



U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy



GAUGING THE USE OF HCBS SUPPORT WAIVERS FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES:

FINAL PROJECT REPORT

April 2007

Office of the Assistant Secretary for Planning and Evaluation

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**GAUGING THE USE OF HCBS SUPPORT WAIVERS
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Final Project Report**

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The opinions expressed in this report do not necessarily reflect the views of the U.S. Department of Health and Human Services or RTI International.

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I. INTRODUCTION

The per person cost of furnishing Medicaid home and community-based services (HCBS) to people with intellectual and other developmental disabilities (I&DD)¹ is significantly higher than the cost of serving other target populations (e.g., older persons, younger persons with physical disabilities) and state I&DD systems are experiencing substantial annual increases in service demand. As a result, in recent years, a growing number of states have launched what have commonly come to be termed “supports waivers” for persons with I&DD.

These Medicaid waivers operate under the authority of §1915(c) of the Social Security Act that authorizes a state to furnish HCBS to persons who otherwise require the level of care that is furnished in a Medicaid-reimbursable institution. Seventeen states now operate supports waivers side-by-side with the traditional “comprehensive waivers” that provide more extensive services, including licensed residential services furnished outside the family home. The per waiver participant cost in comprehensive waivers is substantially greater than in supports waivers.

Supports waivers are designed to complement the unpaid supports that are provided to individuals with I&DD by family caregivers. Compared to the waivers that have traditionally provided services to this population, supports waivers impose relatively low dollar limitations on the total amount of HCBS that may be authorized for waiver participants. These dollar limitations are significantly lower than the costs of institutional services. Within the dollar limitation, individuals and families usually have flexibility in the selection of services and supports.

HCBS supports waivers are characterized by:

- A relatively low dollar cap on the total amount of HCBS waiver services that may be authorized on behalf of a beneficiary.
- Flexibility in the selection of services within the dollar cap.
- The expectation that unpaid family caregivers will provide significant support to waiver participants.

The use of two distinct HCBS waivers with markedly different cost caps is a new approach to employing the §1915(c) waiver authority to furnish long-term services and supports to people with I&DD. States have expressed various rationales for changing over to a dual or tiered waiver configuration. These include:

- Reducing the high per person costs of HCBS by avoiding the high costs of furnishing 24/7 residential services and focusing on delivering services and supports in the family home.

¹ Note that term “intellectual and developmental disabilities” (I&DD) is used throughout this report in place of the more traditionally known term “mental retardation and developmental disability” (MR/DD).

- Leveraging and complementing the supports that are furnished by family caregivers to people with I&DD.
- Obtaining additional federal Medicaid dollars by leveraging state dollars that underwrite non-residential services in the community, which many states had not formerly covered under Medicaid.
- Complying with the requirements set forth by the Centers for Medicare & Medicaid Services (CMS) State Medicaid Director Letter #01-006 (a.k.a., *Olmstead* Letter #4, discussed in more detail later).
- Expanding services to more economically serve people with I&DD who have been wait-listed for services, sometimes in response to a lawsuit.

In some instances, supports waivers have also served as a vehicle for states to introduce consumer-direction of services into the delivery of Medicaid HCBS for persons with I&DD.

Study Scope

To gain an understanding of how and why states are reconfiguring their HCBS waivers for people with I&DD, the Office of the Assistant Secretary for Planning & Evaluation, U. S. Department of Health & Human Services, sponsored this study in order to compile systematic information about the supports waivers that states operate. This study was conducted by the Human Services Research Institute (HSRI) under subcontract to Research Triangle Institute (RTI).

The aims of this project included:

- Determining how and why supports waivers have emerged as a means to address the needs of people with I&DD.
- Compiling systematic descriptive information about the comprehensive and supports waivers for people with I&DD that operate side-by-side in 17 states.
- Obtaining a better understanding of the range of participant characteristics and experiences that distinguish supports waivers from other HCBS waivers for people with I&DD.
- More fully understanding how states view supports waivers as a strategic tool to address the need for HCBS.

Report Overview

This report contains the following major sections:

- **Methods.** This section briefly describes how the information contained in this report was obtained and compiled.
- **HCBS for People with I&DD.** This section provides background information concerning the role that Medicaid HCBS waivers play in supporting people with I&DD, critical factors affecting state I&DD service systems that have spurred the implementation of supports waivers, and federal Medicaid policies that affect how states use Medicaid HCBS waivers.
- **Overview of Supports Waivers.** This section provides descriptive information about the supports waivers that are presently operating.
- **Summary of Case Studies.** This section synthesizes information gleaned from case studies of six states that operate supports waivers.
- **Impact of Supports Waivers.** This section presents observations about the impact that supports waivers appear to be having on the delivery of Medicaid waiver services to people with I&DD and identifies some of the issues that have emerged around the use of these waivers.
- **Appendix A: State Supports Waiver Profiles.** These profiles present detailed information about the supports waivers operated by the 17 states.
- **Appendix B: Case Studies.** This Appendix contains state-by-state results of the six case studies conducted by HSRI. The discussion protocols used to conduct these case studies are contained in **Appendix C.**

II. METHODS

This study entailed two major data collection activities. The first was to compile systematic profiles of the supports waivers that are operating in 17 states. The second was to conduct follow-up inquiries to complete more in-depth “case studies” of six states that operate supports waivers.

State Profiles

At the outset of the study, we identified 17 states operating supports waivers:

Alabama	Louisiana	Ohio	South Dakota
Colorado	Missouri	Oklahoma	Tennessee
Connecticut	Montana	Oregon	Texas
Florida	Nebraska	Pennsylvania	Washington
Indiana			

HSRI designed a computer-based template and a database to compile and sort a standard set of information about the HCBS waivers operating in each of these 17 states. This template and database were designed to capture consistent and comparable information about each state and to document a variety of defining characteristics of each state’s supports waiver (e.g., services offered, descriptive features, number of participants and associated costs by year, extent of consumer-direction, and text notes related to particular topics). This information was also used to aggregate information across the 17 states.

From January through December 2006, information was compiled on each state and its HCBS waivers for people with I&DD. Our actions included:

- Contacting state staff to acquire CMS approved or submitted waiver documents, CMS 372 annual waiver statistical reports, relevant state documents, and other applicable reports.
- Acquiring electronic information available at state websites.
- Reviewing the national I&DD data sets compiled by the Research and Training Center on Community Living, Institute on Community Integration/ University Centers for Excellence in Developmental Disabilities at the College of Education & Human Development at the University of Minnesota.
- Reviewing an earlier report on the supports waivers compiled by the National Association of State Directors of Developmental Disability Services.

Every effort was made to acquire the most up-to-date and accurate information about supports waivers. Where information from one source did not match with that from another or information was outdated, state officials were contacted to reconcile the differences in the data sets or acquire more current information. An initial set of state profiles was prepared. HSRI continually updated the database as the project progressed. The 17 state profiles are located in Appendix A of this report.

Case Studies

The project case studies were completed in three steps. First, six states were selected to explore more thoroughly--Florida, Missouri, Oklahoma, Oregon, Pennsylvania, and Tennessee. In selecting these states, the following factors were taken into account:

- length of time the supports waiver(s) had been in operation;
- services offered;
- self-direction features;
- the number of people enrolled in state comprehensive and supports waivers;
- the level of waiver spending; and
- trends in both enrollment and spending.

Second, two discussion guides were prepared. These guides are in Appendix C. The *Core Elements Protocol* was designed to gather from state officials supplementary detailed information concerning how the state's HCBS waivers for people with I&DD are structured and operate. The *Case Study Discussion Protocol* guided discussions with selected key state informants about the waivers. These protocols addressed topics such as:

- The policy goals that underpin the waiver(s) (e.g., reducing wait-lists, containing spending, redirecting service budgets, promoting consumer-directed approaches, and others).
- Descriptive information on waiver utilization and waiting lists.
- Operational elements related to program eligibility and access, individual budget allocations, service planning, service use, and quality assurance.
- Opinions about how the waivers are functioning, their impact, and how they might be improved.

HSRI then identified key informants in each of the six states. HSRI sought to identify individuals who were familiar with the operation of the supports waiver. Consultations with state HCBS waiver operating agency personnel were essential to collect more in-depth information about various aspects of waiver operations. Such

individuals included the state director of developmental disability services and the individual(s) responsible for HCBS waiver operations.

In addition to these informants, HSRI also identified individuals with varying perspectives who would be knowledgeable about the waivers and their impact. Depending on the state, HSRI talked with representatives from the Administration on Developmental Disabilities network (i.e., developmental disabilities planning councils, protection and advocacy agencies, university-based centers of excellence), the advocacy community (e.g., state ARC representatives, family advocacy groups), and the service delivery network (e.g., representatives of provider associations, case managers, planning agents or brokers).

On average, HSRI had discussions with 11 informants in each state. Discussions were conducted by telephone with four states--Missouri, Oklahoma, Pennsylvania, and Tennessee--and in-person during site visits to Oregon and Florida. HSRI completed the discussions and site visits between August and October 2006. The state-by-state results of these case study discussions are in Appendix B.

HSRI and RTI express their appreciation to the state officials and other key informants who generously provided both information and insight into the operation of supports waivers for people with I&DD.

III. HCBS FOR PEOPLE WITH I&DD

This section provides background information concerning the role that Medicaid HCBS waivers play in supporting people with I&DD. First, information is presented about the characteristics and prevalence of I&DD. This is followed by a summary explanation of how HCBS waivers are employed to provide services to people with I&DD. Finally, factors are identified that are prompting states to design and implement supports waivers.

Persons with I&DD

There are nearly five million children and adults with I&DD in the United States or 1.58 percent of the general population.² The term “intellectual disability” has replaced “mental retardation” to describe individuals who have a significant mental or intellectual impairment that begins at birth. The term “developmental disabilities” refers to other conditions that are manifested after birth but before age 22 and are attributable to a mental or physical impairment or a combination of both types of impairments. I&DD are life-long. People with I&DD have one or more major functional limitations and often require assistance in one or more Activities of Daily Living and/or Instrumental Activities of Daily Living. Individuals with substantial mental and/or physical impairments may require daily or around-the-clock assistance, including supervision to assure safety.

