Americans with Disabilities

State and Local Financing and Systems Reform

Michael Morris & Johnette Hartnett

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AMERICANS WITH DISABILITIES: STATE AND LOCAL FINANCING AND SYSTEMS REFORM*

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PREFACE

The current picture of long-term services and supports (LTSS) documented by families, policymakers, researchers, and service providers is complex, confusing, and frustrating. It is a ship struggling with the weight of escalating costs and an increasing number of passengers seeking access and safe passage. Services and supports are scattered throughout numerous federal programs, with uncertain points of entry and different rules of eligibility defined by geography, income level, age, and nature and type of disability.There is no comprehensive national policy focused on LTSS that is free from the medical model and institutional bias of long-term care (LTC). However, at the state and local levels, there is a push to move forward: setting new policies, reallocating resources, testing new service delivery approaches, and engaging individuals with disabilities and families in a public dialogue to redesign the ship to support a consumer-responsive system that encourages choices, seeks flexibility in service delivery, invests in public-private collaboration, and values the role of formal and informal caregivers. None of the highlighted activities can offer a comprehensive roadmap to reform of existing systems. However, each highlighted state or local system focuses a spotlight on innovative thinking, including policies, processes, and methods of administration to help guide the redesign efforts for the future.

This book identifies and highlights selected activities at the state and local levels that are leading toward increased access to LTSS with federal and state dollars. A growing number of states are reevaluating their current systems to identify a range of options for consumers to remain in their own homes or communities rather than be forced into more restrictive environments and skilled nursing facilities. Researchers selected five states to profile and analyzed current activities that are in different stages of development toward the goal of comprehensive, person-centered service and support programs.

Part I

INTRODUCTION

The current picture of long-term services and supports (LTSS) documented by families, policymakers, researchers, and service providers is complex, confusing, and frustrating. It is a ship struggling with the weight of escalating costs and an increasing number of passengers seeking access and safe passage. Services and supports are scattered throughout numerous federal programs, with uncertain points of entry and different rules of eligibility defined by geography, income level, age, and nature and type of disability.

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analyzed current activities that are in different stages of development toward the goal of comprehensive, person-centered service and support programs.

Five State Study

The barriers that the selected states had to overcome to achieve preferred and valued results suggest opportunities for the Federal Government to reform LTSS at the national level. Indeed, many of the innovations implemented by the five states have been made possible by recent federal policies and programs that have recognized the hurdles states have to overcome to help people with disabilities lead meaningful, independent lives. The New Freedom Initiative has provided states with grants to achieve the following:

- assist individuals to move out of nursing homes into community settings;
- create regional information and assistance centers that serve as one-stop shopping for consumers to meet their needs for services and supports;
- adopt and improve consumer-directed features in their home care programs and train consumers on their use; and
- form community partnerships to develop accessible and affordable housing and transportation for people with disabilities.

While many of these grants have been modest in amounts, they have helped to keep the momentum going in states faced with tight budgets. The five states selected are using these grants and adopting a variety of strategies to achieve their goals for rebalancing their LTSS systems. They are at different stages in this process. At one extreme is Washington, which has taken a step-by-step approach over more than 20 years to expand home- and community-based services (HCBS). At a different point in the spectrum is Texas, which has only recently embarked on a major overhaul of state agencies that administer LTSS, while also continuing a large-scale effort to move thousands of people out of nursing homes into community living.

The five states were selected because of several characteristics identified as common to the states and instrumental to their expansion of HCBS. These characteristics include a strategic planning process, systems reorganization, involvement of consumers in shaping new policy, and interagency

collaboration. These five states were chosen to reflect geographic diversity and unique program design and development.

Table 1. Five States: Long-Term Services and Supports Reform Strategies

State	Reform Strategies	Importance
Indiana	Public-Private Long Term Care (LTC) Insurance Program—links purchase of private LTC insurance with Medicaid coverage of long-term services and supports (LTSS). State-funded Community and Home Options to Institutional Care for the Elderly (CHOICE) program is for low-income individuals who do not qualify for Medicaid and/or are waiting for Medicaid services. Covered services are case management, home health supplies and services, personal assistance services, transportation, respite care, home delivered meals, and adaptive aids and devices. The program is administered by the Area Agencies on Aging. Twenty percent of service dollars must be used by people with disabilities under the age of 60.	Tax deduction for cost of premium. For every dollar of benefits that a policy pays out, the purchaser earns $1 of asset protection to remain eligible for Medicaid. Targets a population not on Medicaid with a sliding fee schedule based on income level.
Vermont	Coordination of LTSS for people who are aging and/or disabled. One department includes Aging, Physical Disabilities, and Developmental Disabilities. A global budgeting approach allows the state to combine Medicaid home- and community-based services (HCBS) waiver funds with the state's nursing home appropriation.	Single agency improved information flow to consumers. Removes institutional bias and offers eligible people community choice and expanded service options. Increased consumer satisfaction and cost savings.

