SERVICES AND FUNDING FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES IN ILLINOIS: A MULTI-STATE COMPARATIVE ANALYSIS

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I. INTRODUCTION

The purpose of this study is to a) describe the historical and contemporary trends in intellectual and developmental disabilities (I/DD) residential and community services in Illinois; b) analyze current trends in service utilization and financing services; c) compare and contrast performance in Illinois to five Midwestern states and the U.S.; and d) present recommendations for I/DD services in Illinois. In considering these objectives, we focus on recent developments in Illinois, particularly during 2004-06, and address a number of the parameters of comparison that emerge from the just-completed 2008 edition of the State of the States in Developmental Disabilities monograph (Braddock, Hemp, & Rizzolo, 2008).

In the present study, five states were selected for comparison: Indiana, Michigan, Minnesota, Ohio, and Wisconsin. These states share much with Illinois in terms of demography, economics, and histories of I/DD services. Each state is urban and rural in composition; 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 state-operated institutions as the primary model for the provision of I/DD services. However, each state, to a differing extent, has used the HCBS Waiver to expand small-scale community residences, integrated work services, and family support. These states' experiences in financing I/DD long-term care services and supports are illustrative of the policy choices that Illinois continues to face today.

The parameters utilized for the comparative analysis included: state-operated institution and nursing facility utilization rates; spending levels and fiscal effort for I/DD services; utilization of the Medicaid Home and Community-Based Services (HCBS) Waiver; the growth of family support, supported employment and supported living; and efforts to address the expanding need for residential services and day programs as caregivers age.

Progress along these dimensions was assessed for Illinois, the nation, and for the comparison states. Comprehensive revenue, spending, and programmatic data for Illinois, Indiana, 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 et al., 2008).

II. DECLINING USE OF STATE-OPERATED I/DD INSTITUTIONS

This report begins with a brief historical review of institutional services in the United States and in Illinois. There is considerable historical precedent for the utilization of mental retardation institutions in the states (hereafter mental retardation will be referred to as intellectual and developmental disability, I/DD). Samuel Gridley Howe's initial experimental institution in a wing of the Perkins School for the Blind in Boston, Massachusetts, opened in October 1848 (Barr, 1906). The school was designed to provide a temporary residence for individuals who, after a period of education and training, would soon return to community life. Howe (1848) had conducted a thorough investigation of the conditions and treatment of 514 individuals with I/DD living in almshouses and with families in the Commonwealth of Massachusetts, and convinced the Commonwealth to establish an experimental school. Seventeen years later, in 1865, the first I/DD residential facility in Illinois opened in Jacksonville.

Many of the nation's first institutions were developed in reaction to investigations of substandard living conditions in almshouses and jails (Breckinridge, 1927). In 1846 and 1847 Dorothea Dix, a noted advocate for improved care for persons with mental disabilities, traveled to communities throughout the Midwest. Dix's appeal before the Illinois legislature resulted in the construction of a "state asylum" in Jacksonville in central Illinois, a few miles from the state capitol, Springfield (Illinois Department of Public Welfare, 1928). Ms. Dix also traveled throughout Kentucky, Michigan, Ohio, and Indiana (Dix, 1848).

Government leaders in Illinois and other states responded to Dorothea Dix's vivid descriptions of neglect by building the accepted model of the day: large institutional facilities. Institutional development continued throughout most of the 20th Century. In 1851,

New York State's institution at Syracuse became "the first building in America for the specific purpose of care for the feeble-minded" (Barr, 1906, p. 64). Seven more permanent I/DD institutions were then opened in Columbus, Ohio (1857), Frankfort, Kentucky (1861), New York City (1870), Glenwood, Iowa (1876), Lincoln, Illinois (1877), Fort Wayne, Indiana and Faribault, Minnesota (1879) (Fernald, 1917). The nine institutions built from 1848 to 1879 had a combined capacity of nearly 12,000 residents and averaged 1,300 residents per facility in 1917. Large state institutions like these would dominate I/DD service systems in the Midwest and across the U.S. for more than a century (Braddock, 2002).

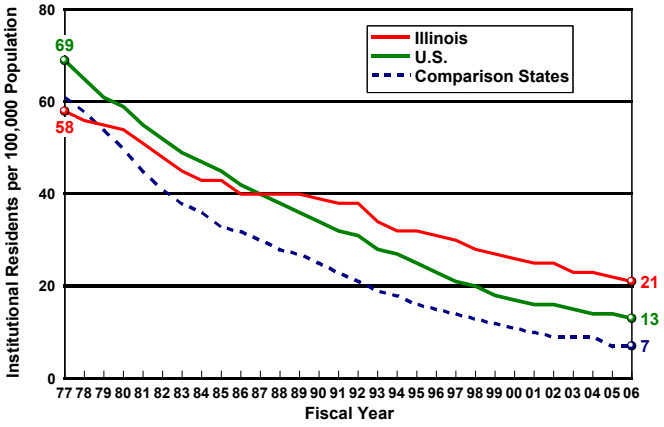
The nation's reliance on large, custodial institutions for persons with I/DD grew after the turn of the Century and substantially accelerated after the Second World War. The abysmal conditions in these institutions soon attracted the attention of the press and media exposés followed (Blatt & Kaplan, 1974). Class action litigation targeted institutional reform and the need for community alternatives to institutions (Herr, 1992). The first class action litigation addressing institutional conditions, *Wyatt v. Stickney* (1972), culminated in Judge Frank Johnson's ruling that the State of Alabama must improve standards of institutional operations at Partlow State School. The judge's ruling was based on the precedent-setting concept of moving residents to the "least restrictive environment"; however, this concept initially included possible placement in the Partlow institution itself. In later litigation, such as *Horacek v. Exxon* (Nebraska, 1973) and *Halderman v. Pennhurst* (Pennsylvania, 1978), judges ruled that states must improve institutional conditions and move residents to community alternatives.

Census Trends in Institutions

The nation's I/DD institutional population, excluding those with I/DD in state psychiatric hospitals peaked at 194,650 in 1967 (U.S. Department of Health Education and Welfare, 1972). The census declined steadily at 3-5% per year through 2006. The average daily institutional population in the United States was 38,299 in fiscal year 2006. During the 10-year period 1997-2006, the institutional population in Illinois declined by an average three percent per year, somewhat less than the national average rate of decline of four percent.

In terms of institutional utilization (placements based on the state general population), Illinois' rate of institutionalization at 58 per 100,000 in 1977 started below that of the five comparison states in the aggregate (61 per 100,000) and the U.S. (69 per 100,000) (***Figure 1***). The Illinois institutional utilization rate began to surpass the comparison states' utilization in 1980 and the U.S. in 1988. By 2006 Illinois' utilization of institutions exceeded all comparison states and the U.S. In 2006, the Illinois rate was 21 per 100,000; the U.S. rate was 13 per 100,000; and the comparison states' rate was 7 per 100,000. To put this in perspective, in 2006 the institutional utilization rate in Illinois was 10 times greater than Michigan and Minnesota, four times greater than Indiana, double Wisconsin's utilization rate, and 1.5 times the rate in Ohio. The comparison states now have substantially less reliance on institutions compared to Illinois.

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



*Comparison states include Indiana, 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).

For example, in 2006 Minnesota operated only one I/DD unit for nine individuals at the Cambridge Mental Health Center; Michigan provided services to 127 individuals with I/DD at one state-operated facility, Mt. Pleasant; and Indiana's last state-operated I/DD institution, Fort Wayne State Developmental Center, closed April 18, 2007 (Bisbecos, 2007).[1] Wisconsin closed Northern Wisconsin Center in 2005, retaining two state-operated institutions, Central and Southern. Ohio closed Springview in 2004 and Apple Creek in 2005. In 2006, there were 10 state-operated facilities in Ohio in 2006, and one fewer in Illinois which had nine facilities. However, the average size of Ohio's facilities was well below the average for Illinois (166 v. 301 persons per facility).

[1] The remaining census of institutionalized persons with I/DD in Indiana consists of persons in units at the Madison, Logansport, Evansville, and Richmond Mental Health Centers. Between 20 and 45 persons are living in each of these units.

Institutions in Illinois

As previously noted, the first Illinois state-operated facility for persons with I/DD was opened in 1865 in Jacksonville, 25 miles west of the capital city of Springfield. The eighth I/DD institution in the United States, it was called the Illinois Asylum for Feeble-minded Children (Fernald, 1917). Due to overcrowding, the facility was re-established in 1877 in the town of Lincoln, and re-named the Lincoln State School and Colony. The second I/DD institution in Illinois, the "Dixon State Colony for improvable epileptics who are not insane" was opened in May 1918 (State of Illinois, 1948). The Dixon and Lincoln censuses increased to a peak of 10,240 persons in 1956 (Hemp & Braddock, 1986). The facilities were managed by the Illinois Department of Public Welfare from 1917 until the Department of Mental Health (DMH) was created in 1961. The DMH constructed three facilities during 1961-66: the Illinois State Pediatric Institute in Chicago in 1961; Murray Center in Centralia in 1964; and Bowen Center in Harrisburg in 1966.

The Veteran's Administration Hospital in Dwight was converted to the Fox Developmental Center in 1965 and the Kankakee and Jacksonville State Hospitals became developmental centers in 1974 and 1975, respectively. Beginning in the early 1970s, I/DD units were established at state mental health facilities in Alton, Anna, Elgin, Galesburg, and at the Meyer Mental Health Center in Decatur and the Singer Mental Health Center in Rockford. Responding in part to a report detailing the need for "construction of a series of small, modern state residential facilities in Northeast Illinois" (Illinois Association for the Mentally Retarded,

TABLE 1
AVERAGE DAILY CENSUS OF ILLINOIS DEVELOPMENTAL CENTERS AND MH CENTER UNITS

Facility/Unit	Location	Year Facility Opened	Year Closed	FY 2006 Average Daily Census
Adler MH/DD	Champaign	1967	1982	
Alton MH/DD	Alton	1916	1995	
Anna/Choate MH/DD	Anna	1875		166
Bowen	Harrisburg	1966	1982	
Dixon	Dixon	1918	1987	
Elgin MH/DD	Elgin	1971	1988	
Fox	Dwight	1965		153
Galesburg MH/DD	Galesburg	1950	1985	
Howe	Tinley Park	1973		409
Illinois Pediatric	Chicago	1961	1974	
Jacksonville	Jacksonville	1975		259
Kiley	Waukegan	1975		254
Lincoln	Lincoln	1877	2004	
Ludeman	Park Forest	1972		414
Mabley	Dixon	1987		99
Meyer MH/DD	Decatur		1991	
Murray	Centralia	1964		339
Shapiro	Kankakee	1974		616
Singer MH/DD	Rockford	1966	2003	
TOTAL AVERAGE DAILY CENSUS				**2,709**

Sources: Braddock et al., 2008; Hemp and Braddock, 1986.

1967), the Department of Mental Health constructed three 400-bed institutions in the Chicago suburbs. The Ludeman Developmental Center in Park Forest opened in 1972, Howe Developmental Center in Tinley Park opened in 1973, and the Waukegan (subsequently Ann Kiley) Developmental Center opened in 1975.

In 1974, a Division of Developmental Disabilities was established within the Department of Mental Health. At that time there were 7,208 residents with I/DD in state-operated facilities (Hemp & Braddock, 1986). In 2006, eight state-operated developmental centers and the MH/DD unit at Anna/Choate Mental Health Center served an average daily census of 2,709 persons with I/DD (***Table 1***).