Developmental disabilities include conditions such as:

- Autism
- Behavior disorders
- Brain injury
- Cerebral palsy
- Down syndrome
- Fetal alcohol syndrome
- Spina Bifida

The prevalence of I&DD is increasing. More infants with severe disabilities are surviving at birth and people with I&DD are living longer. Due to better health care, the longevity of people with I&DD has trended upward along with that of the general population. Most people with I&DD (including adults) live with family members who provide unpaid care and support.³ The increasing longevity of people with I&DD has resulted in a growing cohort of individuals who live with aging caregivers who are over age 60; about one-quarter of persons with I&DD have an aging primary caregiver.⁴ In 2005, state I&DD service delivery systems provided residential services outside the family home to approximately 411,000 individuals; another 30,000 individuals resided in

² Larson et al. (2000). *MR/DD Data Brief: Prevalence of Mental Retardation and/or Developmental Disabilities: Analysis of the 1994/1995 NHIS-D*. Minneapolis, MN: University of Minnesota, Institute on Community Integration, Research and Training Center on Community Living.

³ Some 73.6% of adults with I&DD live with their families. Larson et al. (2001). *MR/DD Data Brief: Demographic Characteristics of Persons with MR/DD Living in Their Own Homes or With Family Members: NHIS-D Analysis*. Minneapolis, MN: University of Minnesota, Institute on Community Integration, Research and Training Center on Community Living.

⁴ HSRI (2000). *Aging Family Care Givers: Needs and Policy Concerns*. Portland, OR.

nursing facilities.⁵ About 500,000 people who live with their families received services through state I&DD service systems. Public systems support approximately 21 percent of people with I&DD.

Once dominated by the provision of services in large state-operated institutions, state I&DD service systems are now primarily community-based. These systems predominantly serve adults with I&DD by furnishing a mix of residential, out-of-home day supports, supported employment, and home-based services.

HCBS Waivers for People with I&DD

Section 1915(c) of the Social Security Act permits a state to obtain federal financial participation in the cost of furnishing HCBS to Medicaid-eligible individuals who require the level of care furnished in a Medicaid-reimbursable institutional setting (i.e., a hospital, nursing facility, or an intermediate care facility for the mentally retarded (ICF/MR)). A state must obtain approval from CMS to operate an HCBS waiver and periodically request CMS approval to continue the operation of a waiver. HCBS waivers serve state-specified target populations. A state must ensure that its waiver is cost-neutral: that is, the average per person cost of furnishing HCBS to waiver participants will be no greater than the average cost of serving such persons in the institutional setting to which the waiver serves as an alternative.

States have flexibility in selecting the types of HCBS that they offer through a waiver. A state may offer services that it could not otherwise provide under its Medicaid state plan or has elected not to cover under its state plan. Waiver participants also have access to the full range of services available through a state's basic Medicaid program. States have the authority to limit the number of persons who may participate in a waiver. Once a waiver's enrollment limit is reached, a state may place individuals on a waiting list for future enrollment.

With respect to individuals with I&DD, waiver HCBS may be furnished to persons who require the level of care in an ICF/MR. ICFs/MR include state-operated institutions, large private facilities, and smaller group home settings. ICF/MR services may be furnished to individuals with an intellectual disability who have substantial limitations and persons with "related conditions."

The term "related condition" is defined in 42 CFR 435.1009. Related conditions include cerebral palsy, epilepsy, and any other condition (except mental illness) that results in the impairment of intellectual function or adaptive behavior similar to the impairments that stem from intellectual disability (mental retardation). The related

⁵ Robert Prouty, Gary Smith, and K. Charlie Lakin (2006). *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2005*. Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living.

condition must have been present prior to age 22 and result in substantial functional limitations. Common related conditions include autism and traumatic brain injury.⁶

In order to qualify for waiver enrollment, individuals must also meet basic Medicaid eligibility tests, including financial eligibility and a determination that the person has a qualifying disability (e.g., the person meets the disability tests under Titles II and XVI of the Social Security Act). The combination of financial and disability-related eligibility criteria reduces the number of people with I&DD (especially children) who can qualify for Medicaid.

Since the 1981 enactment of the federal Medicaid HCBS waiver authority, states have employed HCBS waivers extensively to underwrite the costs of community services and supports for people with I&DD. The use of the HCBS waiver authority as a financing tool for community services for people with I&DD accelerated during the 1990s and has continued to grow over the past several years. In 2005, federal-state expenditures for waiver HCBS provided to persons with I&DD totaled \$17.0 billion.⁷ Nationwide, states furnished waiver services to 443,608 persons with I&DD at an annual cost of \$39,627 per waiver participant.⁸ Between 2000 and 2005, the number of individuals with I&DD participating in HCBS waivers increased by approximately 50 percent.

HCBS waivers for people with I&DD typically include the provision of case management/service coordination, residential services, day supports (facility-based habilitation programs), employment supports, personal care/personal assistance, respite, transportation, and clinical services. In 2005, about 45 percent of HCBS waiver participants with I&DD resided in the family home. Typically, however, the majority of state HCBS waiver expenditures underwrite the costs of furnishing residential services outside the family home.

States rely heavily on HCBS waivers to finance community services for people with I&DD. HCBS waivers have aided states to avoid the high cost of ICF/MR services,⁹ permitted them to leverage federal Medicaid dollars to underwrite the costs of community services that states commonly provide to people with I&DD, and take advantage of the underlying flexibility of the waiver authority to support individuals in a variety of community settings.

State use of the HCBS waiver authority has resulted in a decline in the utilization of institutional ICF/MR services. Between 1990 and 2005, the average daily population in large state-operated I&DD facilities was reduced by half nationally and in most states. In 2005, only 101,821 persons with I&DD were served in ICFs/MR in contrast to 146,657

⁶ The definition of “related condition” is similar to but somewhat narrower than “developmental disability,” which is defined in the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000.

⁷ Steve Eiken, Brian Burwell, and Becky Selig (2006). *Medicaid HCBS Waiver Expenditures, FY 2000 through FY 2005*. Cambridge, MA: Medstat.

⁸ Robert Prouty et al., *op. cit.*

⁹ The average cost of ICF/MR services was \$117,600 in 2005.

in 1991.¹⁰ In 2005, about 77 percent of all persons with I&DD who received Medicaid-financed long-term services were supported through the Medicaid HCBS waiver authority.

HCBS waivers for people with I&DD account for a disproportionate share of total nationwide waiver expenditures for all populations. For example, in 2003, people with I&DD made up 40.4 percent of all HCBS waiver participants nationwide but accounted for 74.8 percent of all waiver expenditures.¹¹ In 2005, HCBS waiver expenditures for people with I&DD accounted for 75 percent of all HCBS waiver expenditures for all populations. Expenditures per waiver participant with I&DD are substantially higher than per person expenditures for waivers that serve other target populations (e.g., older persons and working age adults with non-developmental disabilities).¹²

The relatively high costs of furnishing HCBS to people with I&DD is attributable to several factors, primarily the nature of their disabilities, which often require the provision of continuous personal assistance and supervision in licensed community residences. Individuals with I&DD also typically receive day habilitation services.

Effect of Increasing Service Demand on States

One of the most notable factors affecting states is the rising expressed demand for I&DD services. While the number of people with I&DD receiving Medicaid waiver HCBS has increased substantially since 2000, many states have seen their waiting lists for HCBS continue to grow rapidly. For example, starting in 1999, Florida doubled the number of people served through its HCBS waiver for people with I&DD from 12,000 to 25,000, in order to reduce its waiting list. However, more and more people are seeking services and the state's waiting list for services has climbed to about 12,000 individuals. In Texas, the state's "interest list" for I&DD services has reached 46,000 persons and continues to grow each month.

While there are no reliable comprehensive nationwide data regarding the total number of people with I&DD who are wait-listed for HCBS, the clear trend among the states has been for service demand to grow at a faster pace than the rate at which states have been able to expand service system capacity. Service demand also appears to be growing at a rate greater than underlying general population growth. In many states, the amount of time that people are spending on waiting lists exceeds three or more years. In several states, people who are wait-listed include individuals who are characterized as having "emergency" or "critical" needs.

¹⁰ *Ibid.*

¹¹ Martin Kitchener, Terence Ng, Charlene Harrington, and Molly O'Malley (2006). *Medicaid 1915(c) Home and Community-Based Service Programs: Data Update*. Washington, DC: Kaiser Commission on Medicaid and the Uninsured.

¹² *Ibid.* In 2003, per participant expenditures through I&DD waivers were \$35,888 versus \$8,177 for waivers that served all other waiver target populations (e.g., seniors, people with other types of disabilities).

In many states, the expansion of HCBS waivers for people with I&DD involved shifting the financing of services from programs supported only with state funds to Medicaid funding. Thus, in some states, the expansion of HCBS waivers did not result in a net increase in the number of individuals served. State budget problems earlier in this decade spurred this refinancing while also limiting the extent to which many states could respond to rising demand. The growing number of people with I&DD on waiting lists is also the byproduct of longer-term underlying trends, including increased longevity (which results in lower turnover among people receiving services), and the growing cohort of individuals who live with aging caregivers who over time are less able to provide care.

Twenty-five states have been sued in federal court by persons with I&DD who have been wait-listed for services. Many of these lawsuits have resulted in settlement agreements wherein the state agreed to expand services. More broadly, states are confronted by high and continually rising service demand that will be very costly to meet at the current per person HCBS waiver costs. States also face other cost pressures, including attracting an adequate workforce to provide HCBS.

Supports waivers that operate under relatively low cost maximums represent an effort by several states to address these pressures, that is: (1) reduce waiting lists by providing lower-cost service packages that presume the continued provision of unpaid family caregiver support; and (2) divert demand away from more costly residential services. As discussed in more detail in the next section, supports waivers are designed to complement the supports that family caregivers provide to people with I&DD, including adults.

The premise of supports waivers is that furnishing services to individuals who live with their families will reduce or at least postpone the demand for the costly residential services that have been the mainstay of HCBS waivers for people with I&DD. In their design, supports waivers share some of the same characteristics as waivers for older persons and people with other types of disabilities that rely on caregiver relatives to provide support to the waiver participant. They are not, however, modeled significantly on state family support programs that have traditionally served children living at home.

