



*The* LEWIN GROUP

# **An Independent Assessment of the West Virginia MR/DD Waiver**

*Prepared for:*  
**Bureau for Medical Services**

*March 30, 2005*

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## I. EXECUTIVE SUMMARY

This is an independent assessment of West Virginia's MR/DD waiver conducted for its renewal application to the Centers for Medicare and Medicaid Services (CMS). As background, the report provides a national perspective on the service and support environment for individuals who are mentally retarded or who have a related developmental disability. States continue to experience a growing demand for long term services provided in community settings. As the life expectancy of Medicaid recipients increases and the caregiving population grows older, more individuals are eligible for and need waiver services. At the same time, states are facing budget crises and are looking to balance legitimate service needs with tight revenues. This is the environment in which this assessment took place.

The Lewin Group (Lewin) developed a framework to study West Virginia's MR/DD waiver using the concepts of access, service, quality, and cost effectiveness. Lewin first performed a desk review of state waiver materials including operations manuals, program rules, copies of reports, and guidelines for billing and payment. Next, Lewin conducted a series of interviews and focus groups with state officials, providers, advocacy organizations, and consumers. These interviews allowed Lewin to examine issues each stakeholder group considered important. Finally, Lewin performed a quantitative analysis of services provided under the waiver through a review of a five percent sample of Individual Program Plans (IPPs) and related service and billing documentation. Lewin was then able to provide an assessment of the MR/DD waiver, and recommendations for improvement.

- *Access:* Paths of access to waiver programs vary in states across the country. West Virginia uses its service coordination provider agencies to serve as the main path into the waiver program. Providers are responsible for assisting with applications, facilitating assessments, and then serving as the initial service coordinator. West Virginia does not provide any payment to providers to assist with applications, which can be a time consuming and expensive process. Once enrolled in the waiver, recipients often find themselves receiving service coordination services from the same agency that provides other major direct services such as day habilitation or residential habilitation. Receiving service coordination from an agency which provides other waiver services can create a conflict of interest between the needs of the consumer and the needs of the provider.
- *Service provision:* Both consumers and providers believe that the waiver provides a wide array of services. Since its last waiver renewal, West Virginia has continued to add to the list of available services which now includes both adult companion services and environmental adaptation. However, many consumers still do not receive the level of services called for in participants' IPP. The Lewin analysis found that 77 percent of residential habilitation, day habilitation, and respite care services were delivered below levels authorized in the IPP. Respite care was provided an average of 73 hours (36 percent) less a month to recipients than IPPs authorized. Day habilitation was provided approximately 28 hours (46 percent) a month less. This service pattern may be the result of IPPs not correctly assessing the needs of consumers or a lack of availability of services.

- *Quality Assurance:* West Virginia has implemented a new quality assurance program over the past few years. The new program was developed with input from consumers, families, and providers and closely follows the protocol developed by CMS. West Virginia is currently finishing up its first round of provider reviews and hopes to soon have statewide reports available. While Lewin was unable to perform a full assessment of the quality assurance system due to its recent development, the system appears to be in line with CMS guidance on quality assurance.
- *Cost Effectiveness:* West Virginia's MR/DD waiver is operating well within cost effectiveness requirements laid out by CMS. According to CMS 372 reports, the average monthly waiver cost per person was \$3,528, well under the average monthly ICF/MR cost of \$6,400.

## II. INTRODUCTION

This report summarizes the findings of a comprehensive assessment of West Virginia's Section 1915(c) Home and Community-Based Services (HCBS) Medicaid Waiver for persons with mental retardation and related developmental disabilities (MR/DD).

### A. Purpose

For the 2005 renewal of the MR/DD waiver, West Virginia elected to conduct an independent evaluation of its HCBS waiver for persons with MR/DD. When a state chooses to provide for an independent assessment of the waiver, it must arrange for an independent contractor, such as a state entity that has no responsibilities to the Medicaid agency, a state university, or a non-governmental entity. The contractor must evaluate the quality of care provided, access to care, and the cost effectiveness of the waiver. In October 2004, the West Virginia Bureau for Medical Services (BMS) contracted with The Lewin Group to conduct an independent evaluation of the MR/DD waiver.

### B. Scope

This report reflects The Lewin Group's assessment of West Virginia's efforts to effectively and efficiently operate its MR/DD waiver. The assessment included an evaluation of the quality of services, access to services, and the cost effectiveness of the waiver. Lewin developed the following questions to guide the assessment:

- How difficult is it for West Virginians to access the waiver? Once enrolled in the waiver, do consumers have a choice of providers?
- Do waiver consumers receive the services they need? Which facets of the service system serve as facilitators and which serve as barriers?
- Are the opinions, ideas, and feelings of waiver consumers sought and honored in the planning and delivery of their services?
- Has West Virginia implemented an effective quality assurance system for the waiver to ensure participant health and safety?
- Has the state operated the waiver in a cost effective manner? What changes could be made to increase cost effectiveness?

### C. Methodology

To address the key investigative questions listed above, Lewin assessed the waiver across four dimensions:

- *Access* – Within this area of inquiry, Lewin explored how consumers and families learn about and apply for HCBS waiver services. Lewin examined waiting list procedures as well as how individuals and families access services once enrolled in the waiver.

- **Services** – Lewin reviewed the services offered under the waiver including the service array, service definitions, and limitations on the scope, duration, and frequency of services. Lewin also reviewed a sample of claims to compare services authorized under Individual Program Plans with services delivered (claims paid).
- **Quality**– Lewin reviewed West Virginia’s Quality Management Initiative to assess consumer and family input into the quality process, as well as state and local follow through on problem areas identified by the Quality Management Initiative.
- **Financing** – Lewin studied waiver reimbursement methodology and payments mechanisms, and reviewed State General Funds MR/DD programs. Lewin also reviewed service costs under the waiver and compared those costs to ICF/MR expenditures.

