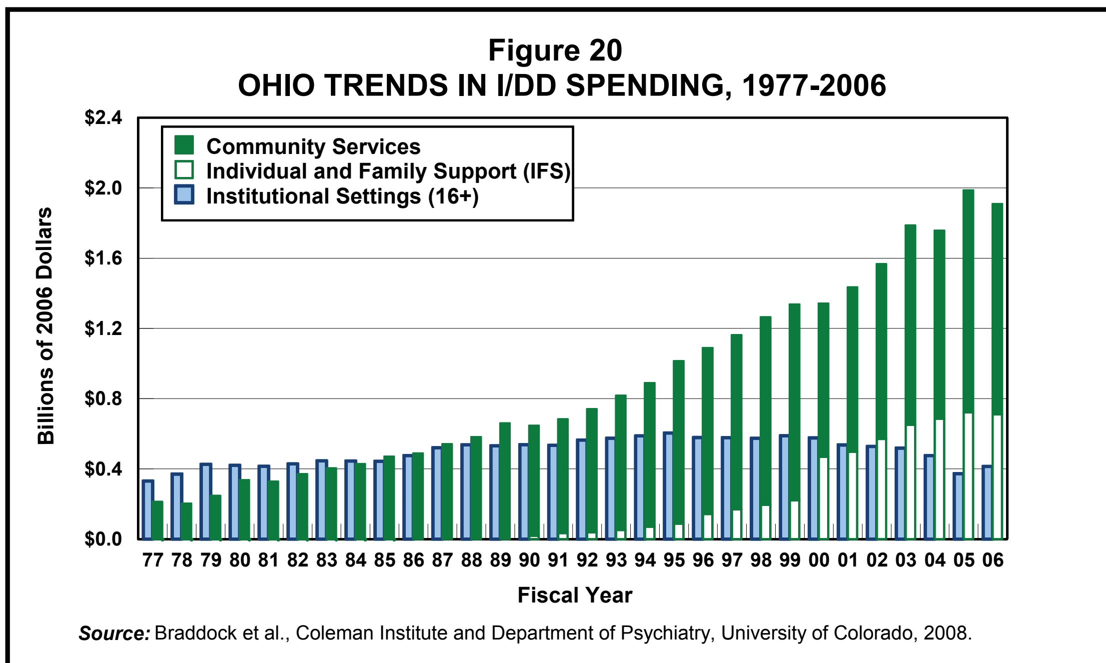


Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2008.

2.4 Ohio

Ohio was an early leader in the financing of supported living services (Braddock et al., 1998). In 2006 it ranked fifth in supported living spending per capita of the general population and also fifth in the number of supported living participants per capita. Ohio's community services spending first reached parity with the State's institutional spending in 1985 (***Figure 20***), five years earlier than Indiana. In 2006 Ohio committed 82% of total I/DD resources to community services, just below Indiana's 84% and exceeding the community shares for the two comparison states Illinois and Wisconsin. There were generally steady increases in inflation-adjusted community spending in Ohio during 1977-2006, with the exceptions of 1978, 1981, 1990, 2000, 2004, and 2006. Institutional spending was essentially flat during 1987-2000, then declined during 2001-2006. The exception was the spending increase in 2006 associated with employee salary and benefit increases at the state developmental centers. Ohio recently closed Apple Creek and Springfield Developmental Centers but retains 10 state-operated institutions.

In 2006, Ohio ranked 32nd in Waiver spending per capita, just below Indiana's ranking of 31st. Ohio continues to finance a considerable network of public and private ICFs/MR. In 2006, in agreement with the Centers for Medicare and Medicaid Services