Federal Policy Factors

The emergence of supports waivers for people with I&DD has also been influenced by the evolution of federal policy concerning the operation of HCBS waivers. In particular, the January 2001 issuance of State Medicaid Director Letter #01-006 (a.k.a., *Olmstead* Letter #4) barred states from operating waivers that restricted some waiver participants to a limited benefit package. CMS policies concerning states' authority to impose dollar limits on the amount of waiver services that a person may receive have also evolved.

Olmstead Letter #4.¹³ Historically, most states operated a single HCBS waiver for people with I&DD. Such waivers provided a comprehensive range of services, ranging from the provision of services and supports in licensed residential settings to services furnished in the family home. In practice, many of these waivers imposed internal capacity controls (i.e., limits on the total number of individuals who may receive specific services) that limited access to the full range of services covered in the waiver. Some states restricted individuals to receiving a smaller package of in-home support services and/or day services but did not allow access to residential and other types of services. Indeed, in some waivers, participants who lived with their families were wait-listed for residential services covered in the waiver.

In January 2001, the Health Care Financing Administration (now CMS) issued State Medicaid Director Letter #01-006 (hereinafter referred to as *Olmstead Letter #4*). This letter addressed the question of whether a state could operate a single waiver but within the waiver restrict some waiver participants to the receipt of a limited package of waiver services. The letter stated:

A state is obliged to provide all people enrolled in the waiver with the opportunity for access to all needed services covered by the waiver and the Medicaid state plan. Thus, the state cannot develop separate and distinct service packages for waiver population subgroups within a single waiver. The opportunity for access pertains to all services available under the waiver that an enrollee is determined to need on the basis of an assessment and a written plan of care/support.

The effect of *Olmstead Letter #4* was to prevent a state from operating what is termed a “waiver within a waiver”--that is, a waiver that was internally partitioned to control the number of persons who could access certain types of waiver services. In essence, the letter made it clear that, once a person is enrolled in a waiver, the person must be able to obtain any service that is available through the waiver if needed. *Olmstead Letter #4* established that a state must provide the full range of waiver services that such individuals might require without respect to budget limitations.

Olmstead Letter #4 has affected how states employ HCBS waivers to support people with I&DD and has spurred the emergence of distinct supports waivers. States interested in furnishing a limited package of waiver services to individuals could no longer operate a “carve out” limited benefit package within a single waiver. Instead, states would have to design a distinct waiver to cover the limited package. The outcome has been the creation of supports waivers that operate side-by-side with comprehensive waivers, with the latter covering more costly residential services. States can enroll individuals in the less costly supports waiver with less budgetary risk to the state. Capacity limits on both the comprehensive and supports waivers can be used to manage overall HCBS waiver spending.

Individual Cost Limits. A defining characteristic of supports waivers is their imposition of an overall dollar limitation on the amount of services that may be authorized for waiver participants. Changes in federal policy have made it clear that a

¹³ Located at: <http://www.cms.hhs.gov/smdl/downloads/smd011001a.pdf>.

state may set this dollar limit at a level that is below the average cost of institutional services, providing a basis for states to design and implement supports waivers.

Federal HCBS waiver regulations (42 CFR 441.301(a)(3)) permit a state to restrict enrollment in a waiver to individuals for whom the cost of waiver services is not expected to exceed the cost of serving the person in the Medicaid institutional setting for which the waiver stands as an alternative. That is, a state may elect to refuse the enrollment of a person in a waiver if the expected costs of supporting the person would exceed the average cost of the institutional services for which the person would be eligible.

With respect to HCBS waivers for people with I&DD, states have varied in whether they have imposed an individual cost limit as a condition of waiver enrollment. As a general matter, most states have not imposed such a limit so that they can accommodate individuals who have intensive support needs, including persons transitioning to the community from state public institutions. States that do not impose an individual cost limit manage waiver spending to an aggregate average through the imposition of utilization and cost controls on the services covered by the HCBS waiver. These states are sometimes portrayed as managing to an “aggregate limit.”

Prior to 2002, CMS permitted states to impose an individual cost limit that was significantly lower than the cost of institutional services. Setting a limit well below the costs of institutional services made it possible for states to exercise great financial control over the costs of waiver services. For example, the Colorado Supported Living Services (SLS) waiver imposed an individual cost limit of \$35,000, well below the costs of ICF/MR services.

In 2002, CMS issued the Independence Plus waiver template, which was designed to facilitate the implementation of self-direction of waiver services. However, the template explicitly barred states from imposing an individual cost limit that was less than the cost of institutional services. At the time, CMS determined that such restrictive cost limits were not permitted under federal law.

In order to accommodate states that wished to limit their financial exposure in operating a waiver, CMS offered the alternative of allowing states to impose limitations on the dollar amount of “clusters” of waiver services that could be authorized. Between 2002 and 2005, CMS approved at least four supports waivers--in Ohio, Tennessee, Texas, and Washington--for people with I&DD that capped the dollar amount of groupings of services and, *de facto*, permitted a state to cap the total amount of services that would be provided to waiver participants.

In 2005, when revising the HCBS waiver application, CMS decided that the waiver statute in fact permitted setting an individual cost limit less than the cost of institutional

services.¹⁴ Appendix B-2 of the revised waiver application permits a state to specify an individual cost limit that is less than the cost of institutional services.

Thus, current federal policy gives states the authority to design and implement supports waivers for people with I&DD that cap the dollar amount of services furnished. The ability to target waiver services to specific groups of waiver beneficiaries allows states to design waivers for people who have family caregivers who can furnish support to them and, further, exclude costly residential services from the array of services offered under a waiver.

¹⁴ The revised HCBS waiver application and accompanying instructions are located at: http://www.cms.hhs.gov/HCBS/02_QualityToolkit.asp.

IV. OVERVIEW OF SUPPORTS WAIVERS

This overview provides summary information about the supports waivers operating in 17 states. Individual state profiles that provide greater detail for each state are found in Appendix A.

Defining Characteristics of Supports Waivers

Supports waivers for people with I&DD generally have the following defining characteristics:

- **Target Population.** The target population of these waivers is persons with I&DD who require the level of care furnished in an ICF/MR but who live with their families and do not require licensed residential services. In other words, the target population consists of persons who have access to unpaid supports that can meet a substantial portion of their overall support needs.
- **Dollar Limit.** Supports waivers operate under a dollar limit on the total amount of HCBS that may be authorized for a participant. In general, these dollar limits are set at levels substantially below the average cost of serving a person in the state's comprehensive waiver or in an ICF/MR.
- **Services.** In general, supports waivers include the provision of personal assistance, day services outside the home and supported employment services (for adults) along with other ancillary services (e.g., therapeutic services). Supports waivers exclude the provision of services in licensed residential settings.
- **Service Planning/Authorization.** As is the case in any HCBS waiver, the services that participants receive are authorized through a service planning process that determines which services a person may receive.
- **Quality Assurance.** Supports waivers are subject to the same federal requirements as all waivers with respect to quality assurance, including periodic monitoring, the identification of issues that may negatively affect the health and welfare of participants, and remediation of such issues.

In some instances, states have incorporated consumer-direction/self-direction features into supports waivers. In the context of Medicaid HCBS waivers, self-direction means that the waiver participant (or a representative) may serve as the common-law employer of direct support workers and/or has the authority to manage an individual budget. The

authority to manage an individual budget may include the allocation and reallocation of funds among goods and services and/or directing the provision of services.

Number of States Operating Supports Waivers

Table 1 shows the trend in the number of states operating supports waivers since 2000. In 2000, four states operated five supports waivers; 13 additional states launched supports waivers between 2001 and 2006. At the end of 2006, 17 states operated one or more supports waivers in tandem with a comprehensive HCBS waiver for people with I&DD. As can be seen, there has been steady annual growth in the number of states operating supports waivers since 2000. Colorado was the first state to operate a supports waiver, launching its SLS Waiver in 1995. Georgia has a request pending CMS approval to reconfigure its waivers for people with I&DD into a comprehensive/ supports waiver configuration that will be implemented in 2007. Additional states are developing supports waivers.

TABLE 1. States Operating Supports Waivers							
	Through 2000	Implemented aft 2000 ...					
		2001	2002	2003	2004	2005	2006
Cumulative Number of States Operating Supports Waivers	4	7	8	12	14	17	17
States	CO OK (2) ⁸ PA SD	LA (1) MT OR	IN	AL MO OH NE (1)	TX WA (2)*	CT FL TN	NE (2)* LA (2)*
Cumulative Number of Supports Waivers in Operation	5	8	9	13	16	19	21
NOTE: Four states (Louisiana, Oklahoma, Nebraska, and Washington) operate two or more supports waivers. Two (Louisiana and Nebraska) began with one and added another later. Two states (Oklahoma and Washington) implemented two supports waivers in the same year.							

Age Groups Served

Of the 21 supports waivers in operation, three (Louisiana, Oklahoma, and South Dakota) target only children with I&DD. Another seven (in Colorado, Louisiana, Montana, Nebraska, Oklahoma, and Oregon) serve only adults with I&DD. The remaining 11 target both children and adults with I&DD.

Funding Limits

Supports waivers' funding limits (i.e., the maximum amount of waiver services that may be authorized on behalf of a waiver participant) range from a low of \$5,000 per year (South Dakota) to a high of \$52,000 per year (Connecticut). Each state's limit is displayed in Table 2. In nine of the 17 states, the funding limit falls in a range between \$13,000 and \$22,000 per year. The funding limits that apply to supports waivers for

children with I&DD tend to be lower than the limits for programs that support adults. These lower limits are due to the availability of the full range of Early and Periodic Screening, Diagnosis, and Treatment Medicaid state plan benefits as well as services funded through education agencies for school-aged children.

In a few states, the funding limit is variable. For example, the Tennessee supports waiver limit is \$30,000 but up to an additional \$6,000 may be authorized to address short-term emergency needs, a practice that Washington State also uses. In the Oregon supports waiver, the funding limit varies based on difficulty of care factors and family caregiver circumstances. In most states, the funding limit functions as an upper limit on the amount of waiver services that may be authorized. The actual amount of services authorized is based on the individual's waiver support plan and the assessed need for a service.