Information used to develop this study came from a number of sources including existing state data on characteristics of HCBS waiver recipients and expenditures, and reports related to the waiver quality assurance strategy, with an emphasis on incident reporting procedures and related follow up activities. This included annual reports submitted to the Centers for Medicare and Medicaid Services (CMS) on waiver performance by the state for each year of this waiver renewal period.

Lewin reviewed a representative sample of individual program plans (IPPs) and related billing and claims payment information; this totaled 300 case files. Service coordination providers compiled the IPPs, including the MR/DD Waiver Program Services Cost Estimate Worksheet, the DD-6 Form, and the Bureau of Medical Services (BMS) produced claims reports for these IPPs. This information was compared to BMS provider billing for the months of April and October 2003.

Lewin conducted a series of meetings with: a) State agency staff with waiver administrative responsibilities; and b) support coordinators, providers, and direct support staff. Approximately fifteen state staff were interviewed over the course of one day. Providers participated in a “town-hall” style meeting facilitated by Lewin; providers also submitted extensive comments by a state provider organization on behalf of its members, the West Virginia Behavioral Healthcare Providers Association.

Lewin also conducted a series of six focus groups with consumers and families. Three focus groups were held in Charleston, while the remainder were held in Morgantown; a total of 60 individuals participated. Lewin also received, and reviewed for this report, written comments from over 30 individuals and families who were unable to participate in the focus groups.

### III. BACKGROUND

The MR/DD service and support environment is one of the most complex disability service systems in the nation. This is due to a number of factors including major Medicaid financing and related regulatory oversight and requirements, ongoing challenges associated with the available supply of services and supports and mounting demand, and ever evolving definitions of what defines quality services. Below, Lewin establishes a context for the assessment of West Virginia's MR/DD waiver.

#### A. National Overview of Medicaid HCBS Waivers for Persons with MR/DD

##### 1. Service Environment

Commonly cited estimates of the number of persons with MR/DD are 4.5 million individuals or approximately 1.58 percent of the U.S. population.<sup>1</sup> In 2002, total public spending for MR/DD services was approximately \$34.6 billion; almost 80 percent of this amount was used to fund community services while the remaining 20 percent covered institutional costs.<sup>2</sup>

The vast majority of persons with MR/DD live with family caregivers, approximately 61 percent or 2.8 million individuals. Others live in their own homes, with spouses, or in supervised residential settings, either community-based or ICF/MR group home settings. Individuals living at home receive the bulk of supports and services from family caregivers or other sorts of informal, unpaid assistance.<sup>3</sup> In fact, the nation's formal long term care service system (i.e., all paid institutional and community-based services) for all persons of advanced age and persons with disabilities of any age provides only a fraction of the total of support and caregiving; the majority of support services are delivered informally by family members or other sources of natural supports.<sup>4</sup>

Growth in public spending for persons with MR/DD and their families has been strong in recent years, weathering all but the most severe budgetary environments in a handful of states. Between 2000 and 2002, public spending for persons with MR/DD grew by 13 percent in inflation-adjusted dollars.<sup>5</sup> Spending on community services has grown significantly and now outpaces institutional spending for persons with MR/DD. However, even with spending growth, demand for MR/DD services continues to outpace availability, especially for residential services, resulting in waiting lists and unmet need.

The MR/DD service system faces several key challenges that impact service availability:

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<sup>1</sup> Larson, S., Lakin, K.C. MR/DD Data Brief, *Prevalence of Mental Retardation and/or Developmental Disabilities: Analysis of the 1994/1995 NHIS-D*.

<sup>2</sup> Braddock, D., et. al. *The State of the States in Developmental Disabilities*. 2004 Edition. American Association on Mental Retardation., Washington, DC.

<sup>3</sup> Ibid.

<sup>4</sup> Arno, P., Levine, C., Memmott, M. The Economic Value of Informal Caregiving. *Health Affairs*, 18 (2), 182-188.

<sup>5</sup> Braddock, D., et. al. *The State of the States in Developmental Disabilities*. 2004 Edition. American Association on Mental Retardation., Washington, DC.

- **Utilization of MR/DD services is rising.** The significantly increasing life expectancy of persons with MR/DD means that individuals enrolled in service programs, including HCBS Medicaid waivers, will receive services for more years than in the past. The outcome is a lower HCBS waiver turnover rate and a more rapid increase in demand than one would find based on population growth alone.<sup>6</sup>
- **Waiting Lists.** A key outcome of the phenomenon described above is the rapidly growing number of persons with MR/DD and their families on waiting lists for services. In 2003, approximately 73,000 individuals and families were waiting for residential services.<sup>7</sup>
- **Aging and Growing Demand for Services.** Aging has a two-pronged impact on the demand for MR/DD services. First, the graying of America is a widely known demographic trend and our aging society directly impacts the need for MR/DD services. As noted above, family members provide the bulk of services to persons with MR/DD; as these family caregivers age and their ability to provide support decreases, appropriate services must be available to assist them. Secondly, as children with MR/DD age, their care and support often becomes difficult for families who are typically lower income and have other children. Research indicates that half of families providing care to a child with MR/DD earn \$20,000 or less a year.<sup>8</sup> In addition to life's daily challenges, these families, both young and old, provide care for children with life threatening health impairments, difficulties in developing and maintaining adaptive skills, difficulties performing activities of daily living, needs for specialized supports, and who often have behavioral difficulties.

While researchers and state MR/DD officials assert that it is impossible to exactly measure the gap between current state MR/DD system capacity and demand, including HCBS waivers, there is unanimous agreement in the field that the difference is significant.

