

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

EXECUTIVE SUMMARY



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Executive Summary

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

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

Growth of Community Services in the United States

The nation's census of persons with intellectual and developmental disabilities living in state-operated institutions has declined steadily from the peak of about 195,000 persons in 1967, to 38,299 today. Forty states have closed or scheduled the closure of one or more of their institutions. Indiana, along with nine other states and D.C.--Alaska, Hawaii, Maine, Minnesota, New Hampshire, New Mexico, Rhode Island, Vermont, and

West Virginia--now operate no state-operated I/DD institutions. Additionally, in 2006 there were only 127 I/DD institutional residents in Michigan and nine persons in a mental health center I/DD unit at Cambridge Mental Health Center in Minnesota. In Indiana, 147 persons resided in I/DD mental health units at the Logansport, Evansville, Madison and Richmond State Hospitals in 2008. Indiana is the most populated American state to have closed all of its free-standing state operated institutions exclusively serving people with I/DD.

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

Community Services Development in Indiana

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

Indiana has indeed made substantial progress in I/DD services development during the past decade. With the closure of New Castle, Northern Indiana, Muscatatuck, and Fort Wayne State Developmental Centers, Indiana's 2008 state-operated institutional utilization rate of two persons served per 100,000 individuals in the general population is substantially below the estimated 2008 U.S. rate of 10 persons per 100,000. *Indiana, however, has not fully reallocated the financial resources "saved" from the institutional facilities it closed to alternative community services, family support, supported employment and supported living.* Although overall community services spending,

adjusted for inflation, grew 93% in Indiana during 1999-2005, community services spending declined four percent during 2005-08 after the closures of Muscatatuck and Fort Wayne Developmental Centers. Indiana's HCBS Waiver spending declined four percent on an inflation-adjusted basis during the same period and the State's I/DD fiscal effort fell 10%. Total spending for I/DD services in Indiana, adjusted for inflation, fell by six percent in 2006, four percent in 2007; and by three percent in 2008. In nominal dollar terms (i.e., dollars as appropriated and not adjusted for inflation), total spending for I/DD services declined by 0.1% in 2006 and increased modestly by 0.4% and 2.9% in 2007 and 2008, respectively.

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

Study Findings Summarized

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

Community Services Development Grew Significantly

1. A new Individual Community Living Budget (ICLB) process, initially implemented for individuals moving from Central State in 1994, helped assure that money follows individuals with disabilities receiving services;
2. The total number of persons served in residential settings increased four percent from

1999 to 2008. The proportion of individuals residing in settings for six or fewer persons increased from 42% of the system in 1999 to 63% in 2008. The 2008 rate, however, was still below the average U.S. state (70%);

3. We previously projected in 2000 that, if then current trends continued, HCBS Waiver revenue in Indiana would surpass ICF/MR revenue by 2006. This benchmark was actually attained two years earlier, in 2004. In 2008, Indiana HCBS Waiver spending exceeded ICF/MR spending by 38%;
4. Waiver spending per capita in 2008 places Indiana near the projected U.S. average, and above projected per capita spending levels in the comparison states of Illinois, Michigan and Ohio. Indiana, however, ranks below Minnesota and Wisconsin in the region; and
5. Community services spending in Indiana, adjusted for inflation, grew 85% during 1999-2008. Institutional spending declined by 81%. Community services spending, adjusted for inflation, declined by four percent during 2005-08. However, a new State of Indiana quarterly financial report projects non-adjusted increases of 10% and 6%, respectively, for the HCBS Waiver and for private ICFs/MR during 2008-09 (Indiana Family and Social Services Administration, 2008).

Utilization of Public and Private Institutions/ Nursing Facilities Declined Significantly

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

Study Recommendations

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

Continue the Expansion of Community Services and Related Supports

1. *Complete the reallocation of institutional services funding to community services.* Only a portion of the spending “saved” in the closures of Muscatatuck and Fort Wayne Developmental Centers has been reallocated to community services. That is hopefully temporary while funds from the closure of I/DD state institutions are being readied for deployment for additional community services. To date, however, total

I/DD spending, adjusted for inflation, declined 13% during 2005-08 (a cumulative \$95.2 million reduction). Indiana should reallocate **all** institutional funding previously “saved” to community services, family support and supported employment initiatives;

2. **Expand HCBS Waiver services.** An estimated 13,935 persons with I/DD in Indiana await Waiver services. The need for such services and supports will grow rapidly in the future due to increases in the number of aging caregivers in the state;
3. **Develop additional support programs for families.** The State should consider developing additional support programs for families, including implementation of a cash subsidy program similar to those in Illinois, Michigan, and Minnesota. Indiana ranked 40th nationally in 2006 in the number of families supported per capita and ranked 30th in family support spending per capita;
4. **Expand supported employment services.** Indiana should seriously consider expanding supported employment services managed by the Bureau of Developmental Disabilities Services. Spending for this program declined in inflation-adjusted terms during 2006-08. Indiana ranked 28th in supported employment spending per capita; and,
5. **Increase wages and benefits for direct support professionals.** Wages and benefits for community-based direct support staff should be increased significantly over the next several years to reduce staff turnover and improve service quality.

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

6. **Reduce the number of persons with I/DD in nursing facilities.** Evaluate and relocate as appropriate to alternative community settings the 1,640 individuals with I/DD residing in nursing facilities in 2008. Indiana’s nursing facility utilization rate is 27 per 100,000 of the state general population (2006 data). This was the fourth highest rate nationwide, and was substantially above both the U.S. rate (11) and the average rate of the five comparison states (12). Since the completion of our last study in 2004, Indiana reduced the average daily I/DD nursing facility population by only 78 persons. This is a reduction of less than 20 individuals per year. A class action lawsuit, *Kraus v. Hamilton*, was filed in St Joseph County Circuit Court several years ago on behalf of residents with I/DD in nursing facilities. A settlement agreement was reached in 2004 to facilitate community placements. This litigation is currently entering mediation (L. Frick, Indiana Attorney General’s Office, personal communication, September 9, 2008); and,
7. **Reduce I/DD mental health units and private ICFs/MR.** Continue to downsize the remaining four I/DD units at the Logansport, Evansville, Madison and Richmond State Hospitals, and the three remaining 16+ person private ICFs/MR. Allocate these resources to strengthen and develop additional community services programs and infrastructure.

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

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