Some states also impose additional dollar/unit limitations on the amount of particular covered services that may be authorized. For example, in Colorado the total amount of environmental engineering services that may be authorized (which include home modifications, special equipment and supplies, and certain other types of supports) is limited to \$10,000 per year.

TABLE 2. Supports Waiver Expenditures and Funding Limits*

State	2006 Expenditures Per Participant	Funding Limit	Percent of Limit Utilized
AL	\$8,950	\$18,000	49.7%
CO	\$15,983	\$35,000	45.7%
CT	\$24,443	\$52,000	47.0%
FL	\$8,700	\$14,700	59.2%
IN	\$8,520	\$13,500	63.1%
LA	\$9,225	\$15,000	61.5%
MO	\$4,222	\$22,000	19.2%
MT	\$6,252	\$7,800	80.2%
NE	\$9,158	\$20,000	45.8%
OK	\$9,661	\$18,899	51.1%
OR	\$8,505	\$20,000	42.5%
PA	\$12,738	\$21,200	60.1%
SD	\$4,015	\$5,000	80.3%
TN	\$18,051	\$36,000	50.1%
TX	\$8,669	\$10,000	86.7%
WA	\$13,581	\$19,000	71.5%
Average			48.4%

* Ohio is not included because it does not have a fixed funding limit.

Utilization: Supports Waiver Expenditure v. Funding Limit

Table 2 also shows the average expenditure for waiver services per supports waiver participant versus the annual funding cap for the supports waiver. As can be seen, in all states actual waiver expenditures per participant are below the applicable supports waiver funding limit. The percentage of the funding limit utilized ranged from a

low of 19.2 percent in Missouri to a high of 86.9 percent in Texas. On average, actual supports waiver expenditures per participant are slightly less than one-half of the applicable funding limit.

The difference between the maximum amount of funding that may be authorized and actual expenditures per waiver participant likely stems from several factors. In some cases, the amount that is authorized on behalf of a specific waiver participant may be lower than the funding limit based on the person's assessed need for specific services and individual/family choices and preferences. In addition, some states impose additional limits on the amount that may be authorized for specific services. Other factors include staff scheduling problems and consumer absences. A relatively common complaint voiced by individuals and families is that they frequently experience difficulty in locating providers to furnish the services that have been authorized in their waiver service plans.

It is not unusual for actual expenditures to be less than the amount authorized in waiver service plans. However, the relatively large gap between the amount that may be authorized and actual expenditures is striking, especially because supports waiver funding limits themselves typically are 20-50 percent below the average costs of the comprehensive waivers with which they are paired.

Supports Waiver Service Coverage

Table 3 shows the types of services that are covered in supports waivers. The table employs a waiver service classification scheme that HSRI developed to facilitate the comparison of service coverages across supports waivers. This classification scheme is further described in the introduction to Appendix A.

As can be seen from Table 3, most supports waivers cover a common set of basic services and supports (e.g., respite, in-home supports [typically personal assistance], transportation, and home modifications). Supports waivers that serve adults with I&DD usually cover one or more types of day supports that are provided outside the family home such as supported employment, group or individual community participation activities, adult day habilitation training, and pre-vocational services.

As a general matter, the service coverages provided through supports waivers often mirror the services that states furnish through their comprehensive waivers except for the coverage of residential services. To the extent that the coverages are the same between both types of waivers, waiver participants are able to select from the state's existing pool of established service providers. Some of the variation among states in the coverage of services is due to differences in the scope of services offered under the Medicaid state plan in each state.

TABLE 3. Supports Waiver Service Coverage																		
Service Category	AL	CO	CT	FL	IN	LA	MO	MT	NE	OH	OK	OR	PA	SD	TN	TX	WA	Total All Waivers
Case Management/ Service Coordination	*	*	*	X	X	X	*	*	*	*	*	X	*		*	*	*	4
Supports for Participation Direction (Support Broker)			X									X			X			3
In-Home Services	X	X	X	X		X	X	X	X	X	X	X	X	X	X	X	X	16
Respite	X		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	16
Day Supports	X	X	X	X	X	X	X	X	X	X	X	X	X		X	X	X	16
Health Related	X	X			X	X		X		X	X	X	X	X	X	X	X	13
Supported Employment	X	X	X	X	X	X	X	X			X	X			X	X	X	13
Transportation	X	X	X	X	X		X	X		X	X	X	X	X	X		X	14
Person Directed Goods and Services											X				X			2
Equipment/ Supplies	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	17
Vehicle Repair/ Modification		X	X		X	X	X		X					X	X			8
Clinical Service	X	X	X	X	X		X		X		X	X	X		X	X	X	13
Environmental Accessibility Adaptations	X	X	X	X		X	X	X	X	X	X	X	X	X	X		X	15
Financial Management Services			**									X	**		X			2
Family and Caregiver Training			X		X	X					X	X					X	6
Other	X	X	X	X	X			X		X		X					X	9
Total by State	10	10	12	10	11	10	9	9	7	8	11	14	8	7	13	9	11	
* Service coordination furnished as Targeted Case Management coverage or via Medicaid administrative claiming rather than as a waiver service. ** Financial management services furnished administratively rather than as a waiver service and are furnished to support individuals who hire their own workers and/or manage an individual budget.																		

In most cases, case management (service coordination) is not covered as a waiver service but instead is furnished under the Medicaid state plan via the Targeted Case Management coverage under §1915(g) of the Social Security Act or as a Medicaid administrative expense. This means that the costs of performing case management on behalf of supports waiver participants does not result in a claim against the funding limit that applies to the waiver.

Consumer/Self-Direction

An important development in the delivery of HCBS is the incorporation of self-direction of services into waivers. A growing number of states are offering waiver participants the opportunity to directly manage their waiver services. However, so far, most states that operate supports waivers have not covered the infrastructure associated with the self-direction of waiver services. This can be detected from the absence of waiver services such as supports for participant direction (support brokers)

or financial management services. Financial management services assist individuals and their families in directly hiring their own workers and/or managing an individual budget. Only five of the 17 states (Connecticut, Missouri, Nebraska, Oregon, and Tennessee) have structured their supports waivers to incorporate consumer/self-direction features. In other states, individuals and families are permitted to select services and service providers within their budget allocation but the full range of self-direction opportunities is not available to waiver participants.

About “Self-Direction”

“Self-direction” refers to service practices that grant individuals significant authority to manage their benefits. Key characteristics generally include:

- An individual budget allocation for services;
- Development of a person-centered plan of services that is driven by individual needs and preferences;
- Individual/family hiring and direct supervision of service providers;
- Specialized methods to process payments to service providers and track expenditures.

Number of Individuals Participating in Supports Waivers

Chart 1 shows the trend in waiver enrollment from 2000 to 2006 for the 17 states that presently operate supports waivers. The chart shows total waiver enrollment and breaks down enrollment between the supports and comprehensive waivers operated in these states.¹⁵

In 2000, these 17 states accounted for 35.3 percent of all waiver participants with I&DD nationwide. During the period 2000-2006, total waiver enrollment in these states increased by roughly 64,000 individuals or 62.7 percent. Comprehensive waiver enrollment increased by 24 percent. Enrollment in supports waivers accounted for 62.9 percent of total enrollment growth. By 2006, 27.6 percent of all waiver participants in these states were enrolled in supports waivers.

The high rate of growth in number of supports waiver participants during this period, of course, is mainly due to the fact that many of these states were just launching their supports waivers. Still, it is evident that these states expanded overall waiver enrollment at a rapid pace and that the implementation of supports waivers accounted for a substantial share of enrollment growth. At the same time, these states also expanded the availability of comprehensive waiver services, albeit at a lower rate. As a general matter, it is evident that as the number of supports waivers in operation scaled up, the expansion of comprehensive waivers decelerated, especially after 2003.

¹⁵ Indiana, Montana, and Washington were unable to provide 2006 enrollment and expenditure figures. In this and the subsequent charts, 2005 enrollments and expenditures for these states have been carried forward.

CHART 1. Supports and Comprehensive Waiver Enrollment 2000-2006 (17 States)