Table 1. (Continued)

State	Reform Strategies	Importance
Washington	Balanced global funding of institutional services and LTSS with consolidated administration under the Department of Social and Human Services. With a focus on movement out of nursing homes, state general revenue funds (up to $816) are available to help a person move from a nursing home to a less restrictive setting. State funds are also used to pay for assistive technology.	Improved coordination in the delivery of services with a client-centered integrated service plan that is managed by a service broker. State investment in one-time transition costs.
Minnesota	Examination of long-term support insurance options to balance public and private responsibility. Creation of benchmarks to assess change over time in state system (for example, a percent of long-term care dollars spent on institutional versus community support). Shared Care is part of the state's Medicaid Personal Care Assistance Choice Program. With Shared Care, two consumers can share a personal assistant, with the cost divided between two people. The worker will be paid one and one-half times the regular rate.	Seek to identify tax incentives and other means to maximize private resource utilization and still achieve state policy goals. Ability to assess change in the state system over time. An approach to increase wage levels and still achieve consumer satisfaction.
Texas	Reorganization of administration with integrated eligibility determination process. Movement of Medicaid funding from its nursing home budget to its budget for Community Care Programs.	Will allow an integrated application process for medical, food, and other LTSS. Money Follows the Person from a nursing home to the community. More than 3,000 individuals have made the transition from nursing home to community living coordinated with supports.

The mandate for planning has generally come from the governor or the legislature. These states have also developed consensus about the direction to take their programs through involvement of key stakeholders from all parts of the community, including advocates, providers, and policymakers. Most of the selected states have a tradition of discussion and collaboration over public policy issues.

Pulling together state agencies that have responsibilities for LTSS has been a starting point (or at least a necessary element) for making services more accessible to consumers and responsive to their needs in the states under review. States that place the responsibility for both nursing homes and home- and community-based care under the same state agency provide greater flexibility for that agency to allocate funds based on the needs of its clients rather than having separate silos for those funds.

Each state has developed some unique programs or approaches to serving people with disabilities. **Washington** was one of the first states in the country (in 1983) to take advantage of the then-new federal Medicaid HCBS initiative, the HCBS waiver program. [1] **Vermont** is pioneering a global budgeting approach to providing services that will pool nursing home and HCBS funds to allow people with disabilities to select whichever option they prefer. The state will establish priorities for meeting the needs of people with disabilities by dividing these people into those with the highest needs (who are the state's first priority) and those with less high or moderate needs.

Minnesota has embarked on an ambitious project to review and prioritize public and private financing options for LTSS so the state can develop a campaign to ensure an optimal combination of the two. The goal is to help address the critical public financial situation that could develop when baby boomers age and need services and supports. **Texas** has broken new ground with a Medicaid managed care system that is serving more than 60,000 aged and disabled people in one area of the state. The state is also revamping its agency structure to provide consumers with easier access to services. The effort, which could take three to fives years to complete, involves 12 agencies, 200 programs, and about 50,000 state employees. **Indiana** has a state-funded home- and community-based care program that is so highly valued by consumers and public policymakers that the program has received ever-rising appropriations, even though the state has been facing difficult fiscal times. [2]

Each state case study is divided into sections that discuss programs and services for different groups of people with disabilities. Additional sections outline residential options and consumer-directed initiatives. A final section singles out two particularly innovative projects in each state.

Taken together, these five state case studies offer an optimistic and encouraging picture of the possibilities for reforms in LTSS. They suggest additional steps that can be taken at the federal level to continue to help states move forward in the evolution of a comprehensive system of support for individuals with disabilities that favors consumer choice and control.

Table 1 offers a summary of each state's reform strategies and its significance to future policy development.

Part II

FIVE STATE CASE STUDIES

Washington

Washington is among the leaders among states seeking to create and maintain a balanced long-term care system that offers real choices for consumers among an array of settings and service options. [3]

—National Academy for State Health Policy for
the Community Living Change Collaborative,
November 2003

Introduction

Like its neighbor, Oregon, Washington began its efforts to limit institutionalization and expand HCBS for people with disabilities in the 1980s, long before most other states. Washington was one of the first states to take advantage of what was then a new federal option: Medicaid HCBS waiver programs, which allow a state to offer people at risk of institutionalization a chance for community care instead.

In FY 2003, Washington spent $1.6 billion on Medicaid-funded LTSS, of which about $770 million (49.5 percent) was allocated to institutional care (nursing facilities and institutions for people with mental retardation or developmental disabilities, MR/DD). Another $784 million (50.5 percent) went to HCBS. This contrasts sharply with the national average allocation, which is about 70 percent for institutional care and 30 percent for HCBS. Over half of the public expenditures for LTSS in Washington are noninstitutional,

and more than 75 percent of participants receive community-based services rather than institutional care.

Allowing consumers the opportunity to direct their services themselves is another important feature of Washington's HCBS programs. The HCBS programs strongly promote choice. Washington has also been in the forefront of states in realizing the importance of providing assistance to family caregivers to enable them to continue caring for family members. The state developed its own program of family caregiver supports before the enactment of the National Family Caregiver Support Program.