Closures of State Institutions

Since 1970, 40 states have closed or are scheduled to close 140 state-operated I/DD institutions (Braddock et al., 2008). Ten states and DC have no state-operated I/DD institutional services at this time: Alaska, Hawaii, Indiana, Maine, Minnesota, New Hampshire,

TABLE 2
COMPLETED AND IN-PROGRESS CLOSURES OF 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	Undetermined
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

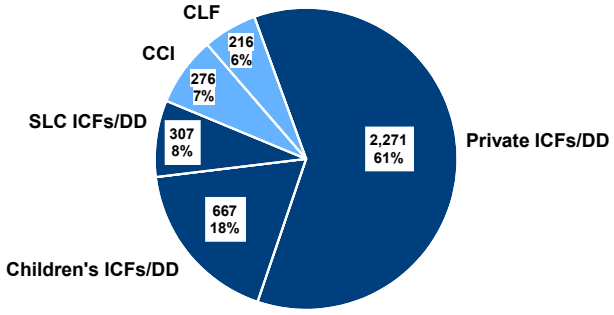
Source: Braddock et al., 2008.

New Mexico, Rhode Island, Vermont, and West Virginia. ***Table 2*** summarizes information on the nation's 26 institutions that have closed since 2000, or are scheduled to close. Indiana closed Muscatatuck in 2005 and Fort Wayne in 2007, and became the first state with a comparatively large general population to close all I/DD institutions. Michigan closed Southgate in 2002, Minnesota closed Fergus Falls in 2000, and Ohio closed Springview in 2004 and Apple Creek in 2005 (Ohio DMR/DD, 2003; State of Ohio, 2003).

Privately Operated Institutions in Illinois

Institutional settings in Illinois also include private facilities serving 3,737 persons in settings for 16 or more persons (***Figure 2***). In 2006, there was an average daily census of 3,245 persons with I/DD in Medicaid-funded Intermediate Care Facilities for the Developmentally Disabled (ICFs/DD)[2] including 667 persons in facilities formerly licensed as Skilled Pediatrics Facilities (children's ICFs/DD in the figure) and 307 persons in Specialized Living Centers (SLC) that were 50 to 100-person facilities constructed by the state in 1974 and privately leased and operated. An additional 276 persons and 216 persons, respectively, resided in non-ICF/DD-certified Child Care Institutions (CCI) and Community Living Facilities (CLF).

FIGURE 2
PRIVATE 16+ INSTITUTIONS: INDIVIDUALS BY SETTING IN ILLINOIS IN 2006



3,737 Individuals Served

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

Nursing Facilities in Illinois

Congress enacted the Nursing Home Reform Act of 1987 (Pub. L. 100-203) in response to the fact that most individuals with I/DD living in nursing facilities had been placed there inappropriately. The Act required that states a) assure that individuals with

[2] ICFs/DD are still referred to as ICFs/MR nationally and in most states.

I/DD be admitted to a nursing facility only if the individuals are in need of services made available in the particular facility; b) assess all nursing home residents to determine any need for "active treatment"; c) provide treatment in the nursing facility or obtain a more appropriate community placement for those assessed to be in need of active treatment; and, d) assure that individuals with I/DD residing in nursing facilities for more than 30 months be given the option of moving or staying. Studies have shown that 75-90% of individuals with I/DD living in nursing facilities were appropriate candidates for alternative community living arrangements (Davis, Silverstein, Uehara, & Sadden, 1987; Lakin, Hill & Anderson, 1988, 1991; Mitchell & Braddock, 1990). As a result of states' efforts in response to Pub. L. 100-203, the number of persons 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).

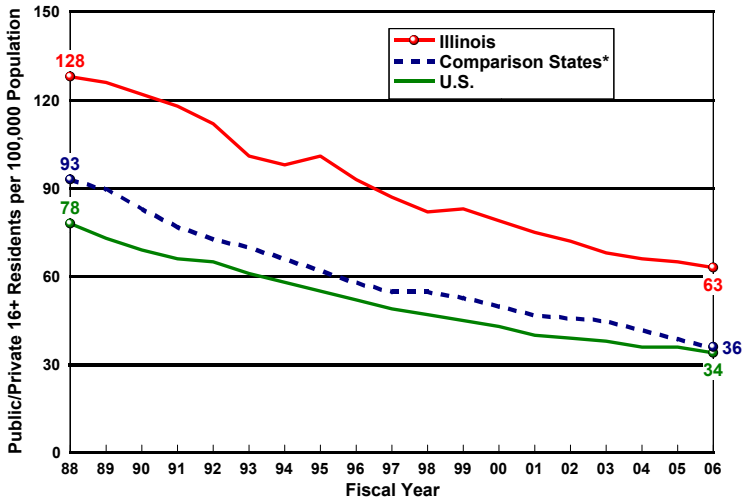
Class action litigation in Illinois, *Bogard v. Duffy*, was filed in 1988 to address the needs of 3,355 individuals with I/DD in nursing facilities at that time (Braddock, Hemp, Fujiura, Bachelder, & Mitchell, 1990). There was a consent decree in 1993, and the case was dismissed in 1998; more than 1,000 persons with I/DD had been relocated from nursing facilities to community settings. In addition to the litigation in Illinois, a case in Michigan (*Kope v. Watkins*, 1993) also had a substantial impact on the state's efforts to find community-based alternatives for individuals with I/DD in nursing facilities.

In 2006, there were 1,535 individuals with I/DD in nursing facilities in Illinois. Illinois' nursing facility utilization rate (12.1 per 100,000 of the general population) was comparable to the U.S. average of 11.4, and well below the rates in Indiana (27.1) and Ohio (20.3). Rates in Wisconsin (8.8), Michigan (8.5) and Minnesota (7.4), however, are lower than the utilization rate in Illinois. In the early 1990s, an Illinois community residential option, "Supporting People in Integrated Community Environments" (SPICE), played an important role in reducing reliance on nursing facilities, and contributed to Illinois' success in its 1993 application for federal Community Supported Living Arrangement (CSLA) funding. The CSLA (Pub. L. 101-508) was a 5-year Medicaid demonstration project promoting community and family-based services (Braddock, Hemp, Bachelder, & Fujiura, 1995). Comparison states Michigan and Wisconsin also received CSLA funding.

Summary: Utilization of Institutions in Illinois

Illinois' utilization of institutions, consisting of state institutions and private facilities for 16 or more persons including nursing facilities, is illustrated in ***Figure 3***. Illinois' utilization rate was 63 per 100,000 of the general population. It was nearly double the U.S. average (34 per 100,000) and that of the five Midwest comparison states in the aggregate (36 per 100,000). Illinois' utilization rate of 63 per 100,000 was also greater than each comparison state: Ohio (59), Indiana (37), Wisconsin (36), Minnesota (19) and Michigan (17). ***Illinois ranked 6th nationally in public/private institutional utilization in 2006; only Arkansas, Iowa, Louisiana, Mississippi and Oklahoma had higher utilization rates.*** Illinois public/private institutional utilization rate exceeded the U.S. trend and all five comparison states during 1988-2006.

FIGURE 3
PUBLIC AND PRIVATE 16+ INSTITUTIONAL UTILIZATION IN ILLINOIS, THE U.S. AND THE COMPARISON STATES



*Comparison states aggregated are Indiana, Michigan, Minnesota, Ohio and Wisconsin.

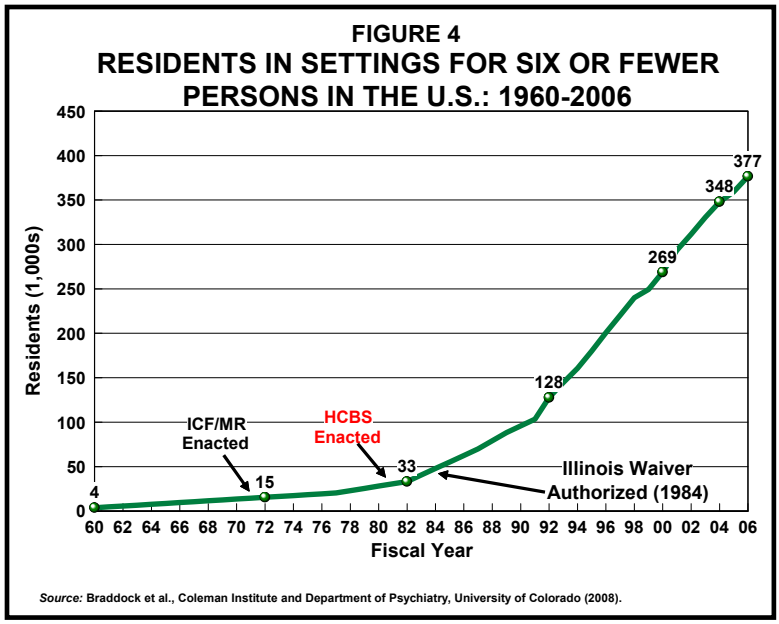
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado (2008).

Not only does Illinois support 2,709 persons with I/DD in state-operated institutions—there are also 3,737 persons in approximately 65 privately operated institutions throughout the state. Some of these private institutions house more than 250 people. In 2006 the utilization rate in Illinois for private 16+ institutions, not including nursing facilities, was 29 per 100,000. ***This rate was nearly three times the national average and Illinois ranked third nationally. Only Iowa and Oklahoma had higher rates of placement than Illinois of persons with I/DD in private 16+ institutions.***

III. GROWTH OF COMMUNITY RESIDENTIAL SERVICES

The United States

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 of ICF/MR funding to settings for 15 or fewer persons in 1974, many states including Illinois began to greatly expand community-based ICFs/MR.[3] Since 1981, the Medicaid Home and Community Based Services (HCBS) Waiver Program has emerged as the principal funding source for the development of smaller, more individualized community settings including supported living.



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.*** These community residences include group homes, ICFs/MR for six or fewer persons, supervised apartments, host homes, foster homes, and supported living settings. The number of individuals served nationally grew from about 4,000 persons in 1960 to 376,567 in 2006.

Residential and Community Services in Illinois

The first "community" residential services in Illinois consisted of Community Living Facilities (CLFs) for twenty persons, and Child Care Institutions (CCIs, also termed "Residential Schools") operated by community-based organizations for special education

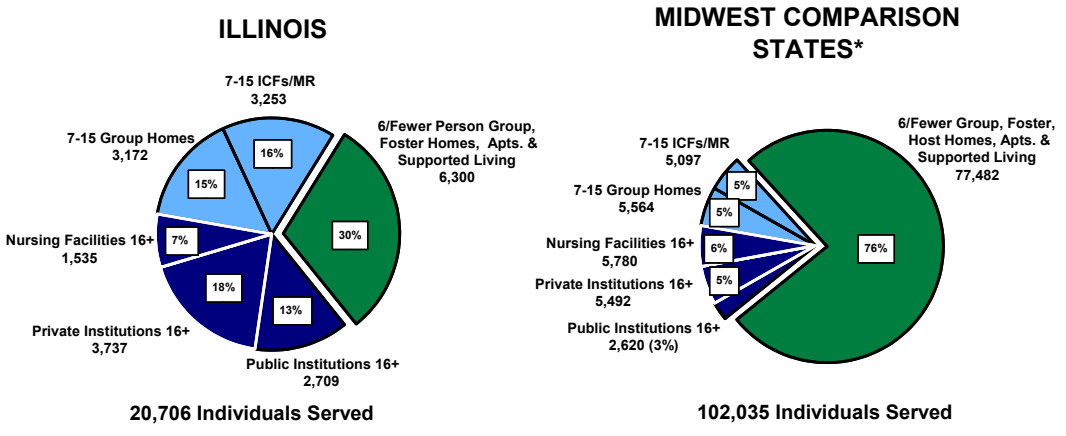
[3] It should be noted that during 1988-92 many private 15-person ICFs/DD in Illinois, per the state's agreement with the federal Health Care Financing Administration, were recertified for 16 beds (Braddock et al., 1995).

students. Funding in Illinois for private ICFs/DD serving seventeen or more persons was instituted in 1978, and ICFs/DD for sixteen or fewer persons received initial funding in 1981. In 2006, the predominant type of community residence for fifteen or fewer persons in Illinois was the Community Integrated Living Arrangement (CILA) program.