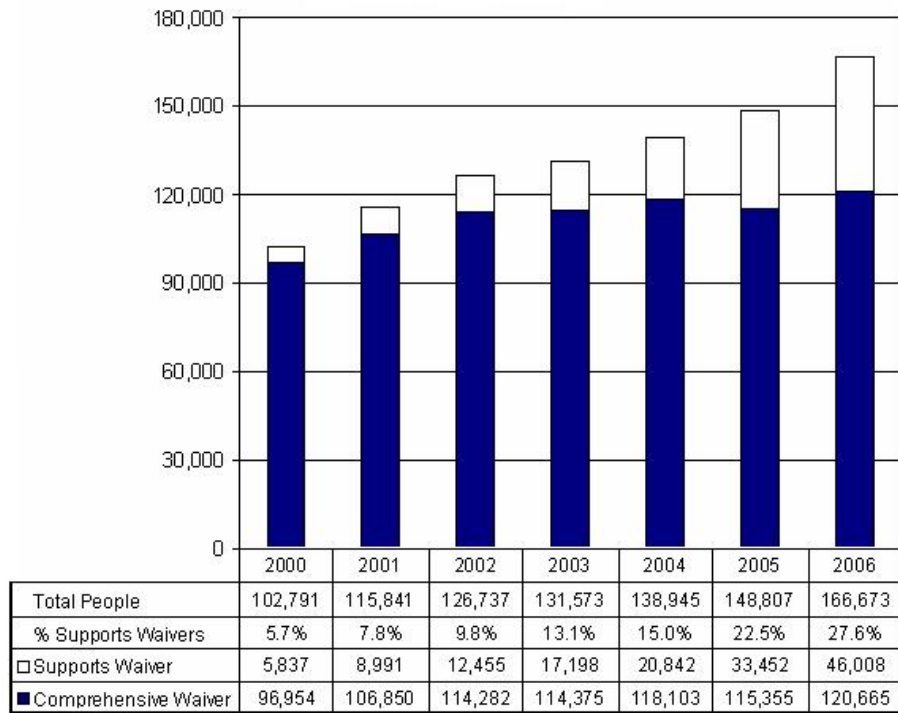
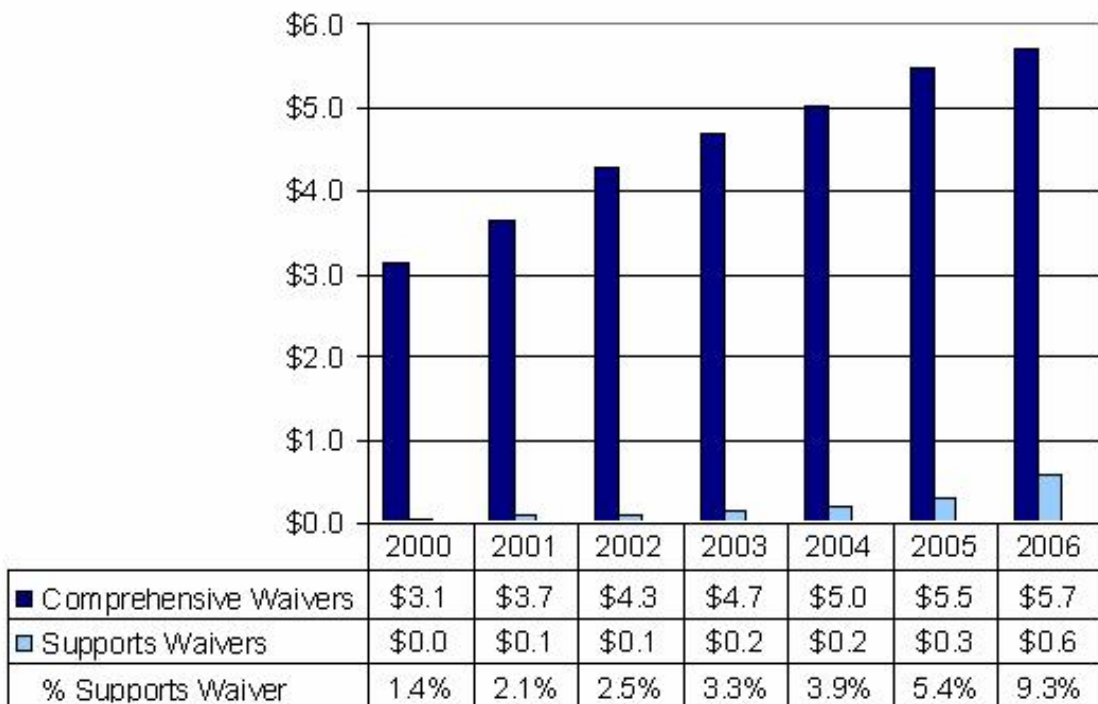


CHART 2. Comprehensive and Supports Waiver Expenditures Trends 2000-2006 (17 States) (\$ Billions)

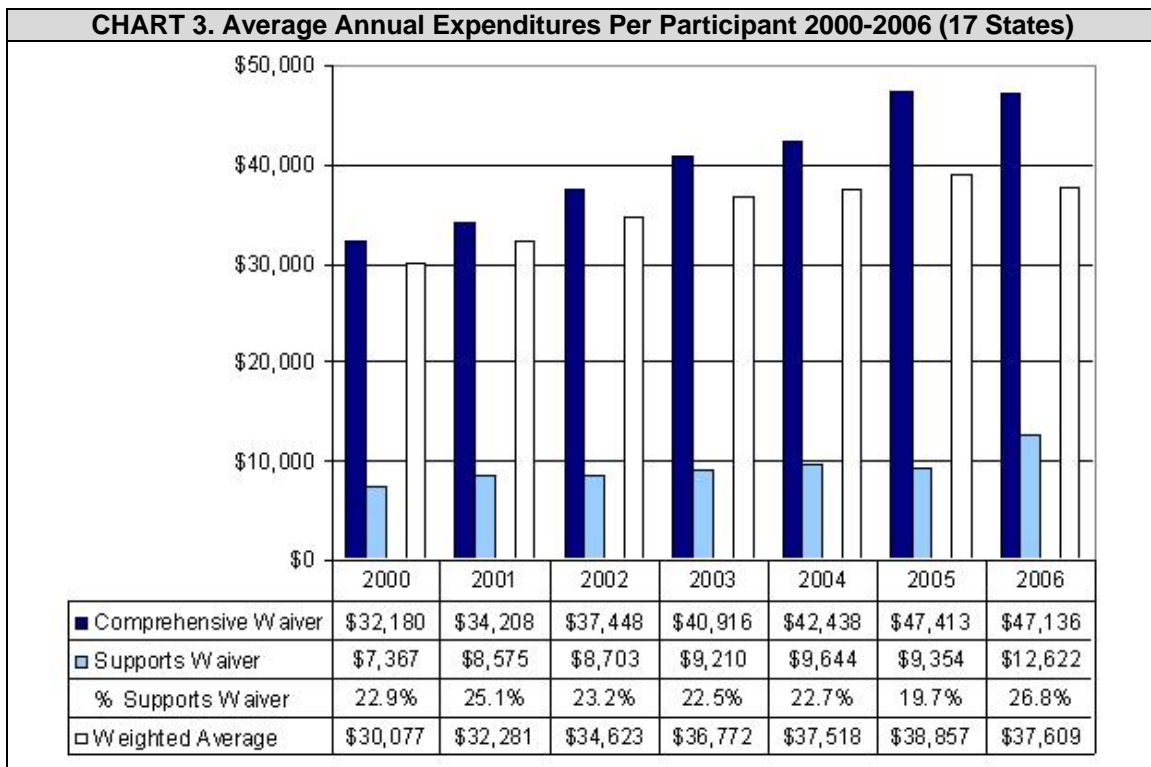


Trends in Total HCBS Waiver Expenditures

Chart 2 shows HCBS comprehensive and supports waiver expenditures during the period 2000-2006. As can be seen from the chart, supports waiver expenditure growth parallels the growth in the number of supports waiver participants. Among the 17 states, supports waiver expenditures made up 9.3 percent of the total \$6.3 billion in I&DD waiver expenditures in 2006 while supports waivers participants accounted for 27.6 percent of the total waiver participants.

Expenditures Per Waiver Participant

Chart 3 shows average per participant expenditures for the comprehensive and supports waivers operated by the 17 states along with: (a) the weighted average per participant expenditure for both types of waivers in combination (weighted by the number of participants in each type of waiver); and (b) supports waiver per participant expenditures as a percentage of comprehensive waiver per participant expenditures.



In 2006 the average expenditure per supports waiver participant was 26.8 percent of the average expenditure per comprehensive waiver participant. During the 2000-2006 period, the relationship between supports and comprehensive per participant costs ranged between 19.7 and 26.8 percent. Year-by-year variation in the relationship of per

participant expenditures between the two types of waivers principally stems from the phase-in of additional supports waivers across the period.

Of potentially greater interest are the effects of the implementation of supports waivers on the weighted average cost of furnishing waiver services in these states. As can be seen from the chart, the effect of the introduction of supports waivers has been to stabilize average waiver participant costs in these states, especially after 2003. Across the 17 states, the weighted average cost per waiver participant for both types of waivers in combination remained essentially unchanged from 2004 to 2006. The increasing proportion of waiver participants served through supports waivers in these states has slowed the rate of increase in per participant expenditures.

Variance Across States in Per Person Spending

Table 4 shows the variance across states in average per person spending for both comprehensive and supports waivers. As shown, for supports waivers, average spending per participant in 2006 was \$12,662, although spending ranged from a low of \$4,222 in Missouri to a high of \$24,443 in Connecticut. This variance is due in part to the different funding limits that states have adopted for their supports waivers. The figures in the last column show per participant expenditures in supports waivers as a percentage of per participant expenditures in comprehensive waivers. States vary considerably with respect to this measure, ranging from a low of 11.3 percent of comprehensive waiver expenditures in Missouri to a high of 46.9 percent in Ohio. To date, no clear relationship has emerged between supports and comprehensive waiver per participant costs.

State	Comprehensive Waiver Expenditures per Participant	Supports Waiver Expenditures per Participant	Supports Waiver Expenditures as a Percentage of Comprehensive Waiver Expenditures per Participant
AL	\$41,433	\$8,950	21.6%
CO	\$54,999	\$15,983	29.1%
CT	\$72,205	\$24,443	33.9%
FL	\$26,303	\$8,700	33.1%
IN	\$65,569	\$8,520	13.0%
LA	\$49,756	\$9,255	18.6%
MO	\$37,208	\$4,222	11.3%
MT	\$29,893	\$6,252	20.9%
NE	\$50,526	\$9,158	18.1%
OH	\$48,435	\$22,733	46.9%
OK	\$63,577	\$9,661	15.2%
OR	\$55,000	\$8,505	15.5%
PA	\$67,574	\$12,738	18.9%
SD	\$33,581	\$4,015	12.0%
TN	\$60,385	\$18,051	29.9%
TX	\$37,480	\$8,669	23.1%
WA	\$56,771	\$13,581	23.9%
Average	\$47,136	\$12,622	26.8%

State Waiting Lists

One of the policy aims expressed by states for launching supports waivers is to reduce or at least slow the growth of the number of people waiting for services. The implementation of supports waivers has enabled these states to expand the availability of HCBS to a great extent. Except for South Dakota, each of the 17 states had a waiting list for services. Collectively, these waiting lists totaled 142,100 individuals. Wide variations in the relative number of people waiting for services existed across the 17 states, ranging from approximately 10 percent of the number of people served to, in some cases, upwards of twice the number of people served. In some states (e.g., Colorado, Louisiana, Oklahoma), supports waiver participants are wait-listed for comprehensive waiver services but are unable to receive them due to funding limitations. In other states (e.g., Florida and Texas), individuals who enroll in a supports waiver may continue to be wait-listed for comprehensive waiver services.

Except for Connecticut, none of the 16 states with waiting lists reported a decline in the overall number of people on waiting lists post-implementation of their supports waivers. The effect of the implementation of supports waivers on waiting lists is difficult to pinpoint. These states are continuing to experience surging service demand. While supports waivers have permitted these states to absorb some of this demand, not enough demand has been addressed to prevent waiting lists from continuing to grow.