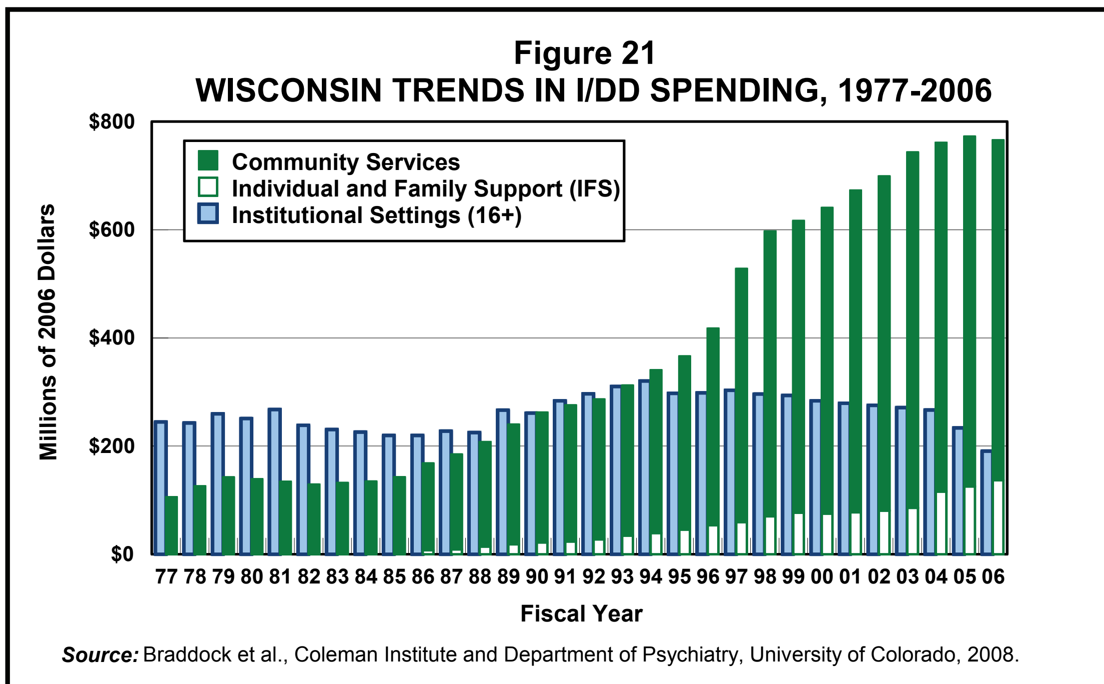


(CMS), Ohio terminated use of Medicaid Community Alternative Funding Source (CAFS) resources for day programs. Some, but not all, of this lost Medicaid revenue was realized in increased HCBS Waiver funding (***Figure 15***).

2.4 Wisconsin

Home and Community Based Services Waiver spending in Wisconsin surpassed ICF/MR spending in 1998, only two years after this benchmark was reached in Minnesota. Wisconsin ranked 16th nationally in Waiver spending per capita in 2006. In 2006, Wisconsin committed 71% of total I/DD resources to community services, less than Indiana and all comparison states, except Illinois. Wisconsin first reached parity in institutional/community spending in 1993, three years after Indiana did so (***Figure 21***). With the recent closure of Northern Wisconsin Center, two state-operated institutions remain, and, as noted, Wisconsin's institutional utilization in 2006 (10 per 100,000 of the general population) was below the U.S. average (13). In addition, Wisconsin has systematically closed private ICF/sMR for 16 or more persons, with a census reduction of 65% from 2,566 persons in 1993 to 900 in 2006. Public and private institutional spending in Wisconsin dropped 12% in 2005 and 18% in 2006.

Wisconsin enacted the Medicaid Family Care Initiative in 1999 as a pilot in five



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2008.

counties. Family Care is a capitated acute care and long-term care managed care program for people with I/DD, older people, and young persons with physical disabilities, managed by the Department of Health and Family Services (DHFS). Medicaid home and community-based services are an entitlement in the pilot counties and there are therefore no waiting lists for services. The original legislation limited enrollment to 29% of the state's Medicaid population of persons with disabilities. However, the Wisconsin Governor and legislature have recognized the program's cost-effectiveness and consumer satisfaction. The State has a five-year plan to expand Family Care to all of Wisconsin's 72 counties and to 50% of the state's Medicaid recipients with disabilities (Folkemer & Coleman, 2006).

3. Summary of Comparison States

Indiana and the comparison states have closed numerous state institutions and private ICFs/MR, reduced the number of nursing home residents with I/DD, and developed community services and family supports. Minnesota, Michigan, and Indiana have the best records in the region in the development of community service alternatives to state institutions. Minnesota closed its last remaining state I/DD institution in October 2000 and now serves only nine persons in a state Mental Health Center I/DD unit. Michigan serves 127 institutional residents in one remaining state-operated facility. Indiana closed its last state-operated I/DD institution, Fort Wayne, in 2007. Minnesota, Michigan, Wisconsin, and Illinois lead the comparison states and Indiana in reducing the numbers of persons with I/DD in nursing facilities. The nursing facility utilization rates per 100,000 of the general population in 2006 were Minnesota (7 persons per 100,000), Michigan (8), Wisconsin (9) and Illinois (12). The rate was 20 in Ohio and 11 in the U.S.--all well below Indiana's rate of 27 persons per 100,000.