In 2006, the proportion of persons served in six or fewer settings in Illinois, 30%, ranked last among the 50 states and the District of Columbia. All five comparison states served proportionately more individuals in settings for six persons or fewer persons than did Illinois. Minnesota utilized settings for six or fewer persons for 90% of all persons with I/DD residing in out-of-home settings. The six person or fewer proportions in the other comparison states were: Michigan (82%), Wisconsin (74%), and Ohio and Indiana (69%). The U.S. average was 70%.

Combining residential services data in 2006 for the five Midwest comparison states indicates that 76% of persons with I/DD in out-of-home settings in the five states aggregated are in group homes, foster homes, host homes, apartments or supported living. This is in contrast to 30% in Illinois (***Figure 5***). Illinois' public and private institutions housed 38% of the State's out-of-home placements, versus 14% in the comparison states. The proportion in 7-15 person settings in Illinois, 31%, was more than three times the 7-15 person share in the five comparison states (10%).

FIGURE 5
OUT-OF-HOME RESIDENTS IN ILLINOIS AND THE COMPARISON STATES, BY SETTING: 2006



*The aggregated comparison states are Indiana, Michigan, Minnesota, Ohio and Wisconsin.

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

During 2004-06, the number of individuals served in smaller settings for six or fewer persons in Illinois grew by six percent. However, as a proportion of total out-of-home residential placements, persons in six person or fewer settings increased by only one percentage point, from 29% to 30%. The census of persons with I/DD in 7-15 person settings in Illinois increased nine percent during 2004-06. ***In 2006, Illinois dedicated 14% of total I/DD resources to 7-15 person settings. The state ranked fifth nationally in the proportion of out-of-home residents living in 7-15 person settings.***

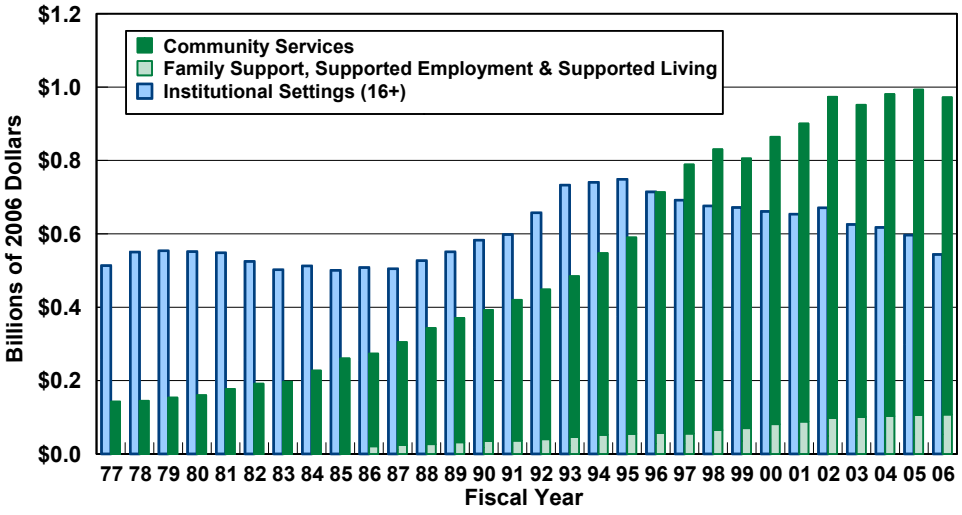
In 2006, persons in Community Integrated Living Arrangements (CILA) and in group homes constituted 62% of all persons served in settings for six person or fewer persons in Illinois. Six-person or fewer settings also included supported living (35% of the total), and ICFs/DD (3%) in 2006. In the U.S., 18% of all individuals with I/DD living in out-of-home settings lived with only one or two other persons. ***In Illinois, approximately one percent of persons with I/DD resided in out-of-home settings for three or fewer persons*** (Prouty, Smith, & Lakin, 2007).

Financing Residential and Community Services in Illinois

Spending for community services in 15/less settings in Illinois first surpassed institutional (16+) spending in 1997. Adjusted institutional spending peaked in 1995 and declined each year from 1995 to 2001. Institutional spending then increased slightly in 2002 before continuing to decline through 2006. In 2006, 64% of total I/DD resources of $1.52 billion in Illinois was allocated for community services, family support, supported employment and supported living; 36% of spending was allocated for state institutions, private ICFs/DD, and other 16+ person settings.

There have been four distinct periods of I/DD spending growth in Illinois during the past 30 years (***Figure 6***). First, during fiscal years 1977-87, inflation-adjusted public and private institutional spending (excluding nursing facility spending) was essentially flat, community services spending expanded modestly, and total I/DD spending increased 23%. In the second period, 1988-95, there was sustained growth in both the institutional and community sectors, and total adjusted spending grew 54% from $880 million to $1.33 billion. In the third period, 1996-2002, total adjusted spending advanced by only 15%, pub-

FIGURE 6
INFLATION-ADJUSTED TRENDS IN I/DD SPENDING IN ILLINOIS: 1977-2006



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

lic/private institutional spending declined, and community spending advanced significantly, but at a somewhat slower rate than during the previous period, 1988-95. In 2003-06, community spending grew only two percent and institutional spending dropped 13%. This reflected modest census reductions in all categories of 16+ settings including state institutions, private ICFs/DD, community living facilities, and child care institutions. ***Combined institutional and community services spending declined by four percent in inflation-adjusted terms during 2003-06.***

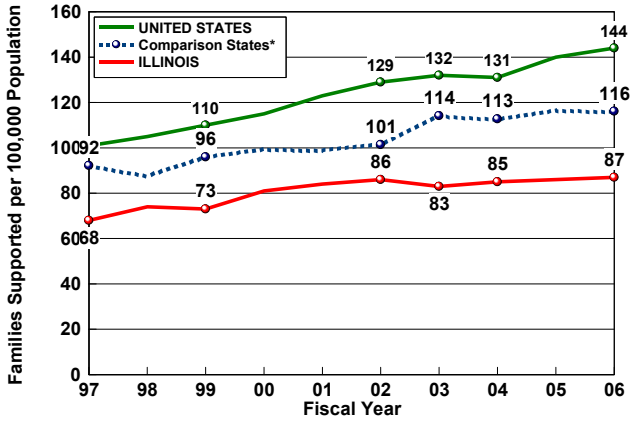
Family Support, Supported Employment and Supported Living

Service priorities in the states are focusing on increasing personal development, autonomy and self-determination, fostering social relationships and community participation, and increasing the inclusion of individuals with developmental disabilities in all aspects of community life (e.g., Breihan, 2007; Caldwell & Heller, 2007; Nerney, 2005; Smith, Agosta, & Fortune, 2007). In this section we will discuss initiatives in family support, supported employment and supported living.

Family Support. Family support in Illinois consisted of the family assistance program, home based services, respite care, and cash subsidies and vouchers for children and

adults living in the family home. The number of individuals with I/DD in Illinois supported in the family home advanced four percent during 2004-06, from 10,720 families in 2004 to 11,114 families in 2006. In the nation as a whole, however, individuals supported in the family home increased 11% during 2004-06. In 2006, Illinois family support utilization of 87 families per 100,000 of the state general population was well below the U.S. average (144 families) and the comparison states in the aggregate (116 families) (***Figure 7***). The number of Illinois families supported on a per capita basis has been essentially flat since 2002. In 2006, Illinois families supported per 100,000 of the state population was lower than all comparison states except Indiana. Illinois ranked 35th among all the states in family support utilization.

FIGURE 7
FAMILY SUPPORT UTILIZATION IN ILLINOIS, THE COMPARISON STATES AND THE U.S.: 1997-2006



*The aggregated comparison states are Indiana, Michigan, Minnesota, Ohio and Wisconsin.

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

In 2006, the 24 states that offered state-funded (as opposed to HCBS Waiver-funded) cash subsidy and voucher programs included Illinois and the comparison states Michigan and Minnesota. Families receiving cash subsidies and vouchers in Illinois advanced from 204 families in the subsidy's first year, 1991, to 2,611 families in 2006. On a per capita utilization basis, Illinois ranked above average among the 24 states with cash subsidy programs with a rate of 21 per 100,000 vs. 14 for the U.S. The number of cash subsidy families per capita in Illinois, like families supported overall, plateaued during 2002-06.

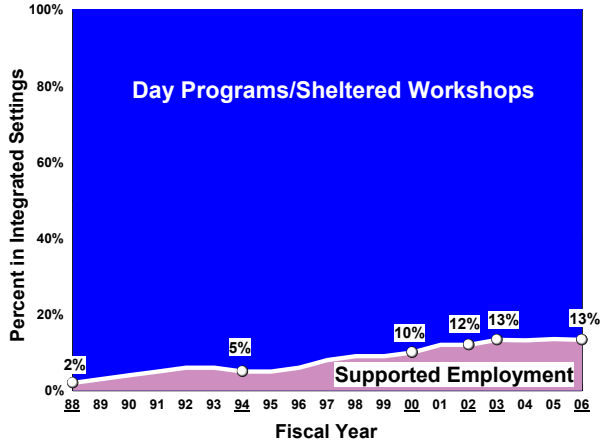
Total inflation-adjusted family support spending in Illinois, including cash subsidy payments, advanced nine percent during 2004-06. This equaled the 2004-06 percentage growth in the U.S. On a per capita basis, family support spending in two of the five comparison states was higher than in Illinois. Illinois expended $4.91 per capita and ranked

29th in this regard. Minnesota, Michigan, Indiana, Wisconsin and Ohio ranked 2nd, 26th, 30th, 31st, 44th, expending $35.15, $5.28, $4.44, $4.17, and $0.91, respectively, on a per capita basis for family support services. The national average family support spending per capita was $7.76. Family support has been a consistent priority in Michigan and an emerging priority in recent years in Illinois, Indiana, Minnesota, and Wisconsin (Rizzolo, Hemp, & Braddock, 2006). There continue to be long waiting lists for family support services in Illinois and the comparison states.

Supported Employment. During 2004-06, supported employment workers with I/DD in Illinois increased marginally, from 3,461 to 3,518. Workers supported on a per capita basis in Illinois ranked 34th among all states (28 per 100,000 vs. 38 U.S.) and the utilization rates in all comparison states surpassed Illinois. Rates ranged from 44 in Michigan to 83 in Ohio. In fact, supported employment spending in Illinois decreased four percent in inflation-adjusted terms from 2004-06. In 2006, Illinois' supported employment spending per capita of the general population of $1.55. This was well below the U.S. average of $2.39 and below each comparison state: Indiana ($2.09), Michigan ($2.45), Minnesota ($2.53), Ohio ($2.86), and Wisconsin ($2.95). The Balanced Budget Act of 1997 afforded the states an opportunity to greatly expand HCBS Waiver funding for supported employment (West, Revell, Kregel, & Bricout, 1999). Illinois began to utilize Waiver funding for supported employment programs in 2001, and in 2006 federal-state Waiver spending in Illinois constituted 19% of total supported employment spending.