V. SUMMARY OF CASE STUDIES

Six states were selected to examine in depth the status of supports waivers and the role they play in meeting the needs of people with I&DD. The states selected were: Florida, Missouri, Oklahoma, Oregon, Pennsylvania, and Tennessee. The case studies were compiled by conducting structured discussions with key informants in these states and the results of these state-by-state discussions are recapped in Appendix B. Unless otherwise cited, the information in this section is based on these discussions.

Each state's supports waiver emerged as a result of circumstances unique to the state and operates under its own distinct policies and protocols. Nevertheless, the six states share much in common. The following summary highlights the findings in several key areas.

Policy Goals

Respondents described two primary policy goals that underpin their state's interest in operating supports waivers: cost containment and wait-list reduction. Another goal that was often cited was to promote self-direction of HCBS.

Cost Containment. Respondents all agreed that supports waivers provide an economical alternative to comprehensive waivers. Reasons cited to illustrate how supports waivers reduce spending per participant are as follows:

- They do not offer 24-hour care and supervision in a person's home or in a community residential facility.
- They allow states to both specify the number of waiver participants and limit the amount spent per participant.

While states can hold down per participant spending within comprehensive waivers, the supports waiver caps are better defined and more readily enforced, enabling states to more accurately predict costs and control spending.

Wait-List Reduction. Most respondents expressed concern about wait-lists. The average number of persons on wait-lists across the six states was 4,988--ranging from 2,000 in Oregon to 12,011 in Florida.

- All of the states have databases that enable them to track people as they move on and off the wait-list. In most states, individuals wait for services for more than two years. Oregon has set a goal to reduce the wait period to 90 days or less when its *Staley* lawsuit settlement agreement is completed. The longest wait time, reported by a Florida respondent, was five years.

- Informants unanimously viewed the supports waiver as an important, practical tool for addressing the wait-list. Though most could not cite empirical evidence to this effect, they reasoned that the lower-costs associated with supports waivers allowed more people to receive services than would have been possible if the state had only a comprehensive waiver.

Self-direction. Some respondents indicated that incorporating self-direction into state policy and practice is an important policy goal of supports waivers. This includes granting individuals significant authority to manage their benefits by: (a) exercising authority over service planning within a specific benefits allocation; (b) selecting service providers; and (c) managing these providers. Some states also allow individuals to choose and manage support workers outside the traditional provider network, such as friends, neighbors, relatives, or others.

Respondents in Oregon said that its supports waiver was designed with the clear intent of promoting self-direction. Tennessee, Missouri, and Pennsylvania also permit some degree of self-direction. Overall, however, although many respondents expressed interest in self-direction as a policy goal, the majority of respondents admit that implementing self-direction is secondary to the goals of cost containment and wait-list reduction.

Waiver Operations

While particular waiver operations vary among states, they have much in common.

Information Available about Participants. Respondents from all states indicated that the ability to track individuals in a supports waiver by key characteristics, service use, and expenditures enabled the state agency to manage its resources more efficiently.

- Most states use a variety of means to gather and analyze basic descriptive information on supports waiver participants (e.g., age, primary disability, living arrangement, functional status, and caregiver characteristics). However, most respondents noted the need to upgrade their information management systems (particularly in Missouri and Tennessee) to gain more in-depth information on beneficiaries and families and to more easily link to other state-managed databases. On the other hand, Oregon compiles especially robust information about its supports waiver participants.
- As systems become increasingly decentralized and self-directed, states reported the need to be able to track in real-time the status of services and individual spending. Presently, states' information systems lack this capacity, although some states, such as Oregon and Florida, are working toward it.

Access and Admission. States differ in how easily people can enroll in the supports waiver.

- States vary in how--and how energetically--they inform potential users about the supports waiver. All states describe the program on their websites and make print materials available.

In all states, case managers are often the ones who first bring the supports waiver to the attention of individuals and their families; but this practice appears to be uneven across a given state. Family advisors to states reported that individuals were not always informed of the option by case managers, but heard about it by word of mouth and at family-focused conferences or other meetings.

- Enrollment depends on the availability of funds and urgency of need. Determining the urgency of need can be a complex process; some needs may not be as urgent as others, but may have greater implications if they are not met. For instance, some individuals may be in “crisis,” others have “urgent” needs but are not in crisis, and so on.
- Some states use a systematic assessment process to sort applicants by urgency of need and give priority to emergency or crisis applications. In Missouri, for instance, a “utilization review team” considers applications to determine individual need status. Oregon uses an “order of enrollment procedure” that is detailed in two pages and includes a method for sorting waiver applicants by urgency of need. Likewise, Pennsylvania uses the Prioritization of Urgency of Need for Services system to obtain information about urgency of need.

Allocations per Participant. All states limit per participant budgets based on a pre-set allocation, which is set using systematic means such as an assessment instrument (e.g., the Supports Intensity Scale). These measures can be used in tandem with other descriptive information to quantify an individual’s level of need and match it to a specific allocation.

Many respondents reported that the process used to set personal allocations is an on-going source of tension. Some argued that formal measures do not always satisfactorily capture individual circumstances and needs and questioned the amounts allocated. They sometimes cited examples where they believed that individuals received too low an allocation. Some also noted that the allocations inappropriately limited the type or amount of services a person could receive.

For example, budget limits can pose dilemmas for individuals and families that affect the selection of services. For example, using the budget to purchase more costly supported employment services can translate into fewer hours of services outside the family home than the selection of lower-cost facility-based day services. From the family’s perspective, facility-based services may be preferred because more “covered hours” per day can be purchased and ensure that their family member has services at a

set time and place each day. While integrated employment might be preferred by the individual, fewer hours can be purchased and the service schedule might be irregular.

In response, others argued that though the procedures may miscalculate by some degree a person's allocation, systematically applied processes offer a "fair" way to allocate resources. Further, some noted that by pre-setting budgets based on individual scores, state staff could more easily manage an overall budget.

Service Planning and Risk Assessment. States use case managers or support brokers within a "person-centered planning" protocol to generate service plans, assess risk, and accommodate requests to switch providers.

- In most states, case managers or brokers are responsible, on average, for 50 people, ranging from a low of 29 in Oklahoma to a high of 70 in Missouri.
- Individuals and families generally are informed of their allocation before they begin planning.
- Many respondents indicated that individuals and their families have significant decision-making ability within their budget allocation, though they are not always fully aware of this authority.
- Individual plans are limited in scope and flexibility depending on the waiver service array.
- Family advisors to states expressed frustration about having a budget allocation for their family members that they hoped would be flexible enough to meet their needs, only to discover that the services permitted under the waiver did not satisfactorily match their needs. Several respondents advocated for expanding the waiver service array. They argued that, if funding is capped, it should not matter what particular services are covered because the cost to the state would be the same.
- Service planning typically does not include a distinct process to identify and address risks related to health and well-being. Risks, however, are typically identified and well documented in the service planning process along with steps to address identified risks in the individualized waiver service plans.
- Some respondents indicated that supports waivers entail the strong involvement of participants' family, with whom they often live, which often reduces concerns about the individual's health and safety. Others fairly noted, however, that some families may not be able to provide the level or quality of support required.
- All states have processes to help participants change their service plan or service providers, starting with contacting a case manager or service planner. The

process that follows can take some time to complete, but respondents reported that it is generally managed easily within an acceptable period of time.

Services and Supports. Supports waivers, especially those emphasizing self-direction, encourage use of a diverse and flexible provider network that can offer individualized and sometimes unique services. We found that states vary in how well-developed local services and supports are. In addition, states must also be ready to respond to needs that exceed what can be offered through a supports waiver.

- Individuals often seek alternative sources of support outside the “traditional” provider network. As a result, respondents explained that local providers are challenged to reshape the services they offer or to diversify their operations to accommodate new service demand. Some service agencies are open to change and seek to provide more flexible service arrays, while others resist change or complain that they cannot deliver services at the reimbursement rates at which they are offered.
- Most respondents reported that provider networks--traditional or alternative--vary in their capacity to meet the emerging service demand generated by supports waivers. Participants sometimes have difficulty finding direct support workers due to workforce shortages--particularly in rural areas--caused in part by insufficient resources to offer wages and benefits that will attract workers.
- Respondents in every state expressed concern about the competencies of workers that individuals and families are hiring, especially friends or neighbors who are not affiliated with service agencies. Respondents often described circumstances where individuals and their families had no assistance to train these workers. Respondents were concerned about the quality of support that these workers are providing.

Many respondents indicated that on one hand, individuals welcome the freedom to hire the workers of their choice, but workers often cannot be found, and a shortage of workers requires individuals to hire workers that they would rather not. Respondents in all states reported that more must be done to recruit, train, and support workers and that this responsibility cannot be left solely to individuals and their families.

All states have developed mechanisms to address the needs of individuals who require more support than the waiver can offer. Sometimes, the funding limit can be adjusted upward so that additional support can be purchased or funding is temporarily augmented from other state funds.

Ultimately, when participants’ needs exceed what the supports waiver can offer, the individual must be referred to the state’s comprehensive waiver.

If this waiver is at its limit, the individual is put on the wait-list but continues to receive services through the supports waiver. Respondents, however, reported that relatively few people need to transfer from supports to comprehensive waivers.

Quality Assurance. Supports waivers present state agencies with unique challenges related to quality monitoring and assurance activities. Respondents indicated that most states apply to the supports waiver the same basic quality assurance and quality management practices they use in their comprehensive waivers. However, they recognized that states need to modify their approach to quality assurance because supports waivers differ from comprehensive waivers in two important ways. First, the individual's place of residence is often not a licensed residential facility, but the family home. Second, the staff hired to provide supports are often not employed by traditional service providers but are recruited from among family, friends, or others in the community.

Because participants' family homes are often their place of residence and the "staff" hired can be other family members or friends, the quality oversight mechanisms for the comprehensive waiver are not always a good match. Respondents wondered how "on-site visits" should be handled and how incident reports should be handled when difficulties arise in the family home. Further they wondered how the actions of a decentralized, "alternative" workforce can be properly overseen.