## 2. HCBS Waiver Growth and Development

Until 1981, Medicaid provided for long term care services virtually only in institutional settings; persons with MR/DD were served in Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR), state-funded institutions, and nursing homes. Growing support for the treatment of individuals in home and community based settings, as well as hopes of cost savings, prompted Congress to enact Section 2176 (Public Law 970-35) of the Social Security Act, which authorized the Medicaid Home and Community-Based waiver authority. Nationally, ICF/MR costs per persons were, and remain, more than twice that of HCBS.<sup>9</sup> The HCBS authority was intended both to meet the requests of consumers and families and to provide states and localities with fiscal relief from the costs of operating large, costly ICFs/MR.

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<sup>6</sup> Standcliffe, R. J., Lakin, K.C. 2004. *Policy Research Brief: Costs and Outcomes of Community Services for Persons with Intellectual and Developmental Disabilities*. University of Minnesota.

<sup>7</sup> Ibid.

<sup>8</sup> *Fast Facts on Families Who Provide Support At Home to Children With Disabilities*. National Center for Family Support, Human Services Research Institute.

<sup>9</sup> Prouty, R.W., Smith, G., and Lakin, K.C. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2003*. June 2004.

Under the HCBS waiver provisions, states may receive federal Medicaid funds to serve individuals with long term care needs in their homes and the community with services that are not Medicaid reimbursable under State Medicaid Plan options. Waivers provide states with vast flexibility in determining who is served, what those services are, and where and how those services are delivered. West Virginia currently operates two Medicaid HCBS waivers, an Aged and Disabled waiver and a MR/DD waiver. In 1982, national Medicaid HCBS MR/DD Waiver spending was \$1.2 million. By 2002 state and federal government expenditures totaled \$7.2 billion for MR/DD waiver services. Today, the number of people receiving HCBS is approaching four times the number of people living in ICFs/MR; just nine years earlier, there were more recipients in ICF/MR than HCBS.<sup>10</sup> All 50 states operate HCBS waivers with programs that vary considerably from state to state due to the flexibility noted above. In fact, several states operate multiple MR/DD waivers.

Because of the costs associated with ICFs/MR and media coverage of abysmal conditions in some of the nation's MR/DD institutions, most states implemented MR/DD waivers many years ago. Consequently, the MR/DD community has gained considerable operational expertise both in waiver design and also in the development of community-based capacity and infrastructure. The number of services and supports for MR/DD individuals the average state offers has grown considerably since HCBS waivers were authorized.<sup>11</sup>

### **3. Service Delivery Trends**

During the early 1980's, states faced a challenging fiscal environment analogous to today's economic environment. During this period, two key trends in MR/DD service delivery emerged because service system stakeholders discovered these strategies provided services efficiently and they aligned more with consumer and family preferences. The first trend was the development of consumer-centered service systems. As caseloads grew, case managers were faced with less time to focus on a single family or individual and, thus, knew less about the individual and his or her family for service planning purposes.

MR/DD stakeholders realized that by providing consumers and families with more control over service design and oversight, less paid professional staff time was needed.<sup>12</sup> Additionally, Ashbaugh, Bradley and Blaney note that the role of consumer direction and person-centered planning is significant "in developing a motivating vision, [that is a] far more powerful prod to action than compliance mandates or programmatic goals" set by disengaged professionals. Stated another way, individuals and their families will find services and supports that they choose and design more useful and fulfilling than those assembled by a third party. Evidence has also emerged, as many expected, that consumer-directed programs typically cost less than agency-driven models because participants blend paid services with natural supports.

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<sup>10</sup> Ibid.

<sup>11</sup> Braddock, D., et. al. *The State of the States in Developmental Disabilities*. 2004 Edition. American Association on Mental Retardation., Washington, DC.

<sup>12</sup> Bradley, V., Ashbaugh, J., and Blaney, B. *Creating Individual Supports for People with Developmental Disabilities, A Mandate for Change at Many Levels*. October 1994, pages 495-496.

A second service trend that emerged during the cash-strapped early 1980's is "family supports."<sup>13</sup> Until this time, the needs of people with MR/DD and their families were often measured and accommodated as though the facets of one's life (e.g., self, family, home, school, leisure) could be separated and treated in isolation. An alternative view, a family life-span view, places the individual within the full context of his or her life (Turnbull et. al., 2003).

Family support consists of services, supports, and benefits, some formal and some informal, that "allow families of people with MR/DD to live as much like other families as possible." Examples of family support include cash subsidy programs, respite care, family counseling, architectural adaptation of the home, in-home training, sibling support programs, education and behavior management services, and the purchase of specialized equipment.

Family support programs also typically offer information and referral services to other non-state or local benefits and services and assist families to coordinate informal supports. Family supports have become increasingly important to state MR/DD agencies because the provision of typical family support services is far less costly than out-of-home placement and because families and consumers have shown a clear preference for these services.<sup>14</sup> Family support data collected from state MR/DD agencies indicate that total family support expenditures continue to grow; from \$1.1 billion in 2000, serving 354,833 families, to \$1.4 billion for 403,306 families in 2002.<sup>15</sup>

## **B. West Virginia MR/DD Services**

West Virginia Medicaid provides MR/DD services using several programs including state general fund programs aimed at providing family support services and certain crisis services, ICF/MR and other State Medicaid Plan services, and the HCBS waiver. The funding for these services comes from a combination of state and federal sources. While the HCBS waiver is a significant source of Medicaid funding for MR/DD individuals, state general fund programs and State Plan benefits, especially ICF/MR, also provide important services and support to this population.