In 2006, supported/competitive employment workers in the U.S. constituted 22% of all sheltered workshops, work activity centers, day training, day habilitation program and supported/competitive employment participants. Supported employment workers in Illinois constituted 13% of the day/work participant total in 2006 (***Fig-***

Figure 8
PERCENTAGE OF TOTAL DAY/WORK RECIPIENTS IN SUPPORTED EMPLOYMENT IN ILLINOIS: 1988-2006



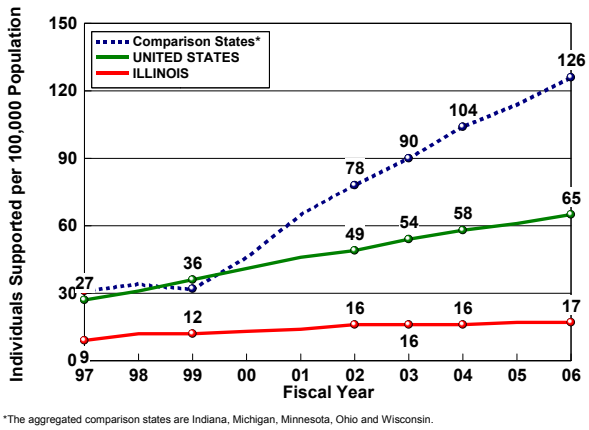
Source: Braddock et al., Coleman Institute and Deparment of Psychiatry, University of Colorado (2008).

ure 8). (In contrast 87% were in developmental training, work activity and sheltered workshop settings). The supported employment proportion did not grow during 2003-06 ***Illinois was below all comparison states in the percentage of workers in supported/competitive employment. Indiana's rate was 28%, Michigan, 24%, Ohio, 22%, Wisconsin, 16%, and Minnesota, 15%.***

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 adapts to individuals' changing needs over time. In 2006, 49 states and DC financed initiatives in supported living and/or personal assistance that were consistent with the stated criteria. Supported living spending totaled $4.90 billion nationally in 2006, for 192,483 participants (Braddock et al., 2008).

In Illinois, supported living spending totaled $24.5 million for 2,182 participants in 2006. On a per capita basis, Illinois' performance was quite similar to family support in the State. Illinois supported living participants per capita was well below the national utilization rate and did not grow appreciably during 2002-06 (***Figure 9***). In 2006, the Illinois supported living participants per capita ranked 42nd among all states and was substantially below the comparison states' rates that averaged 126 and that ranged from 89 in Minnesota to 151 in Indiana. Illinois' utilization was only 25% the U.S. average.

FIGURE 9
SUPPORTED LIVING UTILIZATION IN ILLINOIS, THE COMPARISON STATES, AND THE U.S.: 1997-2006



*The aggregated comparison states are Indiana, Michigan, Minnesota, Ohio and Wisconsin.

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

In 2006, supported living spending on a per capita basis of the general population in Illinois was $2.00. This was substantially below Indiana ($61.08), Ohio ($58.05), Michigan ($24.85), Minnesota ($18.99), Wisconsin ($17.42), and the U.S. as a whole ($16.52). Illinois' supported living spending was essentially flat in real terms during 2004-

06 (0.1% growth). In 2006, the HCBS Waiver financed 62% of supported living spending in Illinois.

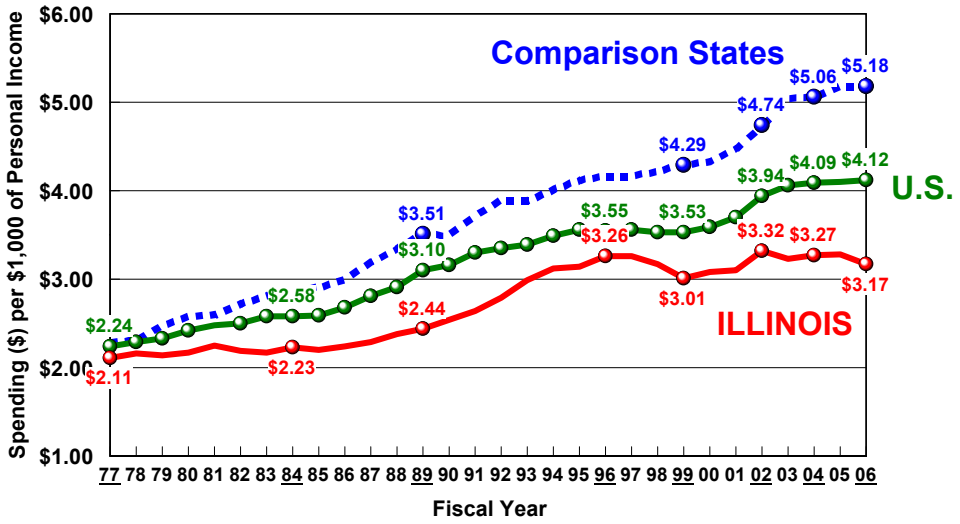
Summary: Family Support, Supported Employment and Supported Living. During 2004-06, family support spending in Illinois increased by nine percent. However; the state committed no additional funding to supported living and reduced funding for supported employment. Altogether, in 2006, aggregate spending of $107.6 million for family support, supported employment, and supported living constituted seven percent of total I/DD spending of $1.52 billion in Illinois. In the U.S., family support, supported employment and supported living spending constituted 18% of total I/DD spending of $43.8 billion, more than double the Illinois level. In 2006, consolidated family support, supported employment, and supported living spending as a portion of total I/DD spending in the comparison states was between approximately seven and two times higher than Illinois spending for such supports.

The HCBS Waiver has become the principal financial source for family support, supported employment, and supported living spending in Illinois and in the U.S. In 2006, federal-state Waiver spending in the U.S. constituted 70% of family support spending, 54% of supported employment spending and 86% of spending for supported living. In Illinois, HCBS Waiver funding constituted 43% of family support spending, only 19% of supported employment spending, and 62% of supported living spending. The Waiver share of family support, supported employment and supported living resources in Illinois was substantially below the proportion financed by the Waiver in the nation as a whole.

Fiscal Effort in Illinois, the U.S. and the Comparison States

"Fiscal effort" is a ratio utilized to compare states according to the proportion of their total statewide personal income devoted to I/DD services (Braddock & Fujiura, 1991). Combined fiscal effort in Illinois for institutional and community services grew substantially between 1984-96, a 46% increase from $2.23 to $3.26. However, Illinois' total fiscal effort declined between 1996-2006, from $3.26 to $3.17. Illinois has diverged from the U.S. fiscal effort trend, with a growing gap evident during 2002-06 (***Figure 10***). During 2004-06 Illinois total fiscal effort declined three percent. In 2006, Illinois ranked

FIGURE 10
TOTAL I/DD FISCAL EFFORT IN ILLINOIS, THE U.S. AND THE COMPARISON STATES*



*Comparison states are Indiana, Michigan, Minnesota, Ohio and Wisconsin.

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

40th in total fiscal effort nationally, a one position change in ranking from 41st in 2004. The comparison states' total fiscal effort rankings in 2006 were: Minnesota (6th), Ohio (9th), Wisconsin (17th), Indiana (24th), and Michigan (36th). Fiscal effort in Illinois in 2006, $3.17 per $1,000 of aggregate statewide personal income, was 23% below the U.S. fiscal effort level of $4.12. Moreover, Illinois' fiscal effort was 39% below the comparison states' average of $5.18.

Community services fiscal effort in Illinois advanced one percent from 2004 to 2006, from $2.01 to $2.04. In 2006, Illinois community fiscal effort was 39% below the U.S. community fiscal effort level of $3.35. Illinois ranked 43rd in community fiscal effort in 2006. There was no change from its ranking in 2004. Comparison state community fiscal effort rankings in 2006 were: Minnesota (4th), Ohio (10th), Wisconsin (12th), Indiana (22nd), Michigan (28th). ***All comparison states were well above Illinois' ranking of 43rd.***

IV. FINANCING I/DD SERVICES WITH MEDICAID

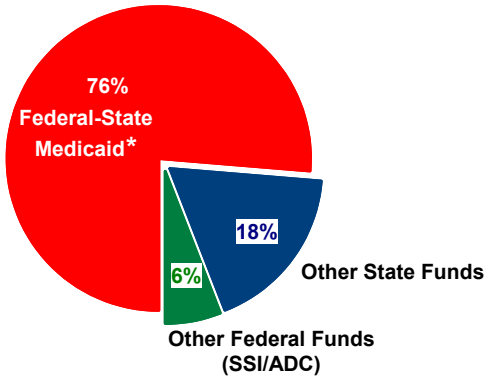
Twenty-five years ago, institutional spending dominated the states' I/DD service systems. Since the mid-1970s, institutional spending was heavily underwritten by Interme-

diate Care Facility for People with Mental Retardation (ICF/MR) reimbursement. The ICF/MR program (Pub. L. 92-223), enacted in 1971, was designed to provide substantial financial assistance to the states to improve conditions in large institutional facilities. By 1984, federal ICF/MR reimbursement made up 45% of the nation's $4.3 billion in state institution spending (Braddock, Hemp, & Howes, 1984). In the 1970s, community funding derived almost exclusively from state or local government appropriations. The notable exception was federal social services funding under Title XX of the Social Security Act. In 1977, federal Title XX revenues comprised 50% or more of total community spending in 12 states, and 18% of community spending in the U.S. That same year, Title XX constituted from 47% to 13% of community spending in Indiana, Minnesota, Illinois and Wisconsin, respectively, and 0% in Michigan and Ohio (Braddock et al., 1995). Beginning in the 1980s, private ICF/MR reimbursement for community settings serving 15 or fewer persons grew steadily in Illinois and in 41 other states.

Today, Medicaid financing provides the vast majority of I/DD long-term care funding. Nationwide federal and state Medicaid funding in 2006 constituted 78% of total spending of $43.8 billion for I/DD long-term care. 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. Related optional community Medicaid services include personal care, targeted case management, and rehabilitative and clinic services.

In 2006, federal and state Medicaid spending was $1.16 billion in Illinois. This constituted 76% of total spending of $1.52 billion (***Figure 11***). "Other Federal Funds" in the figure consisted of

FIGURE 11
MEDICAID IS 76% OF ILLINOIS TOTAL I/DD SPENDING IN 2006



Total ID/DD Spending: $1.52 Billion

*Total Federal-State Medicaid: $1.16 billion
a) HCBS Waiver/Developmental Trng. (42%)
b) Public & Private ICFs/MR (58%)

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

Waiver participants' federal Social Security benefits. The components of federal-state Medicaid spending in Illinois consisted of the HCBS Waiver (35%), Medicaid rehabilitative services funds for developmental training programs (7%), state-operated institutional ICFs/DD (31%), private ICFs/DD for 17 or more persons (14%), and ICFs/DD for 16 or fewer persons (13%).

The Home and Community Based Services (HCBS) Waiver

In 1981, the Federal government was concerned about rising 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 (Braddock, 1981, 1987; Braddock & Fujiura, 1987; Taylor, Brown, McCord, Giambetti, Searl, Mlinarcik, Atkinson, & Lichter, 1981). The HCBS Waiver program providing federal reimbursement for a wide array of community services and supports was authorized in Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (Pub. L. 97-35),.

The services that are reimbursed under the Waiver include 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. As a result of Medicaid amendments in the Balanced Budget Act of 1997 (Pub. L. 105-53), Waiver participants are also eligible for Waiver-financed supported employment services. Nationwide, in 2006, there were 489,394 Waiver participants, far exceeding 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. In Illinois, there were 12,300 Waiver participants and 9,400 ICF/DD residents in 2006.