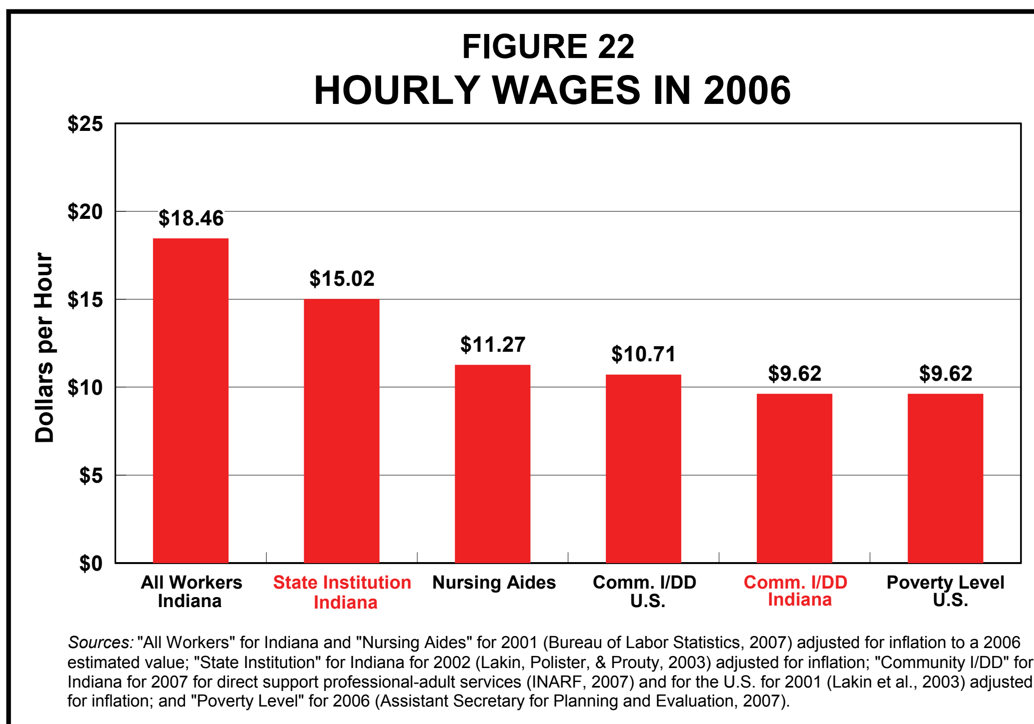
Michigan's cash subsidy and family support programs have had an impact on the state's I/DD service system. Michigan places proportionately fewer individuals with I/DD in out-of-home residential settings (214 per 100,000) than do Wisconsin (333), Minnesota (316), and Ohio (259). The out-of-home placement rates per 100,000 in 2006 were 163 in Illinois and 187 in Indiana. Illinois and Minnesota, with their family cash

subsidy legislation, have both developed family support programs that are good examples for Indiana.

The comparison states, like Indiana, initially relied heavily on ICF/MR reimbursement for group homes as their primary federal funding source for community services. However, the comparison states have all developed significant HCBS Waiver-financed alternatives for substantial numbers of their former ICF/MR residents. Growth in the HCBS Waiver in Indiana during 2002-2005 was also impressive, and the State has moved vigorously in the direction of Michigan, Minnesota and Wisconsin in reducing reliance on ICFs/MR.

All comparison states employed local government funding for community I/DD services, but Indiana did not. In fact, local/county government funding of community I/DD services is a very important component in Ohio (41% of total I/DD spending), Iowa (31%), and Wisconsin (15%). The local government share of community spending was three percent in Minnesota, two percent in Illinois and five tenths percent in Michigan.

Community Wages, Benefits and Staff Training. Turnover of direct support professionals and the inability to recruit replacement staff are detrimental to the quality of I/DD long-term care programs. Direct support professional average wages in privately-



Sources: "All Workers" for Indiana and "Nursing Aides" for 2001 (Bureau of Labor Statistics, 2007) adjusted for inflation to a 2006 estimated value; "State Institution" for Indiana for 2002 (Lakin, Polister, & Prouty, 2003) adjusted for inflation; "Community I/DD" for Indiana for 2007 for direct support professional-adult services (INARF, 2007) and for the U.S. for 2001 (Lakin et al., 2003) adjusted for inflation; and "Poverty Level" for 2006 (Assistant Secretary for Planning and Evaluation, 2007).

operated community-based long-term care programs in Indiana are below the wages of all workers covered by unemployment insurance (Bureau of Labor Statistics, 2007) (***Figure 22***). They also fall below average wages for state-operated direct care staff (Lakin, Polister, and Prouty, 2003). Indiana's average community DSP wages are below those of nursing aides (Bureau of Labor Statistics, 2007) and equal to the 2006 poverty level for a family of four (Assistant Secretary for Planning and Evaluation, 2007).

However, significant new direct support professional initiatives in Indiana include a statewide training initiative at the Indiana University's Institute on Disability and Community (IIDC) and a two-year, $12 million DSP collaborative training program with IIDC and Ivy Tech State College. Also participating in the latter program are Indiana State University, the Indiana Division of Disability and Rehabilitative Services (DDRS) of the Family and Social Services Administration (FSS), and nine provider agencies. Both of these direct support staff initiatives are designed to enhance DSP wages, benefits and academic and career opportunities ("DDRS is leading collaborative effort," 2008).