### **1. State General Fund Programs**

- *Family Support* began in West Virginia in 1991 with an initial appropriation of \$200,000. Today it has a budget of over one million dollars and assists 2,000 families, with expenditures per family varying widely. The program helps individuals and families plan for their needs and find resources. It identifies appropriate community and government programs, provides funding for goods, services, or home modifications, and supplies networking opportunities and support services. The program itself only employs one state employee, the program director, who oversees the project. There are

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<sup>13</sup> *What is Family Support?* National Center for Family Support, Human Services Research Institute. [http://www.familysupport-hsri.org/resources/r\\_fs.pdf](http://www.familysupport-hsri.org/resources/r_fs.pdf)

<sup>14</sup> Standcliffe, R. J., Lakin, K.C. (2004) *Costs and Outcomes of Community Services for Persons with Intellectual and Developmental Disabilities*. Policy Research Brief 14(1). Minneapolis: University of Minnesota, Research and Training Center on Community Living.

<sup>15</sup> Braddock, D., et. al. *The State of the States in Developmental Disabilities*. 2004 Edition. American Association on Mental Retardation., Washington, DC.

14 family support regions that each have a part-time family support coordinator employed by a provider in the region. The family support coordinator works with a regional family support council, which consists of parents, care givers, and people with developmental disabilities. The council reviews applications to the program and decides how it can best serve participating families. The council is also responsible for informing the community of the program through local outreach and may perform fundraising activities.

- *Crisis Services* are coordinated in West Virginia by the state and the West Virginia University Center for Excellence in Disabilities (CED). The state has contracted with providers for 11 short-term crisis beds for adults and seven beds for children. Four additional beds for children are planned to open in the Spring of 2005. The CED provides consulting services to help transition individuals from crisis services back into the community. Services offered by the state and CED include: parent education; consultations; out of home respite; in-home supports; shelters/child care setting, plus DD specialized supports for the setting; and a crisis respite site. The CED does not offer direct services, but works with the individual's team to train them to encourage positive behaviors and to support the development of a plan. After stabilization, the CED continues to offer Positive Behavior Support services, which take a long term approach to teaching participants new behaviors to replace challenging ones.

## **2. State Plan Services**

ICFs/MR were once the traditional delivery model of care for individuals with MR/DD. However, the push to provide HCBS set the stage for the dismantling of ICFs/MR in West Virginia and other states. The number of ICFs/MR around the country continued to decrease in 2002 while the cost per ICF/MR resident increased. In 1998, West Virginia joined nine other states in closing all large state-operated ICFs/MR. ICFs/MR services in West Virginia are now limited to smaller facilities, typically with 15 beds or less.

These homes are located around the state, are privately owned and operated, and have contracts with BMS. In 2003, approximately \$53 million was spent on ICFs/MR services in West Virginia, eight percent of total Medicaid spending on long term care services,<sup>16</sup> for its 515 MR/DD enrollees living in ICFs/MR.<sup>17</sup> The annual cost per person in West Virginian ICFs/MR is approximately \$102,999, ranking West Virginia 28<sup>th</sup> lowest of all the states. In terms of utilization, West Virginia ranked 29<sup>th</sup> lowest in ICFs/MR use per 100,000 of population with a rate of 28 ICFs/MR residents per 100,000 state residents.<sup>18</sup>

Persons with MR/DD who are Medicaid eligible also have access to all other State Medicaid Plan benefits that they are assessed to need. These services include targeted case management, clinic services, personal care services, home health services, and all acute care benefits.

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<sup>16</sup> Kaiser State Health Facts, Distribution of Spending on Long Term Care.

<sup>17</sup> Prouty, R.W., Smith, G., and Lakin, K.C. Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2003. June 2004.

<sup>18</sup> Ibid.

West Virginia received approval for a unique service delivery framework in its 2000 MR/DD waiver renewal; persons enrolled in the MR/DD waiver may not access targeted case management, clinic, or personal care State Plan services. In all other states, HCBS waiver participants may access State Plan benefits they are assessed to need. Should a Waiver service be analogous to a state plan benefit, Waiver participants must first exhaust the HCBS service before accessing the State Plan.<sup>19</sup>

Currently, the following State Plan benefits could be an important source of service to people who are Medicaid eligible, but are unable to access the waiver. Targeted case management provides recipients with case managers who assist the recipients in gaining and coordinating services, including medical, behavioral health, social, and educational services. Recipients are also eligible for screening, evaluation, service planning and linkage, service monitoring, crisis response, and advocacy/ rights protection services. Targeted case management recipients must live in non-institutional settings and may *not* be enrolled in the HCBS waiver.

Clinic Services are an optional Medicaid State Plan service, and a primary source of federal funding for day programs.<sup>20</sup> They are offered to individuals who are outpatients and live in their family's home or a general foster care setting. Clinic Services provide clinical and therapeutic services, as well as day treatment services, which must be provided at an enrolled clinic site. The day treatment services are time limited and must be prior authorized. The day treatment services, although limited, are an important source of support for MR/DD individuals not enrolled in the waiver.

West Virginia also provides personal care services for non institutionalized individuals who need assistance with activities of daily living. In 2002, 22 states had personal assistance programs including West Virginia, which had 1,498 participants and a budget of approximately \$1.2 million.<sup>21</sup> Personal assistance services may only be provided by agencies certified by BMS and the recipients must not reside with caregivers who are legally obligated to provide assistance, such as family members. A small number of individuals with MR/DD who meet all the criteria are eligible for the service. Home health services are also provided to beneficiaries as part of their written plan of care. Services may include visits by registered nurses or home health aides, medical equipment necessary for care, and a range of therapies.

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<sup>19</sup> HCBS services may not be identical to any State Plan Service because of the Medicaid program's non-duplication rules. States may establish differentiation by altering a service definition, or the scope, duration or frequency of a service. States may also offer "extended" state plan services under HCBS waivers that vary according to the above elements.

<sup>20</sup> Braddock, D., et. al. *The State of the States in Developmental Disabilities*. 2004 Edition. American Association on Mental Retardation., Washington, DC.

<sup>21</sup> Ibid.