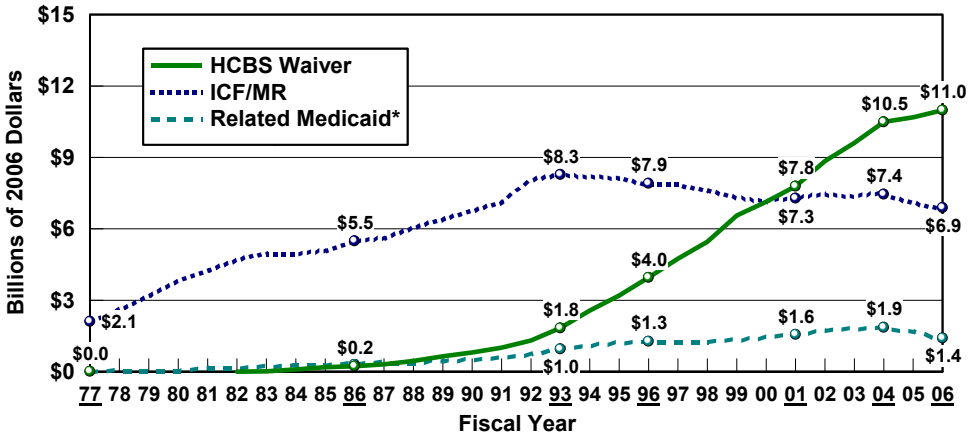
An important collateral benefit of the HCBS Waiver to state governments, it should be noted, is the $603 per month in federal income maintenance benefits which Waiver participants received in 2006 in the form of Supplemental Security Income (SSI) payments or other social security benefits (i.e., Adults 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 only $30-$60 per month in personal allowance from SSI/ADC. Waiver participants' SSI/ADC funds totaled $3.5 billion nationwide in 2006, in addition to the $19.6 billion in federal/state Medicaid Waiver funding. In Illinois, $89.0 million in federal SSI/ADC funding was generated for the State's Waiver participants in 2006.

Federal Medicaid spending for the HCBS Waiver in the U.S. surpassed ICF/MR spending in 2001 (***Figure 12***). After the peak of $8.3 billion (adjusted to 2006 dollars) in 1993, federal ICF/MR spending in the U.S. declined 17% to $6.9 billion in 2006. During 1993-2006 adjusted federal Medicaid spending for the HCBS Waiver grew 17% per year. In 2006, federal Waiver spending in the U.S. was 59% more than federal ICF/MR spending. Also shown in the figure is federal spending for "related" Medicaid, consisting of states' use of optional Medicaid State Plan services. These include personal assistance, clinic services, rehabilitative services (used to fund Illinois' developmental training programs), targeted case management, and administration of community-based programs.

FIGURE 12

FEDERAL I/DD MEDICAID REVENUE: U.S.



*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).

HCBS Waiver Services in Illinois

Illinois established its Waiver program in 1984, and in 2006 financed services for 12,300 Waiver participants. There are three HCBS Waivers for persons with developmen-

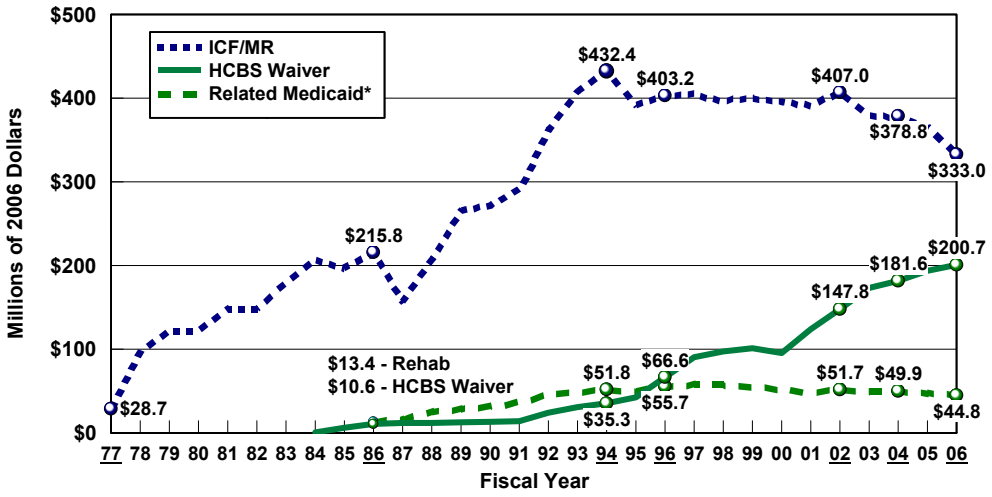
tal disabilities in Illinois. The Adult Developmental Disabilities Waiver, first approved December 1, 1983, was renewed for the period July 2007 through June 2012, with a capacity of 13,600 participants. The Supports Waiver for Children was approved July 1, 2007, with a capacity of 600, and the Residential Waiver for Children, also approved July 1, 2007, had a capacity of 175.

The Adult DD Waiver services consist of residential habilitation including 24-hour, host family, and intermittent CILA and CLF for 16 or fewer persons. It also includes day habilitation and developmental training (DT); supported employment; adult day care; and, with some limitations including monthly cost maximums, the additional services of day habilitation, service facilitation, personal support, nursing, behavior services, physical therapy, occupational therapy, speech/communication therapy, transportation, personal emergency response systems (PERS), training and counseling for unpaid caregivers, and crisis services. Adult DD Waiver services also include behavior intervention, treatment, and counseling; extended state plan services including PT, OT and speech/communication therapies; and adaptive equipment, assistive technology, home accessibility modifications, and vehicle modifications.

The Supports Waiver services for children consist of personal support, assistive technology, behavior intervention and treatment, adaptive equipment, home accessibility modifications, vehicle modifications, training and counseling services for unpaid caregivers, and service facilitation. In addition, the Residential Waiver services for children consist of residential habilitation including child group homes for ten or fewer persons, assistive technology, behavior intervention and treatment, and adaptive equipment. The Residential Waiver has a $15,000 maximum per participant per five-year period for any combination of adaptive equipment and assistive technology, and the Supports Waiver has the same limitation and also limitations on home modifications and vehicle modification (Illinois Department of Healthcare and Family Services, 2008).

In 2006, in marked contrast with the trends in most states, Illinois ICF/DD spending exceeded HCBS Waiver spending by 66% (***Figure 13***). Illinois ICF/DD spending peaked in 1994 at $432 million (adjusted to 2006 dollars). Inflation-adjusted federal ICF/DD spending in Illinois was flat during 1995-2002, then declined an adjusted 18%

FIGURE 13
FEDERAL I/DD MEDICAID REVENUE IN ILLINOIS



*In 2006, "Related Medicaid" was rehabilitative services.

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

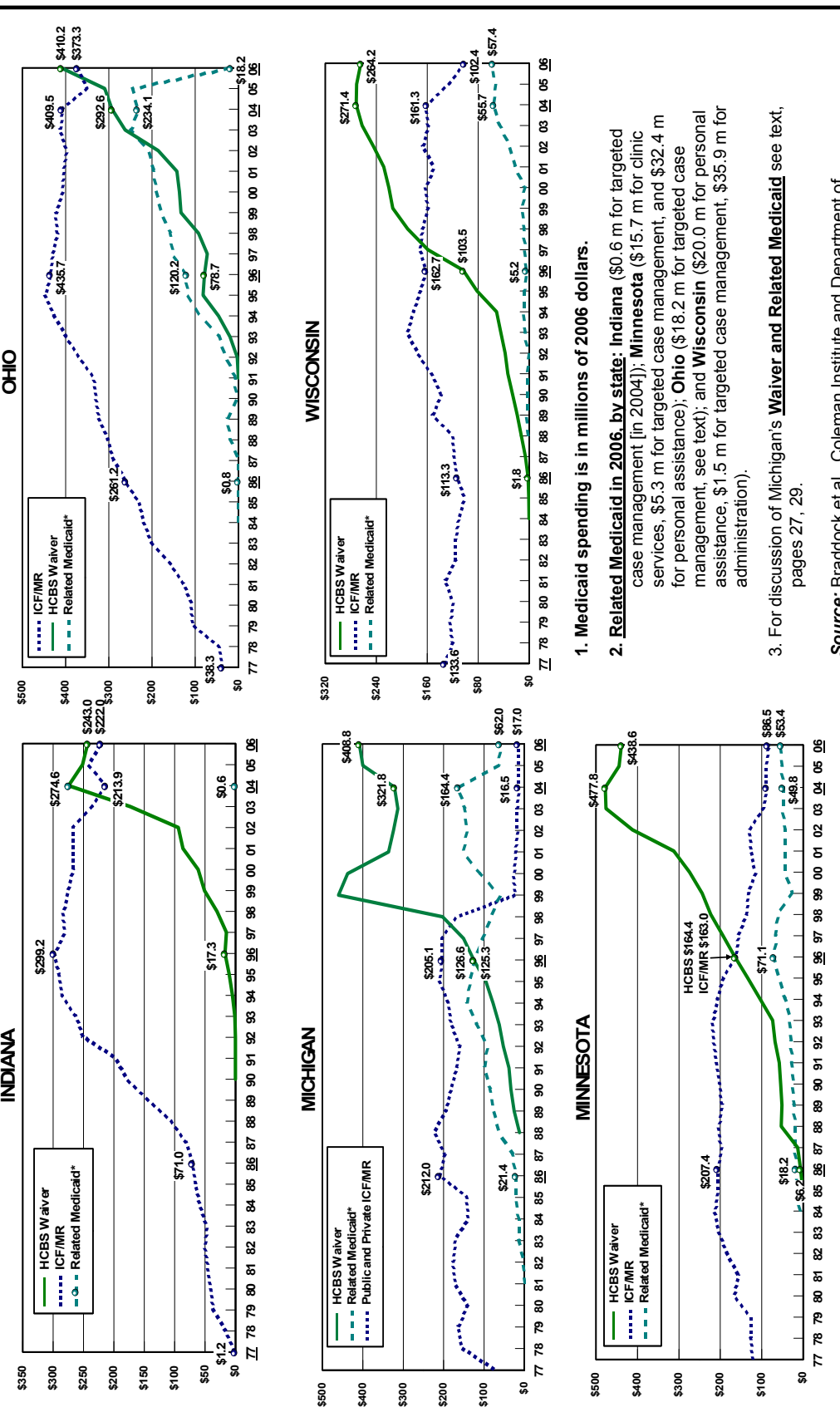
during 2002-06. During the recent period of Illinois' sustained ICF/DD spending reductions during 2002-06, adjusted HCBS Waiver spending increased 39%. Medicaid spending for rehabilitative services declined in real terms by 13% during 2002-06--from $51.7 million (adjusted) to $44.8 million.