VI. AGING CAREGIVERS AND WAITING LISTS IN INDIANA

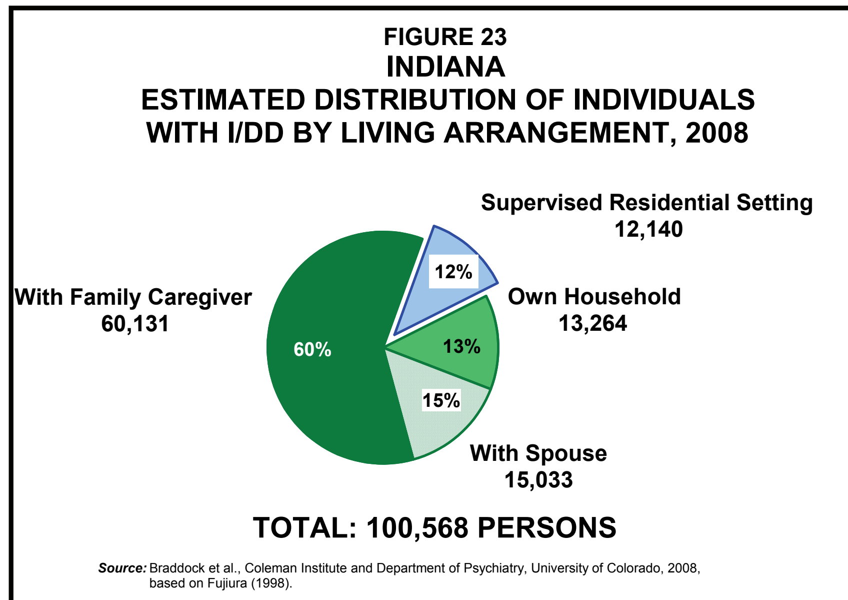
The growing need for I/DD services in our society is strongly related to the aging of our society. The baby boom generation will begin to reach age 65 in 2011. The proportion of Americans aged 65+ years, now 13%, will grow steadily over the next three decades and reach 22% of the U.S. population in 2030. There have also been impressive increases in the lifespan of individuals with I/DD. Persons with I/DD had an average lifespan of 66 years in 1993 (Janicki, 1996). The average age of death for persons with Down syndrome had also increased substantially to 56 years in 1993 (Janicki, Dalton, Henderson, & Davidson, 1999).

Katz (2003), in a recent international review, summarized research on life expectancy for persons with intellectual disability from several countries including the U.S. He concluded that life expectancy for persons with mild and moderate degrees of impairment, the vast majority of persons with I/DD, did not differ significantly from the general population. Patja, Iivanainen, and Vesala et al. (2000) reported, however, a 19-35% diminishment of life expectancy in the much smaller cohort of persons with severe

and profound degrees of impairment (cited in Katz, 2003, p. 268). The Patja et al. study was carried out in Finland (Braddock et al., 2008).

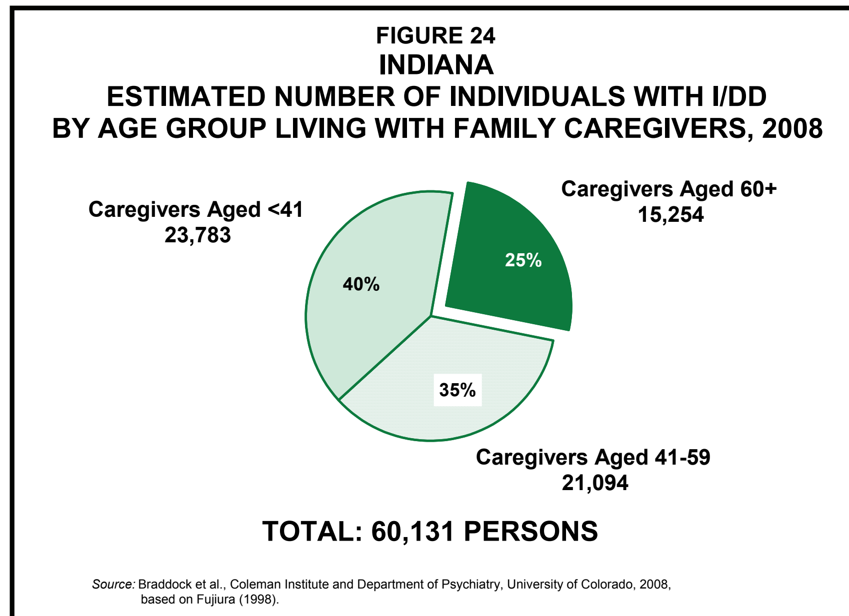
Persons with developmental disabilities who live longer require services for longer periods of time, especially as their caregivers age beyond the point at which they can continue to provide support. The impact that aging caregivers have on state service systems can be based on estimates of the prevalence of developmental disabilities, and the living situations of persons with developmental disabilities. Fujiura (1998) reviewed U.S. Bureau of the Census data to determine the proportion of persons with mental retardation and closely related developmental disabilities living in out-of-home residential care, and the proportion living with caregivers of different ages. Fujiura's (1998) analysis was based on the Census Bureau's Survey of Income and Program Participation (SIPP) data set. Braddock et al. (2008) updated Fujiura's analysis, and applied the methodology to the individual states.