The state has also realized the importance of developing a stable and trained workforce of direct care workers if quality care is to be provided to people with disabilities. The creation by voter initiative and legislation of the Home Care Quality Authority in 2000 is unique among states in its concept and operation.

Perhaps as important as anything else to Washington's ability to create a comprehensive system has been its management of most services for people with disabilities in one agency. The Department of Social and Health Services (DSHS) serves one in five Washington residents (with health as well as support services) and, in some of the mostly rural counties, more than one-third of the population. [4] Within DSHS, the Aging and Disability Services Administration (ADSA) has responsibility for nursing homes as well as HCBS and for people with developmental disabilities as well as the frail elderly and other adults with disabilities. This single-agency focus has made it possible for the state to shift resources from institutions to community services and to coordinate services for people with disabilities who have complex health, mental, and long-term support needs that span several agency programs.

Background

The total population of Washington was about 6 million in 2002. The state experienced a 21 percent increase in population from 1990 to 2000, compared with a national population increase of 13 percent. The number of people age 65 and older in 2000 totaled 662,000, or 11.2 percent of the total population. Between 1990 and 2000, the state saw a 15.1 percent increase in the number of elderly. From 2000 to 2025, the Census Bureau predicts a 131 percent increase in this age group in Washington, the sixth highest growth rate in the country. [5]

The number of people with a disability totaled 981,007 in 2000. The state has a relatively homogeneous population with only 3.2 percent black, 5.5 percent Asian, and 7.5 percent Hispanic. The number of people with incomes below the poverty level totaled 10.6 percent of the population in 2000. [6]

More than three-fourths of the state's residents live in urban areas. In 2003, the state had the largest budget deficit in its history: $2.4 billion.

Integrating Services for People with Disabilities

Washington has been gradually evolving a strategy of integrating LTSS for people with disabilities. In 1986, the state consolidated administration of all long-term supports for older people and people with disabilities into the Aging and Adult Services Administration under the umbrella of the DSHS. The Mental Health Division (MHD) and the Division of Developmental Disabilities (DDD) were also located within the umbrella agency.

Kathy Leitch, assistant secretary of ADSA, says that the 1986 reorganization brought nursing homes and HCBS together under one administration. "There was always this push," she says, "that the nursing home entitlement got in the way of providing home- and community-based services." The purpose of the reorganization, she adds, "was to organize around consumers and have an array of options available to them."

The department estimated that almost 25,000 people received services from two or more of the following DSHS programs in 1999: mental health, aging and adult services, alcohol and substance abuse, and developmental disabilities. In November 2000, DSHS began developing the No Wrong Door care coordination project to design integrated case coordination models for people and families served by several different DSHS programs. The project involves multidisciplinary teams made up of staff from various DSHS programs, local community organizations, and other supports of the person and family. A "client-centered integrated service plan" is developed and a service broker/coordinator then manages joint planning and coordinated delivery of services.

One example of service integration was the October 2002 the creation of the Aging and Disability Services Administration (ADSA) in DSHS, which combined aging programs from the former Aging and Adult Services Administration (including nursing facilities as well as community-based programs) with developmental disabilities programs (both residential centers and community programs). Mental health and alcohol and substance abuse

programs remain within the Health and Rehabilitation Administration in DSHS.

Expansion of Community Supports

Washington has steadily increased the number of people who receive home and community services, while decreasing the number of nursing home residents. State officials say they can place two people in community services for the cost of one person in a nursing home.

In FY 1992, 19,330 people were being provided publicly funded HCBS; by FY 2003, that number had grown to 33,729. Over the same period, the Medicaid caseload in nursing homes had dropped from 17,353 to 12,943. [7] About 33,000 people are now receiving community services from the Division of Development Disabilities through Medicaid Personal Care, Family Support Services, or Community Residential Services, compared with 1,330 people in the state's Residential Habilitation Centers (RHCs). [8]

Moving people out of nursing homes whenever possible has become a major priority for the state. Four funds are available to assist people with their transitions to the community:

- *Medical Institution Income Exemption Fund.* Beneficiaries who qualify for Medicaid nursing home care must pay all their income toward the cost of their care, except for a personal needs allowance. Under the income exemption, a new nursing facility resident may keep income, up to 100 percent of the federal poverty level, for a six-month period. Residents can use this income to maintain their home in the community by paying rent, mortgage, property tax, insurance, and/or utility payments. [9] This means that a person who may have a short stay in a nursing home is less likely to face the prospect of losing his or her residence during that period.
- *Residential Care Discharge Allowance*. This allowance provides up to $816 in state general revenues to help a person move from a nursing home or other residential setting (such as an assisted living facility or adult family home) to a less restrictive setting.
- *Civil Money Penalties.* The state uses fines paid by nursing homes with deficiencies to help people in such nursing homes move to another facility or to an alternative residential setting. The amount is limited to $800 per resident but may be higher if the facility has been