Issues like these are not so easily resolved, and respondents in all states indicate that they are working to determine how to modify quality assurance systems to match the unique service delivery circumstances of supports waivers. All states have methods for resolving complaints or grievances filed by participants. Typically they involve a systematic "Fair Hearing" process for complaints or a protocol designed to air and resolve grievances. States reported a low volume of grievances and complaints.

Waiver Impacts on State Systems

It is too early to report data on system impacts because the states selected for the case studies have relatively new supports waivers and are still focused on implementation--setting governing rules and regulations and working out various procedural difficulties. Oregon officials characterized the state's supports waiver as an evolving program, which they continually review and revise to make improvements and address technical problems.

States are still developing the infrastructure to support these waivers, including: (a) information systems to track service delivery, spending, and impacts per participant; (b) training for service planners; (c) improvements in the capacity of local provider networks; and (d) revisions to quality assurance mechanisms.

While focused on implementation, respondents did report on the waivers' operations and their perceptions of outcomes to date.

- States are generally satisfied with the waiver's ability to contain costs and reduce the waiting time for services, allowing them to serve many more people than would have been possible through the comprehensive waiver alone.
- While self-direction was not typically a driving policy goal of these waivers, all states are interested in administering the waiver to incorporate self-direction. In this regard, Oregon is noteworthy in having a well-developed statewide "service brokerage" model.
- Based on anecdotal reports, participants and their families are satisfied with supports waiver services in large part simply because they are off the waiting list and receiving some measure of support. In this regard, family members also value the supports waiver because they say it helps keep the family together and enables them to engage in other activities, including employment outside the home.

Key Issues in the Operation of Supports Waivers

We asked respondents to tell us about issues their states are dealing with as they implement their new supports waivers and to offer suggestions for improving them. Their comments are summarized below.

- ***Wait-Lists and Resources.*** While the supports waivers have decreased the time spent on wait-lists for many, thousands of people remain on lists, due to lack of funding, an issue that is unlikely to change due to larger state budget issues. To address this problem, several respondents said that states need to redesign their systems to ensure that individuals receive only the supports they need. They felt that some people receiving comprehensive waivers services may be "over-served" and may be more efficiently served in the supports waiver.
- ***Limits in Participant Allocations.*** Respondents differed in their views on funding limits. Some felt increases were needed to provide participants the support they need while others countered that raising the limit would undercut the cost-saving benefit associated with supports waivers, and that individuals with higher needs may be better served by the comprehensive waiver.
- ***Staffing.*** Respondents in all states described difficulties recruiting and retaining staff. Some observed that supports waivers open opportunities to recruit additional workers who may be willing to work part-time or on an as-needed basis but it is still difficult to find workers, especially in rural areas. The inability to find staff can lead to families settling for workers they would not ordinarily hire. In addition to disrupting service delivery, high staff turnover increases training costs.

Respondents in all states recognized that the ability to recruit successfully from appropriate labor pools depends on the wages and benefits offered, including workers compensation coverage and health insurance and that allocations under the supports waivers are not sufficient to provide this coverage. As a result, as respondents observed, the prevailing hiring conditions reduces the labor pool that can be drawn from to secure staff.

- **Liability.** Some respondents expressed concerns about liability for on-the-job injuries when workers do not have either private health insurance or workers' compensation coverage. It was not clear to them who would or could be held legally liable for the costs associated with injuries but some felt it could ultimately be the state. Others, however, argued that if families and individuals acted independently to recruit, hire, train, and manage their own staff, then they alone may be liable for the costs of injuries.

Several respondents felt that workers should be covered by workers' compensation insurance, but this may not be easily achieved given its cost. Covering workers could be particularly difficult for individuals or families who employ several workers, all of whom work part time.

In Florida, some families have purchased riders to their homeowner's insurance to cover potential liabilities associated with workers being injured on-the-job in the family's home. Overall, many respondents agreed that states should implement policies to reduce family liability for job-related injuries.

- **Role of Representatives.** In supports waivers that incorporate self-direction, services are often planned and directed by a representative--typically family members. Some respondents expressed concerns that care needed to be exercised to ensure that families were not "taking over" decision-making from the participant. Given that individuals often have an intellectual disability, respondents acknowledged the lack of a simple solution. Most agreed, however, that there is a growing awareness of the problem among people with developmental disabilities, family members, and policy makers, and attempts are being made by these parties to find workable solutions.

Oregon has developed a "conflict of interest" policy that addresses the potential for a conflict of interest when a representative such as a family member is directly involved in decision-making for an individual, but may derive personal financial benefit from a particular decision. In such instances, local supports brokers are required to: (a) identify and describe potential conflicts of interest; (b) determine if the decision does not accord with the participants' preferences or interests; and (c) seek further action to resolve any apparent conflicts of interest.

- **Systems Infrastructure.** Respondents mentioned several infrastructure shortcomings, including:

- *Management and information systems.* All states operate management information systems to track use of their HCBS waivers. These systems, however, do not presently collect the full range of information on individual beneficiaries and their families that is needed to refine supports waiver policies and practices. In addition, these systems generally are not yet linked to other state-managed databases, such as those with information specific to quality enhancement or assurance. For example, although Florida initiated its supports waiver in 2005, the state has not yet modified its information systems to the degree needed to integrate information across databases.
- *Quality assurance.* States need to develop specific quality monitoring and assurance systems for supports waivers because the systems developed for comprehensive waivers are not always a good match. For instance, states need to develop strategies to better assess the competencies of workers who are not affiliated with provider agencies.

Additionally, states need to develop a more outcome-oriented approach to supports waivers. Quality indicators would help participants and staff members identify areas where improvement is needed.

- **Training.** Respondents acknowledged that states need to address workers' training needs and provide participants and their families with training or other resources to acquire the skills they need to recruit, train, and retain satisfactory staff.
- **Program Design.** Respondents mentioned several program design or procedural issues that states were working to resolve.
 - *How to set reasonable individual allocations.* Respondents disagreed about the best way to set individual service allocations as well as the amount of the allocation.
 - *The comprehensiveness of the service array.* Many respondents believe that supports waivers should at least cover the same services as comprehensive waivers (with the exception of residential care). Given that states set spending limits for each participant, covering a wide range of services can increase an individual's and family's ability to match services to needs without increasing costs.

VI. SUPPORTS WAIVERS: IMPACT AND CONTINUING CHALLENGES

Observations About the Impact of Supports Waivers

It is important to recognize that supports waivers are a relatively recent phenomenon, although they draw upon the long history in many states of furnishing more limited state-funded family support services to people with I&DD. At this juncture, while it is difficult to draw firm conclusions about their effect on state I&DD service delivery systems, based on the information obtained during this study, the following observations are offered:

- ***Supports waivers improve access to HCBS.*** Supports waivers have enabled a greater number of people with I&DD to obtain essential services and supports. The availability of federal Medicaid financial participation for supports waivers has permitted states to leverage their dollars to serve more persons. In general, participants and their families--many of whom have spent extended periods on a wait-list--appreciate that they are now receiving some services. Nonetheless, all the states that operate supports waivers continue to struggle with growing waiting lists. While supports waivers have given states a tool to expand access to HCBS more economically, service demand continues to surge.
- ***Supports waivers have slowed the growth of more costly comprehensive waivers.*** The implementation of supports waivers in the 17 states appears to have at least slowed the growth of comprehensive waiver services and stabilized the overall per participant costs of furnishing waiver services in these states. Service demand is being channeled away from higher cost services--specifically, residential services.
- ***Supports waiver participants appear to have access to comprehensive waiver services when necessary.*** A major concern among families and disability advocates is that people who are enrolled in supports waivers will be cut off from access to comprehensive waiver services when needed. There is no systematic evidence that states are not transitioning individuals to comprehensive waiver services as necessary. In each of the six case study states, individuals have transitioned from one waiver to another based on urgency of need. In addition, states generally provide supplemental services/funding to supports waiver participants when necessary. Still, the lack of guaranteed access to comprehensive waiver services when necessary remains a source of concern for many individuals and families.
- ***Supports waivers appear to be meeting the needs of most participants and their families.*** In the six case study states, there has been relatively little movement from the supports to the comprehensive waiver. This provides some

measure of evidence that supports waivers are adequately meeting the needs of participants and families. In practical terms, the supports waivers appear to be meeting the objective of avoiding costly out-of-home placements through the provision of in-home and community-based day services. At the same time, in many states, there are significant numbers of supports waiver participants who are wait-listed for comprehensive waiver services. This indicates that supports waiver enrollment postpones but does not eliminate the need for comprehensive waiver services. Moreover, in many states that operate supports waivers, there are serious questions about whether supports waivers are fully responsive to the needs of individuals.

The experience to date with supports waivers leaves at least two major questions related to their impact unanswered:

1. What is the appropriate balance between supports and comprehensive waivers? Among the 17 states, different proportions of waiver participants are being served in their supports and comprehensive waivers. Similarly, there are wide differences in the amount of dollars allocated to each type of waiver.
2. What is the appropriate funding limit to apply to a supports waiver to ensure that individuals can be successfully supported in their homes and communities? As previously discussed, there is wide variation in the funding limits that states apply to supports waivers. The amount of the funding limit under which a supports waiver operates has implications for the extent to which the needs of individuals can be met without resorting to costly residential services.

Challenges in the Operation of Supports Waivers

Looking forward, states must grapple with three key challenges in the operation of supports waivers: (a) finding resources to build infrastructure to support service delivery; (b) resolving various design and procedural issues related to their operation; and (c) fitting supports waivers into existing service systems to efficiently and effectively complement comprehensive waivers.

Finding Resources to Build Infrastructure. Supports waivers have some unique infrastructure requirements that are still being identified and addressed. Too often, insufficient resources are available to build the needed infrastructure. For example:

- When resources are limited and spending efficiencies valued, state officials need information systems that allow quick, real-time tracking of individual and aggregate spending. With such data, states can allocate funds more efficiently and serve additional people. Available information systems are not presently up to the task. In at least one state, the lack of these data led to the lapsing of funds that could have been used to support additional individuals.