Figure 23 presents, for 2008, the estimated number of persons with I/DD in Indiana living a) in residential facilities; b) in their own households; c) with spouses; and d) with family caregivers. The estimates are based on the I/DD prevalence estimate of 1.58% of the general population (Larson, Lakin, Anderson, Kwak, Lee, & Anderson, 2001). It should be noted that individuals' needs for support ranged considerably for those living in structured residential facilities, compared to those living in their own households or with spouses. As illustrated in the figure, well over half, 60%, of the estimated 100,568 children and adults with developmental disabilities in Indiana



resided with 60,131 family caregivers.

Figure 24 provides an estimate of the age categories of the caregivers for the 60,131 persons with intellectual and developmental disabilities in Indiana who are living with families. Of particular note is the category of 15,254 persons residing with caregivers who are aged 60 years or more. Clearly, many of these individuals need services now or very soon in the future.



Waiting Lists in Indiana. There are three sources of waiting list statistics for Indiana. First, Prouty et al. (2007) reported that, as of June 30, 2006, a total of 15,068 persons with I/DD in Indiana were awaiting residential services, and ***not*** presently receiving residential services. Second, the Indiana Bureau of Developmental Disabilities Services (BDDS) Monthly Management Report for fiscal year 2008 lists 2,140 persons with I/DD "in application status," and 8,932 persons "eligible but not in setting." Finally, Indiana waiting list data for fiscal year 2006 are available from the Indiana Family and Social Services Administration (FSSA) for the three HCBS Waivers serving people with I/DD. A total of 13,935 children and adults awaited services from the Indiana DD Waiver, 2,861 awaited the Autism Waiver, and 9,454 awaited the Support Services Waiver. However, consumers requesting Indiana Waiver services are directed by the State to apply to the waiting lists for all three Waivers. Therefore, the DD Waiver number (13,935) is probably a better representation of the unduplicated number of individuals awaiting Waiver services.

Waiting list data are not always based on standardized definitions of the urgency of need, and some states distinguish between families with young children registering future need, youth turning 22 years of age, and individuals awaiting services who themselves are older or who live with caregivers aged 60 years or older (Braddock & Hemp, 1997). Major factors that have contributed to growing waiting lists in Indiana and other states, in addition to the growing number of aging caregivers, include the large proportion of nursing home residents who could benefit from receiving services in community alternatives, and students exiting special education programs (U.S. Department of Education, 2007).

Indiana's Progress in Reducing Waiting Lists. Indiana has made significant progress during the Daniels Administration in reducing waiting lists, which fell by 2,000 persons between September 2006 and June 2008. Moreover, Indiana adopted a policy to end the waiting list for caregivers aged 80 and above seeking to access the Developmental Disabilities Waiver and a policy for exiting high school students to access the Support Services Waiver. Waiting list termination policies were also adopted for persons with I/DD who lose shelter, lose a caregiver to death or illness, age out of a children's program, or have a life shortening disease. In addition, the State committed $11 million per year for 24-hour crisis intervention for individuals with I/DD who have behavioral support needs (Indiana Family and Social Services Administration, 2008a).

VII. CONCLUSION

This study a) described the structure of intellectual and developmental disabilities (I/DD) residential and community services in Indiana and the United States; b) analyzed recent developments in service utilization and financing of I/DD services through fiscal year 2008; c) compared and contrasted performance in Indiana to other states and to the U.S.; and d) presented recommendations for the future direction of intellectual and developmental disabilities services in Indiana. The study focused most specifically on I/DD activities during 1999-2008, and built upon our three previous analyses of Indiana services completed in 1996, 2000 and 2004 (Braddock & Hemp, 1996, 2000, 2004).