HCBS Waiver Services in the Comparison States

Figure 14 presents ICF/MR (ICF/DD in Illinois), HCBS Waiver, and related Medicaid 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, Michigan and Wisconsin did so in 1998, Indiana in 2004, and Ohio in 2006. As noted, ICF/MR spending in the U.S. surpassed HCBS Waiver spending in 2001, but in 2006 Illinois ICF/DD spending exceeded Waiver spending by 66%. ***Besides Illinois, only seven states, Arkansas, Iowa, Mississippi, New Jersey, North Carolina, North Dakota, Texas, and the District of Columbia spend more for the ICF/MR program than for the HCBS Waiver.***

Per capita Waiver spending in Illinois was less than half the U.S. average in 2006, The five comparison states' Waiver per capita levels ranged from nearly double the Illinois

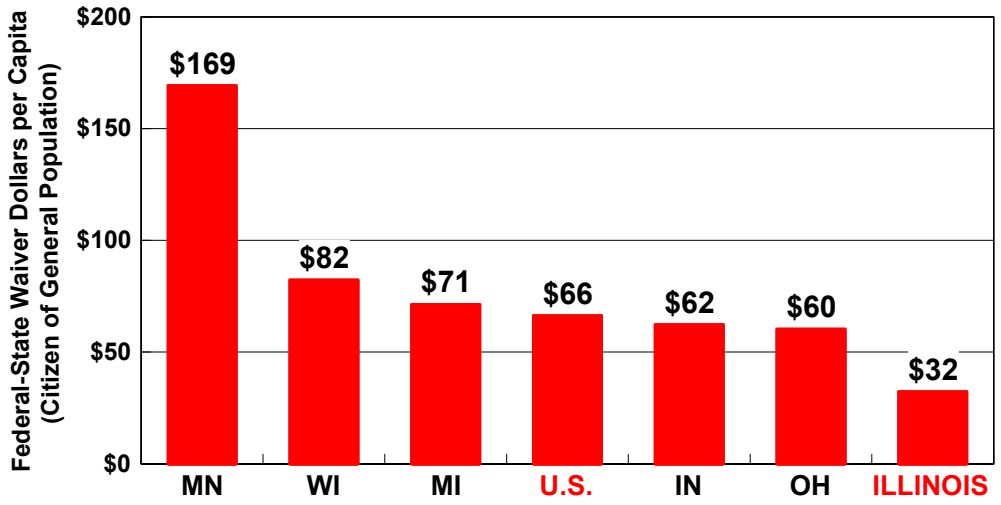
FIGURE 14
TRENDS IN FEDERAL HCBS WAIVER, ICF/MR AND RELATED MEDICAID SPENDING IN THE COMPARISON STATES: FY 1977-06



1. **Medicaid spending is in millions of 2006 dollars.**
2. **Related Medicaid in 2006, by state: Indiana** ($0.6 m for targeted case management [in 2004]); **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 27, 29.

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

FIGURE 15
FEDERAL-STATE WAIVER SPENDING PER CAPITA, 2006



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

rate in Ohio and Indiana to five times the Illinois rate in Minnesota (***Figure 15***). Waiver utilization in Minnesota provides an excellent example for Illinois. Minnesota relied heavily on federal Medicaid 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 76% of Medicaid spending for I/DD long-term care services.

In 2006, Illinois federal-state HCBS Waiver spending constituted only 35% of total I/DD Medicaid spending. The five comparison states substantially outperformed Illinois in their utilization of the HCBS Waiver. Minnesota, Wisconsin, Michigan, Indiana, and Ohio ranked 3rd, 16th, 25th, 31st, and 32nd, respectively, in federal-state Waiver spending per capita of the general population. ***Illinois ranked 47th in federal-state Waiver spending per capita. Only Texas, Nevada, Georgia, and DC were below Illinois.***

V. FINANCING COMMUNITY SERVICES IN THE COMPARISON STATES

This section addresses the community services expansion of the five comparison states, providing a perspective on directions for Illinois. Indiana, Michigan, Minnesota, Ohio, and Wisconsin are compared to Illinois along three additional dimensions: 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, family support and supported employment that the comparison states utilized in community services development (Braddock et al., 2008).

Indiana

Indiana shares much with Illinois in terms of the two states' histories of services for persons with I/DD. Lincoln in Illinois and 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 ICFs/MR serving 16 or more persons, and ICFs/MR for 15 or fewer persons. In Indiana, these were termed CRFs/DD and in Illinois, as noted, many ICFs/DD were certified for 16 persons. Indiana and Illinois were relatively late in establishing the HCBS Waiver as a significant funding source for community services; however, by 2006 Indiana's Waiver per capita was nearly double the per capita in Illinois.

Waiver expansion, the development of six person or fewer community residences and supported living, and the substantial increases in community spending have propelled Indiana past Illinois in terms of a stronger system of community services and reduced reliance on institutions. As noted, Indiana closed Fort Wayne in 2007 and joined the nine other states and DC no longer financing state-operated institutions for individuals with I/DD. Indiana first reached parity in spending between institutional and community services in 1990, seven years before Illinois did so. In 2006 Indiana committed 88% of total I/DD resources to community services, compared to 64% in Illinois (***Figure 16***).

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 state's 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 16***). "Alternative intermediate services/mentally retarded" (AIS/MR) settings were certified as private ICFs/MR for 15 or fewer persons and were the initial foundation for community services in Michigan. 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.

Contemporary I/DD resource allocation 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. 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 14***. 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.

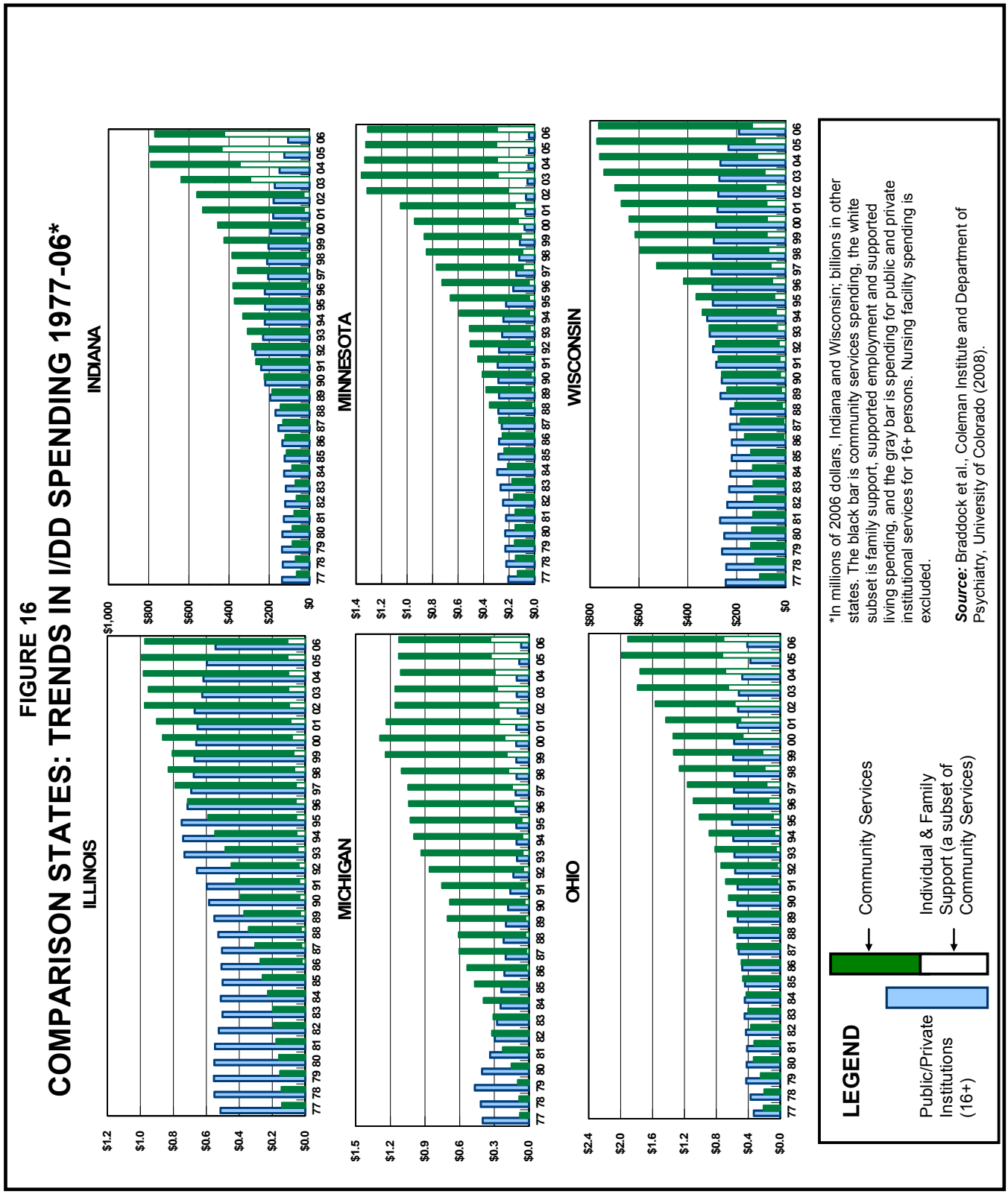


FIGURE 16
COMPARISON STATES: TRENDS IN I/DD SPENDING 1977-06*
ILLINOIS
INDIANA
MICHIGAN
MINNESOTA
OHIO
WISCONSIN
LEGEND
Community Services
Individual & Family Support (a subset of Community Services)
Public/Private Institutions (16+)
*In millions of 2006 dollars, Indiana and Wisconsin; billions in other states. The black bar is community services spending, the white subset is family support, supported employment and supported living spending, and the gray bar is spending for public and private institutional services for 16+ persons. Nursing facility spending is excluded.
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado (2008).

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. Person-centered planning amendments in Michigan's 1995 Mental Health Code became an integral part of the Medicaid managed care proposal. 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).

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 uses a prepaid health plan (PHP) contracting mechanism that enables the State's CMHSPs, when they realize cost savings, to either purchase alternative services for enrollees or provide additional services beyond those mandated in their contract. 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, Carpenter, Doty, Kennedy, Burwell, Mollica, & Williams, 2000).

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 14***). In 2006, Minnesota ranked 3rd 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 16***). 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, an I/DD unit at the Cambridge Mental Health Center that served nine individuals during fiscal year 2006.

Ohio

Ohio, like Indiana, shares much with Illinois in terms of the states' histories of institutional services for persons with I/DD, slow initial growth in HCBS Waiver services, and sustained use of private ICFs/MR as a principal component of community services. Ohio's I/DD institution in Columbus was the second such facility in the U.S., opening in 1857. In 2006, Ohio ranked 32nd in Waiver spending per capita, well above Illinois' ranking of 47th. 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 14***).

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 16***), 12 years earlier than Illinois. In 2006 Ohio committed 82% of total I/DD resources to community services, above Illinois' 64% but lower than Indiana, Michigan and Minnesota. As noted, Waiver spending in Ohio first surpassed ICF/MR spending only in 2006, well after the other four comparison states. Nevertheless, in 2006 the Ohio's federal-state Waiver spending per capita was nearly double Illinois' ($60 vs. $32). Ohio recently closed Apple Creek and Springfield Developmental Centers but retains 10 state-operated institutions.

Wisconsin

Home and Community Based Services Waiver spending in Wisconsin surpassed ICF/MR spending in 1998, only two years after this benchmark was attained in Minnesota. Wisconsin ranked 16th nationally in Waiver spending per capita in 2006. In 2006, Wiscon-

sin committed 71% of total I/DD resources to community services, less than all comparison states, but still above Illinois's proportion of 64%. Wisconsin first reached parity in institutional/community spending in 1993, four years before Illinois (***Figure 16***). With the recent closure of Northern Wisconsin Center, only 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) and less than half Illinois' rate (21). Wisconsin has also systematically closed private ICF/sMR for 16 or more persons, with a census reduction of 31% during 2004-06.

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

Summary: Analysis of the Comparison States

In varying degrees, Illinois and the comparison states have closed state institutions and private ICFs/MR, reduced the number of nursing home residents with I/DD, and developed community services and family supports. Indiana, Michigan, Minnesota, and Wisconsin have the best record 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 facility. Indiana closed its last state-operated I/DD institution in 2007. Minnesota, Michigan, Wisconsin, and Illinois lead the comparison states in reducing the numbers of persons with I/DD in nursing facilities. Utilization rates per 100,000 of the general population were seven, eight, nine and 12 persons, respec-

tively. Other regional rates were 20 in Ohio, 27 in Indiana, and the U.S. average was 11. Illinois' combined 16+ public and private institutional utilization rate was well above the U.S. average, well above rates in each of the Midwest comparison states, and ranked 6th highest in the nation.