#### IV. WEST VIRGINIA'S MR/DD WAIVER

West Virginia first implemented its Waiver program in March, 1984. Since its inception, CMS has renewed the waiver four times, and it is currently approved through June 30, 2005. According to the West Virginia Waiver Manual, the state's program allows individuals, who require an ICF/MR level of care, to receive certain services in a home or community based setting for the purpose of encouraging increased independence, personal growth, and community inclusion.

West Virginia's MR/DD Waiver program currently provides services to approximately 3,400 recipients. This figure represents an increase of over 1,100 individuals since 1999. Since 1999, enrollment has grown and the state has added four services (Adult Companion, Environmental Adaptation, Extended State Plan, and Skilled Nursing) (see below). At the same time, however, the average annual per person cost has fluctuated between \$43,517 in 2000 to \$42,343 in 2003.<sup>22</sup>

In 2003, West Virginia ranked 13<sup>th</sup> highest among all states in average annual waiver expenditures for all MR/DD recipients,<sup>23</sup> Although West Virginia was ranked highly, it is important to note that the state no longer operates large ICF/MR facilities and therefore serves a number of individuals with severe disabilities through the waiver. New Mexico, Rhode Island, and Maine who also no longer operate large ICFs/MR facilities had average annual expenditures of over \$60,000. *Table 1* compares ICF/MR and waiver spending in West Virginia and its neighboring states.

**Table 1**  
**Comparison of Spending for**  
**Waiver Services and Institutional Care**

State	% Waiver Spending	% ICF/MR Spending	Total Spending (in millions)
West Virginia	72.7	27.3	\$194
Maryland	83.8	16.2	\$354
Ohio	28.3	71.7	\$1,384
Pennsylvania	67.2	32.8	\$1,553
Virginia	51.4	48.4	\$443
United States	55.2	44.8	\$25,596

Source: Prouty, R., Smith, G., Lakin, K.C. Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2003. June 2004.

Sixty-two percent of West Virginia HCBS recipients live in a family home. The next largest group, 24 percent, live in their own homes, while 9 percent live in residential facilities, and 5

<sup>22</sup> CMS 372 Reports, 1999-2003.

<sup>23</sup> Prouty, R., Smith, G., Lakin, K.C. Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2003. June 2004.

percent live in family foster homes.<sup>24</sup> Of West Virginia's total Medicaid expenditures, 11.6 percent is devoted to HCBS waiver expenses in 2002. Between 1999 and 2001, West Virginia's MR/DD spending increased by 20 percent, 23 percent faster than the gross state product.<sup>25</sup> This rapid growth was due, in part, to a lawsuit and related settlement agreement that mapped out elimination of the state's MR/DD waiver waiting list.

## **A. Access and Other Administrative Functions**

West Virginia's Medicaid agency, the Bureau for Medical Services (BMS), contracts with the Office of Behavioral Health Services (OBHS) to manage the MR/DD Waiver. A formal Letter of Agreement between BMS and OBHS specifies the responsibilities of the various parties. The Office's mission is to "support quality services and the development of resources in partnership with the community to build equal opportunities for people with developmental disabilities to live responsible, individually determined lives." The state MR/DD waiver staff includes nine members: two full time monitors, four program staff, two registered nurses, and an office assistant.

In the past, OBHS relied on 19 Comprehensive Behavioral Health Centers (CBHC) to serve as "single entry points" into the waiver program. Consumers and families interested in waiver services had to go to one of these centers to file an application. Today, consumers and families may apply at any of the 43 provider agencies offering service coordination services or local state agency offices. The service coordinator, in turn, facilitates and monitors the financial eligibility application as well as the psychological, social, and medical assessments that are required.

Applying for the West Virginia Waiver is a multi-tiered process involving the consumer, providers, and the state. First, an application must be submitted to the State Waiver office. These applications may be obtained at provider agencies, a local behavioral health center, a local DHHR office, or from the State MR/DD waiver office. The application must indicate the immediacy of an individual's need for care and the individual's choice of a service coordination agency.

Once the state receives the application, it sends a letter to the Service Coordination Agency informing them that they have 45 days to complete the full application packet. The full application packet contains all required information and the three primary formal consumer assessments – social, medical and psychological. The service coordinator is responsible for arranging the assessments and compiling the necessary information within the 45-day timeline. The packet also includes an initial plan of care or Individual Program Plan (IPP), explanation of consumer rights or choice, and a cost estimate for projected services. The service coordinator then sends the completed application packet to the State MR/DD waiver office where the state office makes a final eligibility determination within another 45 days. The application process can be delayed beyond the 90-day time-frame due to the assessment process. Each of the three assessments expire within 90 days and therefore, if the application process is delayed, applicants are forced to reapply with new assessments.

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<sup>24</sup> Prouty, R., Smith, G., Lakin, K.C. Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2003. June 2004.

<sup>25</sup> Braddock, D., et. al. *The State of the States in Developmental Disabilities*. 2004 Edition. American Association on Mental Retardation., Washington, DC.

If a waiver slot is not available, the applicant is placed on a statewide wait list. The wait list for Waiver placement in West Virginia is now centralized at the state level, as opposed to locally maintained by the former 19 CBHCs. Allocation of waiver slots is based on chronological order by date of state receipt of the initial application packet, not by immediacy of need. The Individual Program Plan (IPP) is created within 30 days of admission to the Waiver program. IPPs detailing specified service categories, cost, or service code limits must be approved by the central office.