In the present study, five Great Lakes states were compared to Indiana: Illinois, Michigan, Minnesota, Ohio, and Wisconsin. We analyzed these states' experiences in the

development of community services, reallocation of institutional resources, development of Home and Community Based Services (HCBS) Waiver options, and in the provision of family support, supported employment, and supported living. The study was designed to assist public officials, families, advocates, and consumers in Indiana to quantitatively gauge their state's progress toward implementing appropriate services and supports for people with developmental disabilities and their families during the past 10 years, and to determine progress needed in the years ahead.

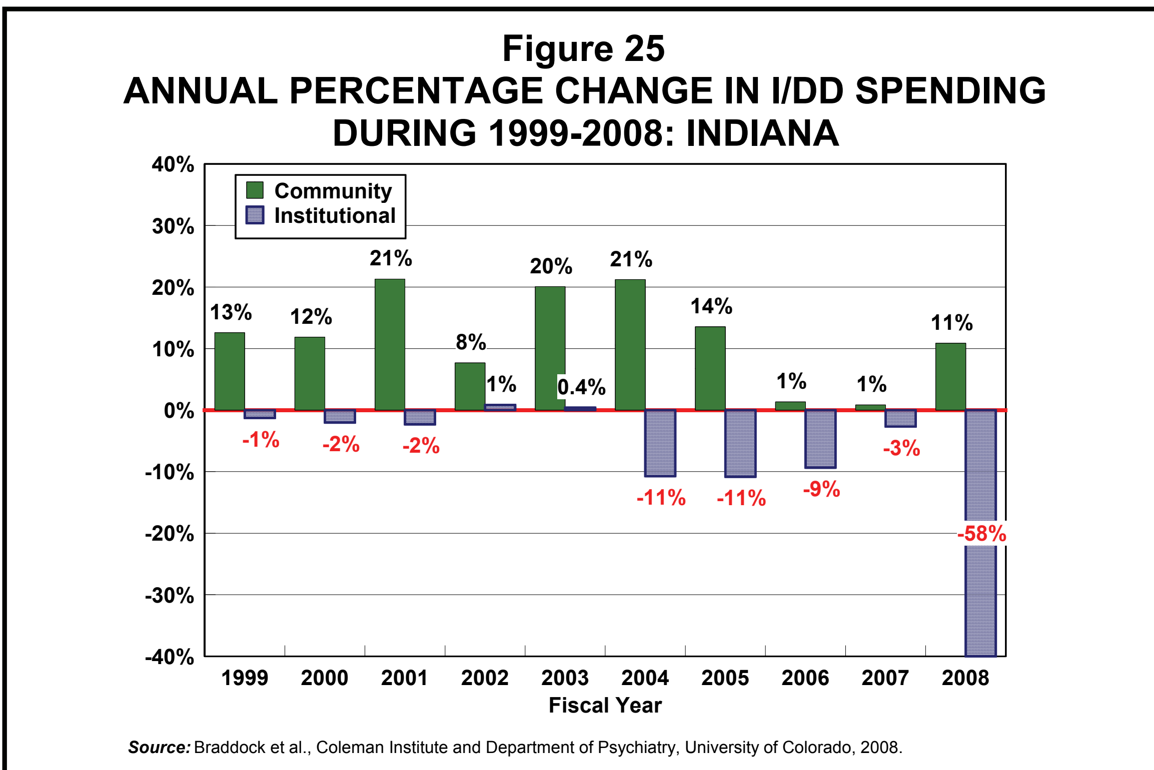
Indiana's "317 Task Force" of consumers, advocates, and state officials published a seminal report in 1998 entitled *A Comprehensive Plan for the Design of Services for People with Developmental Disabilities.* The Plan addressed key issues including waiting lists for services and the provision of necessary resources to support people with developmental disabilities in their homes and at work. The Plan's recommendations provided the framework for extensive program development activities by the Indiana Family and Social Services Administration.

Indiana has indeed made substantial progress in I/DD services development during the past decade. With the closure of New Castle, Northern Indiana, Muscatatuck, and Fort Wayne State Developmental Centers, Indiana's 2008 state-operated institutional utilization rate of two per 100,000 persons in the general population is substantially below the estimated 2008 U.S. rate of 10 per 100,000. *However, Indiana has reallocated insufficient resources from the institutional facilities it closed to community and family support services.* Although inflation-adjusted community services spending grew 93% in Indiana during 1999-2005, it declined four percent during 2005-08 after the closures of Muscatatuck and Fort Wayne Developmental Centers. HCBS Waiver spending declined four percent on an adjusted basis during the same period and the State's fiscal effort for I/DD services dropped by 10%. Total spending for I/DD services in Indiana, adjusted for inflation, declined by six percent in 2006, four percent in 2007 and by three percent in 2008.

I/DD Resource Allocation for Institutional and Community Services. In nominal dollar terms, not adjusted for inflation, institutional services spending in Indiana declined or showed minimal growth for every year during the 10-year period 1999-2008.

