

# **The State of the States in Developmental Disabilities 2008**

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# THE STATE OF THE STATES IN DEVELOPMENTAL DISABILITIES: 2008

## I. INTRODUCTION

This monograph presents the results of a recurring nationwide study of services and funding in the states for intellectual and developmental disabilities (I/DD). It evaluates trends over the past 30 years. Demographic, legal, and political forces continue to stimulate demand for I/DD residential and community services in the United States. The number of persons over age 65 will more than double within the next 30 years (U.S. Census Bureau, 2004). Demand for services for people with developmental disabilities who reside with aging family caregivers will significantly increase. In 2006, for example, approximately 2.8 million of the 4.7 million persons with I/DD in the United States were receiving residential support from family caregivers. An estimated 715,000 of these individuals were residing with caregivers age 60+ and many will require out-of-home residential support (Braddock, 1999; Fujiura, 1998; U.S. Census Bureau, 2007).

Increased longevity of persons with I/DD is also stimulating demand for services and supports. Janicki, Dalton, Henderson, and Davidson (1999) have observed that individuals with intellectual disabilities without the most severe impairments have a life-span approximately equal to that of the general population. Increased life expectancy has accounted for an estimated 10-20% increase in demand for residential services over the past three decades (Braddock, 2002a). This trend is likely to increase in the future.

Class action litigation also remains a force in the states in shaping the provision of services to persons with I/DD. Three types of class-action lawsuits have been filed in recent years. Litigation has sought to a) expand services to people with I/DD on waiting lists;

b) meet the requirements of the community integration mandate of the Americans with Disabilities Act (ADA) and the *Olmstead* U.S. Supreme Court decision (1999); and c) provide Medicaid services for eligible individuals who were not receiving those services. Thirteen waiting list lawsuits, 10 *Olmstead* lawsuits, and 10 Medicaid-access lawsuits were active in 22 states in 2007 (*Mental and Physical Disability Law Reporter*, 2007; Priaulx, 2007; Smith, 2007). Limitations of the ADA as a force for change in class action litigation is discussed in the monograph's summary and conclusion section. An overview is also provided of the United Nation's recently adopted landmark Convention on the Rights of Persons with Disabilities.

## II. APPROACH

### Data Collection

New I/DD financial and programmatic data from the states were collected and analyzed for fiscal years (FY<sup>1</sup>) 2005 and 2006. This extended our overall longitudinal analysis of trends in the United States across the entire 30-year period from 1977-2006. Data collection procedures included the: 1) acquisition and analysis of budget and program documents from each state; 2) development of 51 specialized state survey instruments reflecting the fiscal and programmatic idiosyncrasies of each state and the District of Columbia (DC); 3) implementation of these surveys in all states and DC; and 4) extensive collaboration with state agency officials to obtain, verify, and interpret the I/DD financial and programmatic data collected.

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<sup>1</sup> Unless otherwise noted, all years refer to states' fiscal years, which typically run July 1 - June 30.

Federal, state, and local program/budget categories employed in our analysis are outlined in *Table 1*. This framework is the basis both for the survey instruments we constructed for each state, and for our comparative state-by-state statistical summaries. In addition to the federal, state, and local revenue and expenditure categories specified in *Table 1*, spending, revenue and participant data were collected for family support, supported living, and supported employment in each state, along with revenue and participant data for day and work programs. A minimum data set for participants in residential services settings was also collected to generate cost of care statistics specifically tied to the financial data we collected (*Table 2*).

Numerous methodological problems are encountered in any nationwide study of public spending. In this study, four empirical problems were confronted in regard to state budgets used in the states (Braddock, Hemp, & Fujiura, 1986; 1987): 1) the wide variety of budgeting systems (e.g., *program budgets* vs. *line-item budgets*); 2) several types of capital, equipment, and debt service budgeting methods and varied budgeting practices for *fringe benefit costs*; 3) the varied *reliability* of the spending figures reported in official state budget documents (i.e., whether the budget reports "actual," "revised appropriations," "governor's recommendation," or "legislative request" data); and, 4) the difficulty of *disaggregating* state, federal, and local funds reported in states' executive budget documents.

Fiscal data available in *program budgets* are frequently unavailable or available only in part in *line-item budgets*, and vice versa. Comparative nationwide financial studies are thus constrained by the lowest common denominator; that is, by the amount of detail in the least detailed state budget. As noted,

**Table 1**  
**PROGRAM/BUDGET CATEGORIES**  
**UTILIZED FOR DATA COLLECTION**

**I. INSTITUTIONAL SERVICES FUNDS**

A. PUBLIC 16+ INSTITUTIONS

1. STATE FUNDS
  - a. General Funds
  - b. ICF/MR Medicaid Match
  - c. Other State Funds
  - d. Local Funds
2. FEDERAL FUNDS
  - a. Federal ICF/MR
  - b. Title XX/Social Services Block Grant
  - c. Other Federal Funds