- In some respects, case managers are more important to the success of supports waivers than they are for comprehensive waivers where residential provider agencies manage services. Yet, respondents noted insufficient numbers of case managers, too high caseloads, insufficient training, and high turnover.
- Supports waivers also challenge states to fashion new methods to monitor and ensure service quality, as well as participants' health and well-being, within systems that are increasingly decentralized. Some services are delivered by traditional providers where time-tested practices still apply. Participants also receive services in their home, provided by relatives, neighbors, or friends. In this context, traditional quality assurance practices are not always appropriate.

With limited resources and pressure to serve additional people, states must determine what portion of available resources to dedicate to infrastructure development as opposed to increased enrollment.

Resolving Operational Challenges. To date, the implementation of supports waivers in most states has not been accompanied by expanded opportunities for individuals and families to direct the full range of their services and supports. A few states (Oregon and Connecticut) provide for the full range of opportunities for individuals to self-direct their supports waivers, by providing person-centered planning, individual budgets, choice of services and providers, and specialized means for processing payments to providers. Most states, however, do not provide such opportunities at all or only to a limited extent.

Implementation of full-featured self-direction appears to pose significant operational challenges for most states that operate supports waivers. Many of these challenges are relatively new to the state systems that serve individuals with I&DD, where services traditionally have been managed by/through a single provider agency. Some of the challenges include setting individual funding allocations, defining a satisfactorily broad service array, ensuring sufficient flexibility in service choice and delivery, ensuring that individuals lead the service planning process, finding ample numbers of support workers, offering these workers wages and benefits that will increase recruitment and retention, and others.

Another operational challenge is the development of methods to allocate individual funding limits. The application of single one-size-fits-all funding limits to supports waivers may be problematic, particularly when a crisis brings participants up against the waiver funding cap. Some supports waivers are already addressing this issue by allowing additional temporary funding increases to the waiver cap (e.g., Ohio, Tennessee, and Washington).

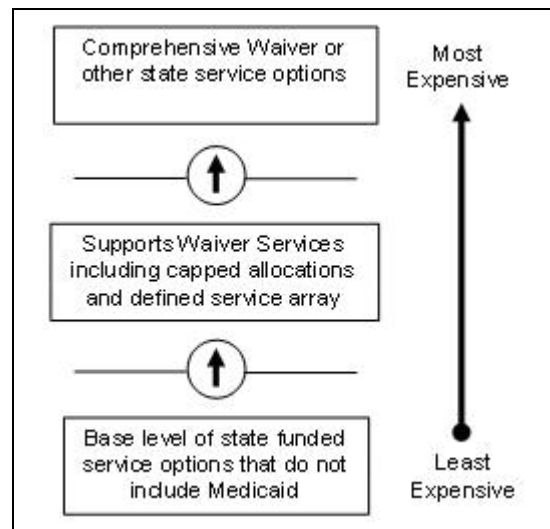
As states gain more experience operating supports waivers, they will likely need to develop more sophisticated approaches to setting budget allocations. Some states are already using assessment data and other information to establish individual or tiered funding limits within a supports waiver in order to graduate the amount of funding that is

available to individuals. Different approaches to establishing funding limits/budget allocations may enable states to serve individuals in supports waivers that have a wider range of service needs while maintaining appropriate financial controls.

A potentially satisfactory alternative approach is to adopt graduated funding limits that scale upward from a base funding limit. Oregon uses such an approach in its supports waiver for people with developmental disabilities. All waiver entrants are subject to a standard funding limit (\$9,600 per year). Oregon has created a tool that steps up the maximum amount of services that can be authorized based on participant “difficulty of care” factors and/or limitations on the ability of family caregivers to provide support. This tool is scored and funding can be increased to \$14,400 and then \$20,000, based on the score.

Fitting Supports Waivers into the Overall System Structure. A major challenge for states is determining how to incorporate supports waivers in the larger service system so they will complement comprehensive waivers and other state-funded options to create a seamless, cost effective approach to supporting people with I&DD in the community. Currently, states are using supports waivers as one service option among several to primarily address cost containment and wait-list goals.

Several state leaders, however, view supports waivers as an option within a range of supports that includes the comprehensive waiver and other state-funded options, configured from least to most costly. Ideally, these options would fit together to provide a seamless, cost effective approach whereby individuals would be matched to the option that most effectively meets their needs. Individuals might start by accessing modest amounts of state-funded services that may suffice without any use of waiver services. If more supports are needed, individuals could be enrolled in a supports waiver. Finally, if still more supports were needed, the individual could be enrolled in the more costly comprehensive waiver.



Current systems are not nearly as efficient. Individuals, for example, may be enrolled in a more expensive comprehensive waiver when they could be ably served in a supports waiver. Alternately, some may be “getting by” in a supports waiver but might be better served in a comprehensive waiver. But supports waivers are still relatively new and modestly funded and individuals are not so easily assigned or reassigned to various service options. Individuals enrolled in the comprehensive waiver, for example, cannot be transferred to a supports waiver without their agreement.

If supports waivers and comprehensive waivers grow apart in policy and procedure over time, the resulting community services and supports system may be neither seamless nor coordinated. To prevent this from happening, states may need to revise the boundaries between supports and comprehensive waivers. For example, Colorado does not permit the delivery of comprehensive waiver services in the family home but is now considering changing that policy so that people who need especially intensive services can continue to reside with their families. In contrast, Oregon already provides for the continuation of services in the family home when people need to transition from the supports to the comprehensive waiver.

Concluding Observations

States face major challenges in addressing the needs of people with I&DD. Nearly every state is grappling with a large waiting list for services and the prospect that demand for services will continue to climb due to a wide range of demographic factors, including the aging of family caregivers with whom most people with I&DD reside. The high per person costs of furnishing comprehensive waiver services has led states to search for lower-cost alternatives to address rising service demand.

Clearly, operating supports waivers offers a means for a state to channel demand away from costly residential services and, thereby, address service demand more economically. Supports waivers have provided states with a vehicle in which to deliver community services and supports for people with I&DD more economically by leveraging family caregiving and employing tighter financial controls on the amount of services that are authorized. The rapid growth in the number of states operating these waivers--especially since 2003--is noteworthy.

States are using these waivers as a means to respond to rising service demand. There seems little doubt that the number of states operating these types of waivers will continue to grow. Additionally, because supports waivers offer a lower-cost alternative to comprehensive waivers, state policy makers may be more amenable to periodic increases in funding for services for people with I&DD.

Still much work remains. To make most effective use of supports waivers, states will need to ensure that proper resources are in place to support them, operational difficulties are resolved, and an appropriate role for these waivers is found within the larger state system. Within this context these waivers show great promise for establishing a next generation of person-centered home and community services for individuals with I&DD.

ACRONYMS

A	
APD	Florida Agency for Persons with Disabilities
B	
BSCI	Basic Supplement Criteria Inventory (Oregon)
C	
CAP	Community Alternatives Program (Washington)
CCB	Community Centered Board (Colorado)
CDDP	Community Developmental Disability Programs (Oregon)
CLASS Waiver	Community Living Assistance and Support Services Waiver (Texas)
CMS	U.S. Centers for Medicare & Medicaid Services
CSLA	community supported living arrangements (Colorado)
CSP	Community Supports Program (Nebraska)
CSW	Community Supports Waiver (Missouri, Montana)
D	
DADS	Texas Department of Aging & Developmental Services
DD Waiver	Developmental Disabilities Waiver (Indiana)
DDSD	Oklahoma Developmental Disability Services Division
DDSPD	Oregon Office of Developmental Disability Services Seniors & Persons with Disabilities
DMRS	Tennessee Division of Mental Retardation Services
DPW	Pennsylvania Department of Public Welfare
F	
FICS	family and individual consultation and support (Connecticut)
FSL Waiver	Family and Supported Living Waiver (Florida)
FSW	Family Support Waiver (South Dakota)
FY	fiscal year
H	
HCB-DD Waiver	Home and Community-Based Services for the Developmentally Disabled Waiver (Colorado)
HCBS	home and community-based services
HCFA	U.S. Health Care Financing Administration
HCS	Home and Community-Based Services Program (Texas)
HSRI	Human Services Research Institute
I	
I&DD	intellectual and other developmental disabilities
ICF/MR	intermediate care facility for the mentally retarded

IFS Waiver	Individual and Family Support Waiver (Connecticut)
IO Waiver	Individual Options Waiver (Ohio)
ISO	intermediary service organization (Pennsylvania)
ISP	individual support plan
L	
LAH Waiver	Living at Home Wavier (Alabama)
M	
MOCDD Waiver	Missouri Children with Developmental Disabilities Waiver
MR/DD	mental retardation and other developmental disabilities
MRLA	Mental Retardation Local Authorities (Texas)
MSO	managed services organization
N	
NOW	New Opportunities Waiver (Louisiana)
O	
OBRA	Omnibus Budget Reconciliation Act
OCA	Oklahoma Office of Client Advocacy
OMR	Pennsylvania Office of Mental Retardation
P	
PERS	personal emergency response system
PFDS Waiver	Person and Family Direct Support Waiver (Pennsylvania)
PSR	Physical Status Review (Oklahoma)
PUNS	Prioritization of Urgency and Need for Services (Pennsylvania)
R	
RFW	Residential Facility Waiver (Ohio)
RTI	Research Triangle Institute
S	
SDWP	Self-Determination Waiver Program (Tennessee)
SLS Waiver	Supported Living Services Waiver (Colorado)
SSAW	Supports Services for Adults Waiver (Oregon)
SSI	supplemental security income
T	
TCM	Targeted Case Management (Nebraska)
TxHL	Texas Home Living Waiver
U	
UR	Utilization Review (Missouri)

GAUGING THE USE OF HCBS SUPPORT WAIVERS FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES: FINAL PROJECT REPORT

Files Available for This Report

Main Report

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr.pdf>

Appendix A. State-by-State Supports Waiver Profiles

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr-appendA.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr-appendA.pdf>

Appendix B. State-by-State Case Study Results

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr-appendB.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr-appendB.pdf>

Appendix C. Case Study Discussion Guides*

PDF: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr-appendC.pdf>

* This Appendix is currently not available as an HTML file.