Institutional spending declined 58% in 2008 (see ***Figure 25*** below, which is not adjusted for inflation). Alternatively, during 1999-05 community spending increased by 8% to 21% annually. However, community services spending grew only one percent in 2006 and 2007 on an unadjusted basis. ***Community services spending rebounded to grow by 11% in 2008***. The State forecasts additional increases in Waiver and ICF/MR spending in 2009 (Indiana Family and Social Services Administration, 2008a).

During 1999-2005, total *inflation-adjusted* I/DD spending in Indiana grew 50% but then declined 13% during 2005-08. During that three year period, in contrast to the $25.8 million cumulative adjusted increase for community services spending, institutional services spending dropped $121.1 million. Thus, during 2005-08, cumulative adjusted spending for total I/DD services in Indiana fell $95.2 million. Spending is expected to rebound in 2009. A July 24, 2008 State of Indiana report indicated that the HCBS Waiver and private ICF/MR programs will be increased by 10% and six percent, respectively, during FY 2009 (Indiana Family and Social Services Administration, 2008a).



Study Recommendations

Recommendations are provided in two broad categories: those relating to the growth of community services and supports, and those pertinent to the utilization of institutional settings.

Continue the Expansion of Community Services and Related Supports

1. ***Complete the reallocation of institutional services funding to community services***. To date only a portion of the spending "saved" in the closures of Muscatatuck and Fort Wayne Developmental Centers has been reallocated to community services. Adjusted for inflation, total I/DD spending declined 13% during 2005-08 (a cumulative $95.2 million reduction). Indiana should reallocate **all** institutional funding previously "saved" during the institutional closures to community services, family support and supported employment initiatives;
2. ***Expand HCBS Waiver services***. An estimated 13,935 persons with I/DD in Indiana await Waiver services. The need for such services and supports will grow rapidly in the future due to rapid increases in the number of aging caregivers in the state;
3. ***Develop additional support programs for families***. The State should consider developing additional support programs for families, including implementation of a cash subsidy program similar to those in Illinois, Michigan, and Minnesota. Indiana ranked 40th nationally in 2006 in the number of families supported per capita and ranked 30th in family support spending per capita;
4. ***Expand supported employment services***. Indiana should seriously consider expanding supported employment services managed by the Bureau of Developmental Disabilities Services. Spending for this program declined substantially in inflation-adjusted terms during 2006-08. Indiana ranked below the median in supported employment spending per capita; and,
5. ***Increase wages and benefits for direct support professionals***. Wages and benefits for community-based direct support staff should be increased significantly over the next several years to reduce staff turnover and improve service quality.

Continue to Reduce Reliance on Public and Private Institutions/Nursing Facilities

6. ***Reduce the number of persons with I/DD in nursing facilities***. Evaluate and relocate as appropriate to alternative community settings the 1,640 individuals with I/DD residing in nursing facilities in 2008. Indiana's nursing facility utilization rate is 27 per 100,000 of the state general population (2006 data). This was the fourth highest rate nationwide, and was substantially above both the U.S. rate (11) and the average rate of the five comparison states (12). Since the completion of our last study in 2004, Indiana reduced the average daily I/DD nursing facility population by only 78 persons. This is a reduction of less than 20 individuals per year. A class action

lawsuit, *Kraus v. Hamilton*, was filed in St Joseph County Circuit Court several years ago on behalf of residents with I/DD in nursing facilities. A settlement agreement was reached in 2004 to facilitate community placements. This litigation is currently entering mediation (L. Frick, Indiana Attorney General's Office, personal communication, September 9, 2008); and,

7. ***Reduce I/DD mental health units and private ICFs/MR***. Continue to downsize the remaining four I/DD units at the Logansport, Evansville, Madison and Richmond State Hospitals, and the three remaining 16+ person private ICFs/MR. Allocate these resources to strengthen and develop additional community services programs and infrastructure.

The View Ahead

During the past decade, Indiana substantially reduced reliance on institutions and established the HCBS Waiver as the major federal funding source for community developmental disabilities services. However, to continue this progress in providing I/DD services, the State must reverse the recent trend during 2005-08 of resource reductions for community services spending. Funding for the HCBS Waiver program was $10.7 million higher in inflation-adjusted terms in FY 2005 than in FY 2008. Nonetheless, Indiana remains well-positioned to continue to build on its notable achievements in I/DD services development over the past decade. Indeed, State leadership is to be commended for several recent and in-progress services initiatives including: 1) mandating that all high school graduates with I/DD be enrolled in the Support Services Waiver; 2) assuring eligibility for appropriate services and supports for all family caregivers aged 80 and above and for persons with I/DD who lose shelter, lose a caregiver to death or illness, or age out of a children's program; 3) providing commitments for Waiver services for nursing facility residents who wish to access community services; and 4) providing $11 million in annual funding for 24-hour crisis intervention services for persons with I/DD and behavioral support needs (Indiana Family and Social Services Administration, 2008).