## **B. Services and Service Delivery**

### **1. Overview of Services**

The MR/DD waiver offered the following services (2003 data):

- *Case management*, commonly called service coordination in the MR/DD Waiver program, was provided to 2,935 recipients, nearly all of the Waiver recipients. One service coordinator is assigned per recipient, with the responsibility of coordinating and monitoring assessments and ensuring the needs of the recipient are met.
- *Day habilitation* was utilized by 2,905 of the 2,962 Waiver recipients. Services are generally provided outside of the home with the goal of obtaining increased independence through development and maintenance of activities of daily living (ADLs).
- *Prevocational training services* were provided outside of the home to 440 individuals. To be funded, these services must be an essential part of the recipient's IPP and help them acquire and maintain basic work skills.
- *Supported employment* was offered to 279 waiver recipients. This service enables recipients to engage in paid work by supporting them through services including job assessment, coaching, transportation, counseling, and additional assistance.
- *Residential Habilitation* services were provided in home settings to 1,361 waiver recipients. These services, like day habilitation, are supposed to assist with acquisition, retention, or improvement of skills related to ADLs.
- *Community Residential Habilitation* services are provided in natural home settings to 1,633 recipients. These services assist with the acquisition, retention, or improvement of skills related to ADLs.
- *Respite Care* services were provided to 1,767 recipients, a significant increase since the 1999 independent evaluation. Respite care services provide temporary care for individuals due to the absence or need for relief of the primary care provider. Recipients may only receive 720 hours (30 days) of respite care a year.
- *Adult Companion* services were added to West Virginia's waiver in 2001. These services provide non-medical assistance to individuals for tasks such as meal preparation, laundry, and shopping. 707 waiver recipients utilized adult companion services.

- *Environmental adaptation* services were also added to the waiver in 2001 and are limited to \$1,000 a year per recipient. This service provides funding for physical adaptations to a recipient’s home, as required by their IPP, to ensure greater independence and the safety of the individual in their home. These improvements can include ramps, widening doors, installation of grab bars, modification of bathroom facilities, and vehicle modifications or lifts. 212 recipients used the environmental adaptation service.
- *Transportation* services are offered to recipients to get to and from other waiver services. Recipients are limited to 6 one-way trips a day for a total of 77 trips per month or a limit of 1,300 miles per month. 2,790 recipients received transportation services.
- *Skilled Nursing* services were offered to 933 recipients in 2003.

The most heavily used services included residential habilitation services, service coordination, day habilitation, respite, and transportation. The least used services were environmental adaptation and supported employment. *Table 2* provides an overview of waiver program spending by type of service.

**Table 2**  
**West Virginia FY 2003 MR/DD Waiver Spending by Type of Service**

Service	Expenditures	Unduplicated Number of Users	Percentage
Service coordination	\$7,685,573	2,935	6.13%
Day Habilitation	\$23,839,379	2,905	19.01%
Transportation	\$7,589,048	2,790	6.05%
Extended State Plan Services	\$1,691,111	2,606	1.35%
Respite Care	\$15,423,105	1,767	12.3%
Community Residential Habilitation	\$15,466,588	1,633	12.33%
Residential Rehabilitation	\$39,838,108	1,361	31.76%
Skilled Nursing	\$4,594,215	933	3.66%
Adult Companion	\$6,686,160	707	5.33%
Prevocational	\$1,577,170	440	1.26%
Supported Employment	\$836,971	279	.67%
Environmental Adaptation	\$193,869	212	.15%
<b>Total</b>	<b>\$125,421,297</b>	<b>2,962</b>	<b>100%</b>

Source: CMS 372 Report, 2002-2003 reporting period

Service coordination is the linchpin service. Staff arrange and/or provide for an array of critical services by coordinating development of the IPP and ensuring its implementation. West Virginia is unique in the low service coordinator case loads (i.e., a maximum of 20 individuals) that it has been able to maintain and in its requirement that service coordinators visit each person on their case load monthly. Until recently, service coordinators also were responsible for reviewing all provider billing before submission to BMS for payment. Providers now bill BMS directly. Due to concerns about freedom of choice among service coordination providers, West Virginia shifted away from the CBHC single point of entry system to the current system

where consumers and families may apply for services through several avenues including the 43 providers offering service coordination services and local DHHR offices.

Nationally, and in West Virginia, day habilitation is an important service for families when the consumer lives with family members. In cases where the consumer is unable to stay by him or herself, participation in a day program ensures that family members have time to conduct day-to-day chores and responsibilities, rest, and, possibly most importantly, work. Without day programming, family members in national surveys have reported the need to reduce or resign from employment.

## **2. Service Delivery and Providers**

There are 48 MR/DD providers in West Virginia, some with multiple locations. Of these 48 providers, 43 are Service Coordination agencies which not only provide service coordinators to recipients, but other services as well. New providers in West Virginia are required to receive a certificate of need (CON) from the West Virginia Health Care Authority. Current providers must obtain CONs before adding or expanding health care services, exceeding the capital expenditure threshold of \$2 million, obtaining major medical equipment valued at \$2 million or more, or developing or acquiring new health care facilities. To receive a CON, providers must prove that the new service would address an unmet need, generally through population-based quantifiable need methodologies. Providers must also show that serving individuals who otherwise would not be served would not cause West Virginia to incur increased expenses. Providers often hire outside consultants to help them complete the CON process. Additionally, depending on which services they choose to offer, some providers face as many as four layers of licensure and certification (i.e., BMS, CON, Office of Health Facilities Licensing and Certification, and DRS). West Virginia established a CON Summary Review Process to streamline the process for MR/DD Waiver provider applications for CON. The summary review process allows agencies that want to be MR/DD Waiver providers to apply directly to OBHS for certain community based waiver services. The Office has a committee to review applications and assess if a provider meets the specific criteria outlined in the legislation that established this process. If the committee believes the applicant meets the criteria, the Office recommends that the DHHR Secretary forward the application to the Health Care Authority asking that the applicant be exempt from the full CON process.