In the early years of community services development, Illinois and the five comparison states relied heavily on ICF/MR reimbursement for group homes as the primary federal funding source for community services. Except for Illinois, the states discussed here have now developed HCBS Waiver-financed alternatives for substantial numbers of their former ICF/MR residents. There was moderate growth in the HCBS Waiver in Illinois in the last four years; but unlike each of the other comparison states and all but seven states nationwide, ICF/DD spending in Illinois still exceeds HCBS Waiver spending (by 66%).

Along with 23 other states including the comparison states Michigan and Minnesota, Illinois has a family support cash subsidy and voucher program. Illinois family support spending per capita of the general population in 2006 for cash subsidies and other family support was well below the U.S. average ($4.91 vs. $7.76 U.S.). Illinois ranked 29th among all the states in 2006. In both supported employment and supported living, Illinois' spending per capita lagged all comparison states and the U.S. Illinois also lagged the comparison states in the percentage of total day work participants in supported employment (13% in Illinois vs. 22% in the U.S.).

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%). Only Indiana among the comparison states did not have county funding for I/DD services. The local government share of community spending was three percent in Minnesota, two percent in Illinois and five tenths percent in Michigan.

Issues in Community Wages and Benefits for Direct Support Professionals

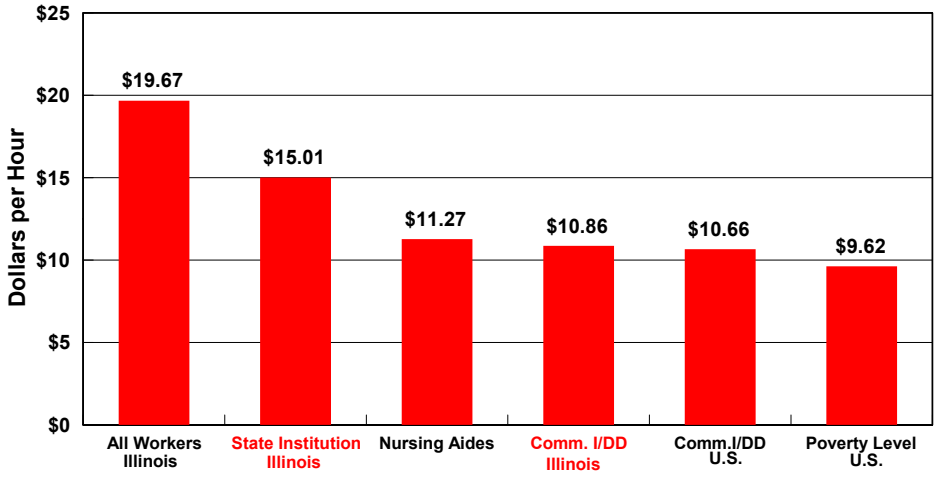
Turnover of direct support staff and the inability to recruit staff are detrimental to the quality of I/DD long-term care programs. High turnover means that persons with disabilities experience a steady withdrawal of the support staff upon whom they depend for

nurturing, consistency, understanding, and appropriate habilitation programs (Lakin, 1988). Employee turnover affects all organizations, but its impact is magnified in human service organizations. Adequate wages are a major factor in recruiting and retaining qualified staff. Braddock and Mitchell (1992) found, in a large nationwide sample of providers, that starting and average wages (adjusted for states' differing costs of living) were correlated inversely with turnover in community residential programs. Lower wages led to higher turnover (Mitchell & Braddock, 1993, 1994). Similar results on the relationship of low wages and turnover were also reported by Lakin and Bruininks (1981); Minnesota Department of Employee Relations (1989); Pivirotto & Bothamley (1986); Larson, Hewitt, & Lakin (2004); Larson & Lakin (1999); and Larson, Lakin, & Bruininks (1998).

In a national study, BDO Seidman (2002) noted three general economic constraints in the recruitment and retention of I/DD direct support staff: 1) rapidly increasing health insurance costs; 2) growing demand in competing service industries; and 3) the advantage that private sector "supply and demand" employers have over publicly funded human service systems that are restricted by fixed appropriations. For example, fixed public sector appropriations can be used as a means of legislative control over total costs, thereby suppressing staff wages and benefits that constitute 60-70% of I/DD community program budgets. In contrast, for state-operated services such as state institutions, salary increases are typically tied to the cost of living, they increase annually, and they rise in relation to employee length of time on the job (Braddock et al., 2008). Because of the large buying power of states, state employee fringe benefits are usually much more generous than those for community direct support staff (e.g., Braddock & Mitchell, 1992).

Direct support professional average wages in privately-operated community-based long-term care programs in Illinois are well below the wages of all workers covered by unemployment insurance (Bureau of Labor Statistics, 2007). They also fall below average wages for state-operated direct care (Lakin, Polister, and Prouty, 2003). Illinois' average community wages are below nursing aides (Bureau of Labor Statistics, 2007) and just above the 2006 poverty level for a family of four (Assistant Secretary for Planning and Evaluation, 2007) (***Figure 17***).

FIGURE 17
HOURLY WAGES IN 2006



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

A number of states, including Illinois and the five comparison states: a) have lawsuits addressing community wage issues, b) have recently completed direct care wage studies, or c) have mounted other initiatives related to inadequate direct support staff wages and benefits. In Illinois, community developmental disabilities programs received a zero percent Cost of Living Adjustment (COLA) in fiscal year 2005, three percent in 2006, zero percent in 2007, and 2.5% in 2008. However, Illinois state-operated institutions received increases of two percent, four percent, three percent and three percent, respectively, during 2005-08. This was in addition to step increases based on employee tenure (The Arc of Illinois, 2008). In 2004, in another project funded by the Illinois Council on Developmental Disabilities, 18 community agencies in Illinois and 10 individuals who directly hired their own support professional participated in a direct support professional (DSP) workforce study (Keiling, 2008). The average DSP wage in Illinois for vocational, residential, in-home and child care settings was $10.12 per hour. The average DSP starting wage for the 18 reporting organizations was $9.00 and the average highest wage was $14.56.

Litigation in Minnesota (*Association for Residential Resources in Minnesota et al. v. Goodno et al.*, 2003; *Masterman et al. v. Goodno*, 2003) addressed community direct support staff wage issues. Minnesota legislation in 2007 would have increased, by five percent, wages and benefits for ICF/MR, I/DD HCBS Waiver services, day training and

habilitation, and adult residential programs. It was vetoed by Governor Tim Pawlenty May 8, 2007. However, Minnesota HF 1078 was signed by Gov. Pawlenty on May 25, increasing the operating payment rate adjustment for ICFs/MR by two percent for rate periods October 1, 2007 and October 1, 2008. Seventy-five percent of the money resulting from the rate adjustment must be used for increases in compensation-related costs for employees (wages and benefits) (The National Council, 2007). The Wisconsin DD Council-funded a statewide wage study in 2003 and found that the average hourly wage for direct service workers in both residential and vocational programs, regardless of tenure, was $9.00 per hour (Melissa Mulliken Consulting, 2003).

VI. IMPACT OF AGING CAREGIVERS IN ILLINOIS

The aging of our society relates directly to the service needs of persons with I/DD and their families. 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, compared to 70 years for the general population (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). In a recent international review, Katz (2003) summarized research on life expectancy for persons with intellectual disability from several countries including the U.S. Katz (2003) 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) noted, 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 I/DD 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. Estimating the magnitude of the impact that aging caregivers has on state service systems can be based on estimates of the prevalence of I/DD, and the living situations of

persons with I/DD. 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 (1999) and Braddock et al. (2008) updated Fujiura's analysis, and applied the methodology to the individual states.

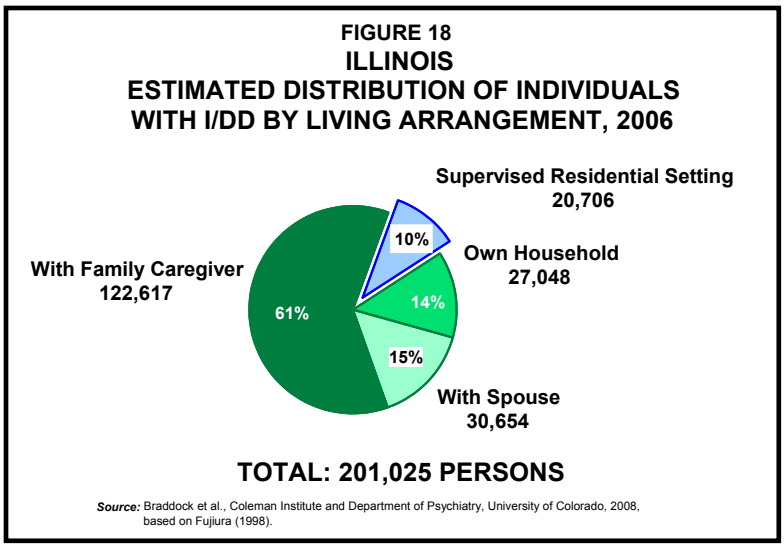


Figure 18 presents the estimated number of persons with I/DD living in Illinois in 2006, and the proportions living a) in supervised residential settings; b) in their own households; c) with spouses; and d) with family caregivers. The numbers are based on an intellectual/developmental disabilities prevalence estimate of 1.58% of the general population (Larson, Lakin, Anderson, Kwak, Lee, & Anderson, 2001). It should be noted that individuals' needs for support varied considerably for those living in structured residential facilities, compared to those living in their own households or with spouses. As illustrated in the figure, 61% of the estimated 201,025 children and adults with I/DD in Illinois resided with family caregivers.

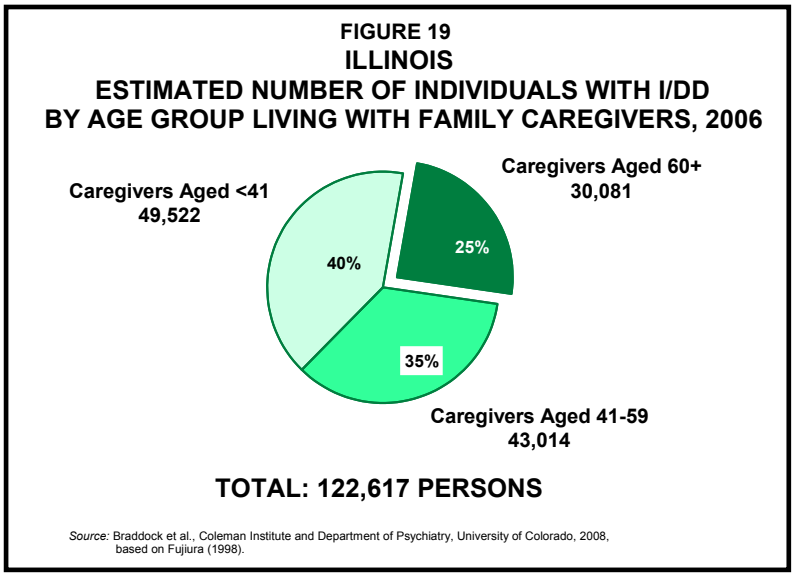


Figure 19 provides an estimate of the age categories for the caregivers of the 122,617 persons with I/DD in Illinois who were living with families in 2006. Of particular note is the category of 30,081 persons estimated to be residing with caregivers who are aged 60 years or more. Clearly, many of these individuals need services now or very soon in the future.

Waiting Lists. Prouty, Smith, & Lakin (2007) reported that, as of June 30, 2006, an estimated 84,523 persons with I/DD nationwide were awaiting residential services, and ***not*** presently receiving residential services. Illinois was one of nine states that did not furnish data to Prouty et al. (2007). However, based on Illinois' Prioritization of Urgency of Need for Services (PUNS) data set, an unduplicated 12,958 persons with I/DD had "emergency," "critical," or "planning" needs and were awaiting services as of March 2008. They awaited a wide range of residential and other support services including speech or occupational therapy, assistive technology, work activities, and respite care. Those awaiting residential services specifically totaled 5,907 and of these, 4,459 had "emergency" or "critical" needs (Illinois Department of Human Services, 2008).