B. PRIVATE 16+ INSTITUTIONS

1. STATE FUNDS
  - a. General Funds
  - b. ICF/MR Medicaid Match
  - c. Other State Funds
  - d. Local Funds
2. FEDERAL FUNDS
  - a. Federal ICF/MR
  - b. Other Federal Funds

**II. COMMUNITY SERVICES FUNDS**

A. COMMUNITY SERVICES FOR 15 OR FEWER PERSONS

1. STATE FUNDS
  - a. General Funds
  - b. Medicaid Match
  - c. Other State Funds
  - d. Local Funds
  - e. SSI State Supplement Funds
2. FEDERAL FUNDS
  - a. Public ICF/MR (< 16 persons)
  - b. Private ICF/MR (< 16 persons)
  - c. HCBS Waiver
  - d. Other Medicaid Services
    1. Rehabilitative Services
    2. Clinic Services
    3. Targeted Case Management
    4. Personal Care Services
    5. Administrative, Other Services
  - e. Title XX/Social Services Block Grant
  - f. Other Federal Funds
    1. Temporary Assistance for Needy Families (TANF)
    2. Other Federal Funds
  - g. SSI and Adult Disabled Child (ADC) benefits for HCBS Waiver Participants

Sources: Braddock (1981, 2002a); Braddock, Hemp, & Fujiura (1987).

extensive interpretive contact is required with state agency officials to supplement budget document analysis. Access to state agency administrative records also is typically required.

Several types of *capital*, equipment, and debt service budgeting methods are used in the 50 states and the District of Columbia. A number of states integrate these expenditures into

**Table 2**  
**SUMMARY OF KEY PROGRAM/PARTICIPANT**  
**CATEGORIES FOR DATA COLLECTION**

- I. PUBLIC & PRIVATE INSTITUTIONAL SETTINGS (16+ PERSONS)
  - A. State-Operated Institutions
  - B. Private ICF/MR
  - C. Other Private Residential Facilities
  - D. Nursing Facility Residents with I/DD
- II. COMMUNITY RESIDENTIAL SETTINGS (7-15 PERSONS)
  - A. Public ICFs/MR
  - B. Private ICFs/MR
  - C. Other Residential for 7-15 Persons
- III. COMMUNITY RESIDENTIAL SETTINGS (1-6 PERSONS)
  - A. Public ICFs/MR
  - B. Private ICFs/MR
  - C. Supported Living
  - D. Personal Assistance
  - E. Other Residential Settings  
 (Group Homes, Apartments, Foster Care)
- IV. DAY/WORK PROGRAM PARTICIPANTS
  - A. Sheltered Employment/Work Activity
  - B. Day Habilitation ("Day Training")
  - C. Supported/Competitive Employment
- V. HCBS WAIVER PARTICIPANTS

Sources: Braddock (1981, 2002a); Braddock, Hemp, & Fujiura (1987).

their regular operating budgets, and these amounts have to be carefully extracted from operating expenditures to ensure comparability across states. Also, *fringe benefit costs* for state employees are often reported separately from I/DD agency budgets. These nontrivial sums, which can exceed 20% of state agencies' personnel budgets, must be obtained directly from other state agencies, usually personnel management agencies, and subsequently aggregated with developmental disabilities operating expenditures managed by the principal I/DD state agency.

A third methodological problem stems from the different levels of *reliability* in the spending figures reported in official state budget documents. The stability of a reported spending figure depends upon the stage of the budget process in which it is captured. Gubernatorial "recommended" or "requested" figures are subject to substantial change because they are subsequently reviewed and often modified by legislative appropriations committees. "Actual expenditures" are not subject to change and represent fixed values

after the official closing of the books. "Actual expenditures" are generally available within two years of the initial appropriation. Intermediate stage spending data include "revised appropriations" and "obligations," the latter reflecting legally binding financial commitments incurred by an agency. Revised appropriations figures are adjusted periodically during and after the fiscal year in which the funds were originally appropriated. Data used for the analysis of trends in I/DD state spending should be based on actual expenditures and obligations, or, at a minimum, revised appropriations. As different iterations of this study have been completed over the years, we have worked closely with the states to continuously revise and improve the reliability of prior years' data.

State executive budget documents typically provide three years of data. Most governors' executive budgets for FY 2008 were published in early calendar year 2007. They typically presented actual expenditure data for FY 2006, revised appropriations for 2007, and the "governor's recommendation" or "legislative request" for 2008. We often use state budget documents for general background information on I/DD-related budget priorities in the states.

In some states, the budgets also provide some detail on I/DD institutional and community services spending and related performance measures such as participant data. However, useful budget detail in gubernatorial executive budgets is the exception, not the rule. We must also obtain fiscal and programmatic data via state-specific survey instruments, in repeated communication with state I/DD, Medicaid, and social services agency officials, and from national data bases.

Many states also fail to *disaggregate* state, federal and local funds in their official executive budget documents. Resolving this problem requires supplementing budget document analysis with extensive correspon-