### **C. Quality Assurance System**

In October of 2001, West Virginia began the process of updating its Quality Management Program. The state formed two focus groups, one for state officials and providers, and a second for consumers, families, and advocates. In 2003, West Virginia received a 3-year \$499,995 CMS Systems Change Grant for Quality Assurance and Quality Improvement (QA/QI) for both of its HCBS waivers. The primary purpose of the grant is to develop a systematic QA/QI system that enlists the participation of consumers, families, and advocates. An initial quality committee consisting of a wide array of stakeholders, including the two initial focus groups, was established during West Virginia's annual MR/DD conference. The committee, using input from conference attendees, developed quality principles to shape the new QA/QI system and formed an oversight committee, the Quality Improvement Council.

The Council's membership includes grant staff, MR/DD waiver staff, a MR/DD waiver recipient family member, Aged and Disabled Waiver staff, and an Aged and Disabled waiver recipient. Each waiver also has its own Quality Improvement Council. The MR/DD Waiver Council includes state staff from BMS, OBHS, the Office of Health Facility Licensure and Certification (OHFLAC), as well as family members, consumers, providers, and advocates. The MR/DD Council receives statewide results of the quality reviews and identifies issues for action. The MR/DD Council contributed to the development of West Virginia's new Quality Tool and Quality Management System.

The MR/DD Waiver Quality Assurance Unit surveys providers every eighteen months. The staffing for a review varies based on the number of consumers the provider serves, ranging from two staff to five or six for larger providers. For larger providers undergoing a full review, quality staff conduct a pre-meeting with senior provider staff to review the process and discuss any "red flag" issues. Prior to the review, quality assurance staff also collect baseline information on the provider and demographics of consumers served.

In addition to a review of business documents, surveyors pull a ten percent random sample of all consumer files, as well as ten percent of personnel files. The sampled consumer population includes consumers in a variety of housing situations as well as age groups. Survey staff compare IPPs in the sample with amounts billed. The Quality Tool allows for a survey of health and welfare, consumer experience, provider qualifications, level of care, plan of care development and implementation, financial review, on-site review of homes or programs, and review of infrastructure within the provider agency (systems, policy, and resources).

During the provider quality reviews, the team also assesses provider incident reporting policies, types of incidents, actions taken, and systems for tracking of agency incidents for health/safety or quality improvement purposes. The Quality Assurance Unit reviews a sample of incident reports to analyze the operational implementation of incident reporting at the direct care level and agency level. The Unit reports findings to the executive director and chair of the board of directors for the agency and requests plans of action when systems are found to be lacking. An overall assessment of health and welfare is presented to the Quality Improvement Council for review of statewide trends from the provider agency quality reviews.

After the survey process, quality assurance staff also hold a post-meeting with the provider to discuss any pressing findings, as well as to de-brief with senior provider staff. The staff then draft a report and send it to BMS, which reviews the report and forwards it to the agency within a six week time frame. The agency has an opportunity to review the report and dispute the findings. After the initial start-up delay is overcome, providers should receive their final report six weeks after they send in comments. Currently the process is six to eight months behind schedule, but improvements are expected.

In a typical survey month, the quality unit completes three surveys – one large provider and two smaller agencies. OBHS's goal is not to create a "policing" environment, but rather an emphasis on providing technical assistance (TA) and quality improvement. The quality unit plans to convene annual TA conferences and is exploring other TA strategies such as registered nurse mentoring programs, as well as for doctors, in hopes of reducing nursing home and hospital admissions.

The Quality Assurance Unit is responsible for conducting an annual MR/DD conference for all stakeholders including providers, consumers, families, and advocates. Statewide provider workshops are conducted for provider agencies with waiver contracts to discuss policy, service utilization, operations, or critical issues.

Currently, a sample of waiver consumers are surveyed and interviewed as part of the review process. West Virginia uses the Core Indicators Project (CIP), a national consumer experience survey that is conducted both by written survey and face-to-face interviews of consumers or families once a year. The survey participants are not limited to waiver consumers, but also includes a cross section of DD services. Through the survey, West Virginia is compared to other participating states nationally by means of project outcomes data. The Quality Council is currently considering incorporating aspects of the CIP survey into the quality tool in order to gather more MR/DD specific data. MR/DD contracts out in-home consumer interviews in order to get more objective information. The state discovered that consumers and families were reluctant to be interviewed by state staff out of fear that services might be withdrawn.

#### D. Financing

West Virginia provides a wide array of services for people with mental retardation and developmental disabilities. The state has followed national trends in increasing its spending on waiver services while diminishing its dependence on ICFs/MR. *Table 3* shows the yearly expenditures for West Virginia’s MR/DD waiver and the state’s ICF/MR spending, as well as the changes in expenditures from year to year. The data show significant increases in waiver spending, but not in ICF/MR spending. It should be noted that during this time frame West Virginia has had a moratorium on ICF/MR beds.

**Table 3**  
**Waiver Funding Trends**

	FY1998	FY1999	FY2000	FY2001	FY2002	FY2003
WV Waiver Expenditures	\$60.8 million	\$73.6 million	\$85.7 million	\$103.7 million	\$127 million	\$144.5 million
Waiver increase from previous year	---	21%	16.5%	20.9%	22.5%	18.9%
WV ICF/MR Expenditures	\$48.6 million	\$45.8 million	\$47 million	\$47.8 million	\$47.5 million	\$53 million
ICF/MR increase from previous year	---	-5.8%	2.8%	1.4%	-0.5%	11.6%

Source: Burwell, Brian. The MEDSTAT Group. Medicaid LTC Expenditures FY 2003.

While an increase in waiver expenditures is noteworthy, for the purposes of CMS renewal, the waiver must also be cost effective, meaning that the average cost per waiver recipient cannot be more expensive than the cost of supporting recipients in an ICF/MR facility. The cost effectiveness of West Virginia’s waiver is discussed in the Findings and Recommendations section of the paper.