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 Illinois 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). There have been recent waiting list class action lawsuits in Illinois (*Bruggeman et al. v. Blagojevich et al.,* 2004) and in Ohio (*Martin et al. v. Strickland et al.,* 1989).

VII. CHALLENGES FOR ILLINOIS

The nation's census of persons with intellectual and developmental disabilities (I/DD) living in state-operated institutions has declined steadily from the peak of 194,650 in 1967, to 38,299 persons today. Forty states, including Illinois, have closed or scheduled the closure of one or more of their institutions and 10 states--Alaska, Hawaii, Indiana,

Maine, Minnesota, New Hampshire, New Mexico, Rhode Island, Vermont, and West Virginia--now have no state-operated I/DD institutions.

Many states have closed institutions and reallocated institutional funding to more individualized residential alternatives in community and family settings. Between 1980 and 2006, the number of individuals with I/DD living in six person or fewer community-based group homes and supervised apartments in the U.S. increased from 28,000 to 376,567 persons. Individuals living in six person or fewer community residences now represent 70% of all persons with I/DD residing in out-of-home residential settings in the United States, but, in stark contrast, only 30% of those living in Illinois.

Several studies recently completed in Illinois provided recommendations for reduced use of institutional care and significant expansion of community services and Waiver programs (Gettings, Cooper, & Chmura, 2003; Powers, Powers, & Merriman, 2005; Smith, Agosta, & Daignault, 2008; Tilly, O'Shaughnessy, & Weissert, 2003). Smith et al. (2008), for example, recommended closing five state-operated developmental centers; barring development of large community residences; enhancing wages of direct support professionals; and providing services for an additional 14,000 persons. They also noted that the average cost for community services for the additional 14,000 persons served in Illinois would be comparable to the ICF/DD rate of $73,000 per recipient. This would be more than double Illinois' HCBS Waiver cost of $30,000 per participant. The five studies noted above and the present analysis all concluded that Illinois is overreliant on public and private institutions and it has made only modest commitments to the development of community services and family support.

The present study compared Illinois on selected dimensions to the United States and to the Midwest states of Indiana, Michigan, Minnesota, Ohio, and Wisconsin. Although Illinois has made some progress in downsizing large congregate care settings and reducing institutional spending, the state committed less funding for community services in 2006, in inflation-adjusted terms, than it did in 2002. Even though the census of state-operated developmental centers in Illinois continues to decline, the utilization rate is more than 60% above the U.S. average and three times the comparison states in the aggregate. In 2006, Intermediate Care Facilities for the Developmentally Disabled (ICF/DD) spending in

Illinois still exceeded Home and Community Based Services (HCBS) Waiver spending by 66%. This is dramatically at odds with trends in the U.S. and in the five Midwest comparison states. In fact, in 2006 Illinois ranked 47th in federal-state HCBS Waiver spending per capita of the general population (Braddock et al., 2008). This was well below each comparison state per capita ranking (Ohio, 32nd, Indiana, 31st, Michigan 25th, Wisconsin 16th, and Minnesota 3rd).

Due in large part to excessive utilization of public and private institutions and minimal HCBS Waiver use, Illinois ranked last among all states nationally in the percentage of persons in settings for six or fewer persons. Moreover, as previously noted, only 30% of persons with I/DD in the Illinois service system lived in settings for six or fewer persons compared to 69-90% in the five Midwest comparison states. Illinois consumers also receive comparatively limited resources on a per capita basis for family support (35th nationally), supported employment (34th) and supported living (42nd). Illinois has 3,643 persons awaiting 24-hour residential services whose needs are termed "emergency," or "critical" by the state (Illinois Department of Human Services, 2008), and the growing number of aging caregivers was estimated to be 30,081 in 2006 (Braddock et al., 2008).

Finally, we concur with recent quality assurance and crisis intervention recommendations of the Disability Services Advisory Committee (Illinois Statewide Advisory Council on Developmental Disabilities, 2008). The quality assurance recommendations of this committee of consumers, service providers, and the state Division of Developmental Disabilities include: a) extending Waiver participants' Individual Service and Support Advocacy services to all Division service recipients; b) developing a consumer-responsive, statewide quality assurance policy; c) constructing clearly defined, measurable standards that are uniformly applied across all service settings and financially supported by the Governor's office and the legislature; d) providing $8 million to the Division to implement a statewide, person-centered Information Technology Management System to track services, supports, individuals' satisfaction with services and individual goals; and e) providing funding to the Division to implement an electronic health record system. The Committee also recommends immediate release of the Division's crisis intervention request for proposal (RFP) that would solicit proposals from community developmental disabilities agen-

cies and human services professionals to describe how best to craft crisis intervention capacity throughout Illinois.

Study Findings

Illinois is Overreliant on Developmental Centers and Private Institutions for 16+ Persons

- Illinois' institutional utilization rate for state-operated 16+ settings in 2006 was 21 per 100,000 of the general population. This is over 60% above the U.S. rate (13), and three times the rate for the five Midwestern comparison states in the aggregate (7 per 100,000);

- In 2006, the combined 16+ public and private institutional utilization rate in Illinois was 63 per 100,000—85% above the U.S. average of 34, and 75% above that of the five comparison states in the aggregate (36).

Illinois Allocates Comparatively Limited Resources for Community Services and Family Support

- In 2006, Illinois ranked last among the 50 states and the District of Columbia in the proportion of out-of-home I/DD placements in six person or fewer settings. Thirty percent of Illinois' 20,706 residential placements were in six person or fewer settings versus 70% in the U.S. and from 69-90% in the comparison states;

- A comparatively large component of Illinois' "community residential facilities" are large group homes for 7-16 persons. They constituted 31% of all persons in out-of-home placements in the state in 2006, compared to 11% in the U.S. and 10% in the comparison states in the aggregate;

- In 2006, Illinois was tied for fifth nationally in the amount of total I/DD financial resources committed to 7-15 person settings (14%);

- Illinois ICF/DD spending in 2006 was 66% greater than Waiver spending. This is in dramatic contrast with the U.S. and all five comparison states, in which the large majority of Medicaid long-term funding is associated with the HCBS Waiver; and

- During 2004-06, inflation-adjusted spending for community services in Illinois declined one percent. Spending for supported employment declined four percent, and spending for supported living did not increase.

- On a positive note, family support spending increased by nine percent during 2004-06 and the number of families supported increased four percent from 10,720 to 11,114 families.

Recommendations

Reduce Reliance on Public and Private 16+ Institutions and Nursing Facilities

- Continue to reduce reliance on the remaining nine state-operated institutional facilities and the large private ICFs/DD. Medicaid ICF/DD resources should be reallocated to the HCBS Waiver;

- Address the needs for alternative community settings for the 1,535 individuals with I/DD residing in nursing facilities.

Increase Community Services and Related Supports to Address the State's Waiting List and Aging Caregivers

- There are currently over 5,900 persons with I/DD on the Illinois residential waiting list (4,459 whose support needs are designated "emergency" or "critical"). The need for additional Waiver services is likely to increase rapidly in the future due to growing numbers of aging caregivers in the state;

- Inflation-adjusted wages and benefits for community-based direct support professionals should be significantly increased over the next several years. Enhanced wages and benefits correlate with reduced turnover, which can lead to improved service quality (see Braddock & Mitchell, 1992; Lakin, 1988; Mitchell & Braddock, 1993, 1994); and

- Additional support programs for families should be developed in Illinois, including expansion of the state's cash subsidy program.

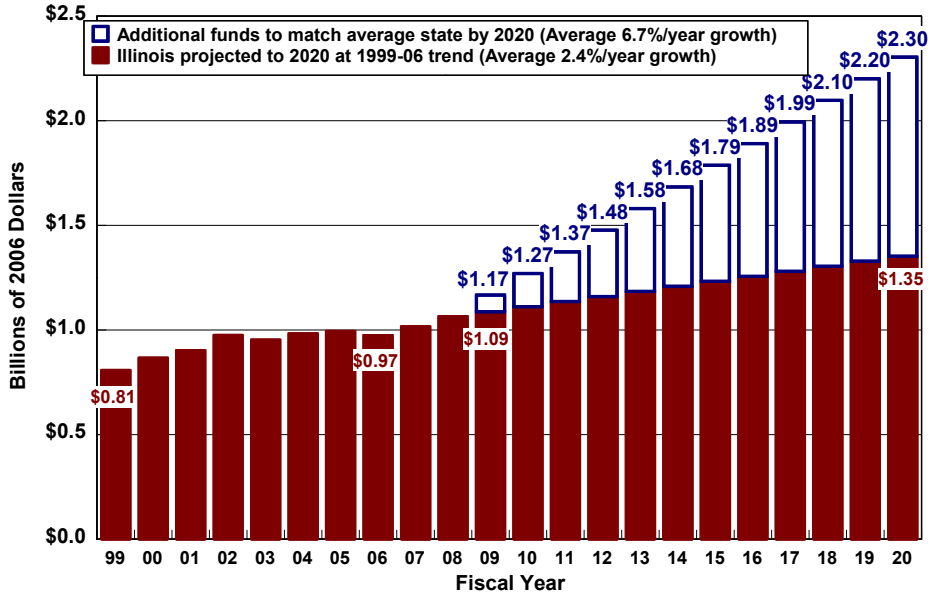
Develop a Plan to Significantly Strengthen Community Services Infrastructure

- Implement quality assurance and crisis intervention recommendations of the Disability Services Advisory Committee, as summarized above;

- A multi-year plan should be developed to increase funding for community-based services and supports. The plan would incrementally increase Illinois spending to match the average state's expenditure for developmental disabilities community spending by 2020.

What is the estimated level of resource expansion necessary for Illinois to match the average state's community services fiscal effort level? To compute this estimate, we provided 12 years for Illinois to "ramp up" community spending to the level of the average state (to 2020). In 2006, Illinois community services fiscal effort was $2.04 per $1,000 of aggregate statewide personal income. This was 39% below the U.S. (i.e., the average

FIGURE 20
PROJECTED ADDITIONAL ILLINOIS COMMUNITY I/DD FUNDING NEEDED TO MATCH THE AVERAGE STATE BY 2020



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

state's) community fiscal effort level of $3.35.

In ***Figure 20*** we projected the rate of growth in community funding to equal that of the average state in 2020. Community fiscal effort for the U.S. was projected through 2020 based on the actual 1999-2006 trend. Illinois community services spending in 2020 (in 2006 dollars) would total $2.304 billion. We also projected where Illinois will be if community services spending trends and inflation across 1999-2006 continue to 2020 and the inflation rate remains at an average of 3.8% per year. In this case projected community spending in Illinois in 2020 is $1.353 billion. Thus, ***Figure 20*** illustrates the "spread" between a continuation of the actual 1999-2006 community services spending trend in Illinois in contrast to the goal of achieving the average state's level of commitment for community I/DD spending by the year 2020. The inflation-adjusted increase in ***community services spending*** necessary for Illinois to match the average state by 2020 is approximately $100 million per year during 2009-2020.

In summary, Illinois has fallen far behind the rest of the country in providing community services and supports for people with developmental disabilities and their families. Significant leadership and substantial financial resources are required in future years to address this challenge. A large portion of the financing for community services and family

support required in Illinois can be reallocated from existing state and privately-operated residential institutions. Up to 50% of the additional financial resources required are reimbursable by the Federal Government under the Home and Community-Based Services Waiver Program.

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