Challenges for Indiana loom large, however, given the emerging U.S. economic and budgetary environment. In June 2008, the National Governor's Association anticipated fiscal problems in the states as follows:

> …fiscal year 2008 marked a turning point for states' finances with a significant increase in states seeing fiscal difficulties…as the economy has weakened, so has the state revenue and spending picture…[resulting in] spending pressures for social programs and health care increases" (p. vii).

The impact of reductions in state general fund spending in Indiana is illustrated in ***Figure 26***. Following state general fund spending growth in Indiana during 2002-04, there were four years of spending reductions during 2005-08. The most pronounced reduction was 4.8% in 2006.

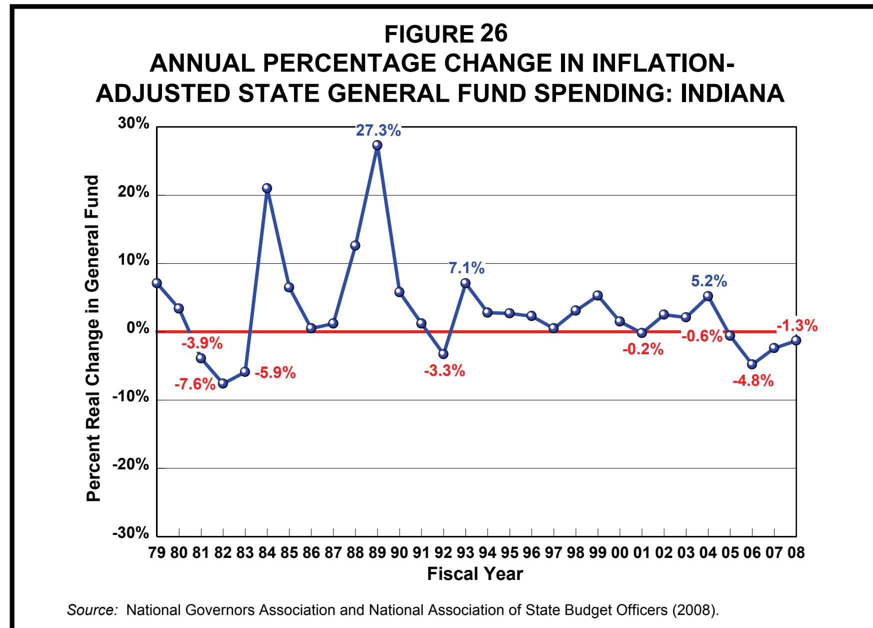


FIGURE 26
ANNUAL PERCENTAGE CHANGE IN INFLATION-ADJUSTED STATE GENERAL FUND SPENDING: INDIANA

Source: National Governors Association and National Association of State Budget Officers (2008).

Most states experienced reasonably robust economic and fiscal conditions during 2006-07. However, 30 states are projected to face budget shortfalls of at least $53 billion in fiscal year 2009 (McNichol & Lav, 2008). *Indiana is not currently one of the 30 states with a projected 2009 budget deficit, but all five comparison states are.* Their projected budget shortfalls, expressed as a percentage of their state general fund, are: Illinois (6.3%), Minnesota (5.4%), Michigan (4.8%), Wisconsin (4.6%), and Ohio (4.5%). The 30-state projected average budget gap as a proportion of the states' general fund was 10%. Indiana presently appears to be the best positioned among the Midwestern comparison states to continue to enhance its commitments to people with developmental disabilities and their families.

Last year Indiana capped overall Medicaid spending growth at five percent per year (vs. the 10% growth projection based on past experience). This action contributed to Indiana's first-ever AAA bond rating by Standard & Poor's. This improved rating lead to significant savings for taxpayers ("Give state leaders credit," 2008). However, the State's annual five percent Medicaid spending cap has implications for the continuing expansion of long-term care services for people with I/DD. Persons with I/DD represent a comparatively small but a very vulnerable and high-needs population receiving Medicaid

long-term care services. Should there be an economic downturn in the State, long-term care support services for people with I/DD, including persons on waiting lists, could be impacted negatively by the costs of addressing the large and growing population of Indiana's indigent non-developmentally disabled Medicaid recipients. The five percent Medicaid growth cap is one of the challenges the State faces over the next several years as it simultaneously continues to implement its progressive reforms in the I/DD service delivery system. However, we expect Indiana to continue to rise to the occasion over the next decade just as it has over the last ten years. A tradition of commitment to people with developmental disabilities and their families is clearly being established.

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