## V. FINDINGS AND RECOMMENDATIONS

The Lewin Group's desk audit of MR/DD waiver materials, a day long series of interviews with state staff, analysis of a sample of IPPs and related claims, as well as the focus groups with consumers and providers revealed both areas of strength and weakness in the program. Lewin's analysis of information from these steps resulted in three common themes with implications for renewal of the waiver:

- Consumer access to the waiver could be enhanced through increased education, a revised application and assessment process, and the provision of service coordination by an entity other than service delivery providers.
- Currently many consumers are not receiving the services suggested in their IPPs. This may be the result of a number of factors including the lack of availability of services or IPPs that do not reflect the actual needs of the consumer.
- The MR/DD waiver is well within cost effectiveness requirements. The average monthly costs of waiver participants in the fourth year of operation were close to half the monthly ICF/MR costs.

Below, under each assessment dimension, are The Lewin Group's findings, based on consumer and family, provider, and state advocate comments and/or Lewin observations from discussions with state staff, as well as review of waiver materials, IPPs and claims. After each finding or group of findings, Lewin offers waiver renewal concerns driven by the issue as well as recommended changes.

### A. Access and Administrative Infrastructure

#### 1. *The role of providers in access*

Providers serve as the access point to the West Virginia waiver and are responsible for assisting West Virginians with the completion of assessments and the waiver application. The state does not reimburse providers for these services; therefore providers do not have a direct monetary incentive or, at times, the necessary staff/financial resources to assist with all waiver applications. Consumers reported difficulty getting providers to process their applications. Other consumer feedback included reports of lost applications, incorrect filings, and unreturned phone calls. Some consumers said they were able to get a provider to process their application only after contacting state representatives or through other personal contacts within a provider agency. Providers were also reported to more readily accept applications of individuals they believed would definitely be approved for the Waiver, while delaying the applications of people they considered borderline or thought would be denied.

Provider agencies often offer service coordination as well as other services, like day habilitation or QMRP services. This service structure yields a potential for conflict of interest, as it requires the same agency to advocate for a consumer's service needs while also being a provider of those same services. Service coordinators in these situations may also feel uncomfortable reporting a poor service by the agency which employs them. Consumers and providers also reported that

some providers required consumers to use one agency for all services, or that an agency would only provide a desired service if the consumer also accepted two or three other services from the agency as well. This structure could result in limiting a consumer's choice of providers. Providers may also selectively serve clients who do not display challenging behaviors or who are in preferable living arrangements, like group homes.

## **2. The assessment process**

Additionally, the West Virginia Waiver application and recertification process requires three assessments: medical, psychological, and social history. Applicants and the provider agency are given 45 days to complete the application, including completing all the required assessments. The assessments have a 90 day expiration date, meaning that after 90 days the assessments must be redone. This is an additional burden on families who sometimes must get repeated assessments, as one assessment expires before the others can be completed. Multiple trips to the doctor, often located in other towns or regions for rural residents, and the financial burden of paying for two or three exams can act as a barrier to families trying to enter the system. Providers also found the assessment process to be cumbersome and outdated. Providers stated that the assessments are often not used to create the IPP, because once the person is approved, the assessments are already out of date. Providers would like to see assessments include areas such as residential needs, long-term needs, family support needs, and more specific recommendations on needed medical therapies.

### **Recommendations for Access Improvement**

To increase consumer access to its MR/DD Waiver, West Virginia has a number of options. One possibility is to explore alternatives to the three-part assessment. West Virginia might consider looking at other assessment tools that provide consumer-driven service plan outcomes, rather than deficit-driven service plans that may or may not have consumer outcomes. Lewin recommends that the state study the American Association on Mental Retardation (AAMR) Supports Intensity Scale (SIS). The tool was developed by a team of disability, psychology, and assessment experts over a period of five years and has been widely lauded in the MR/DD community as a reliable and useful assessment tool. The SIS measures the level of practical supports required by people with intellectual disabilities to live in the community by measuring life activities, medical conditions, and behavioral problems. West Virginia also might consider looking at a sample of tools developed by other states such as North Carolina's SNAP (Support Needs Assessment Profile) assessment. A more refined assessment tool that aids in a consumer-driven IPP, coupled with a more consumer-driven service planning process (see below), could result in programmatic efficiencies and lower costs.<sup>26</sup>

West Virginia should also consider an ongoing outreach and education campaign for families and consumers. This could include educating families about how to access the waiver and their "right to choose" once on the waiver. The state currently requires the service coordinator to discuss the "right to choose" with families and consumers and sign a consent on an annual

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<sup>26</sup> Standcliffe, R. J., Lakin, K.C. (2004) *Costs and Outcomes of Community Services for Persons with Intellectual and Developmental Disabilities*. Policy Research Brief 14(1). Minneapolis: University of Minnesota, Research and Training Center on Community Living.

basis. Further education on available provider resources during the annual IPP process could also be helpful to consumers and families.

At the last renewal, West Virginia made significant changes in its waiver operations to ensure that consumers and families had freedom of choice among providers. Today, there are approximately 48 waiver providers including an array of Service Coordination providers. However, the state should consider a strategy to preclude service coordinators from being employed by the same agency that provides direct, day-to-day services, such as residential and/or day-time services (i.e., day habilitation, pre-vocational services, and supported employment). Separation of case management/service coordination from service delivery reduces the possibility for conflicts of interest and increases the likelihood that the service plan will be completely focused on the needs of the individuals and not the provider organization.<sup>27</sup>

## B. Services

Since its last renewal, West Virginia has continued to add to its wide array of services. The state has added adult companion services and an environmental adaptation service, both of which are popular with consumers. However, despite generous service array, some waiver recipients may not be receiving needed services. Using a five percent sample of West Virginia MR/DD waiver Individual Program Plans (IPPs) and related service documentation from April and October of 2003, Lewin compared the description of assessed service needs for 300 recipients with the actual services billed to Medicaid. The randomly selected sample accounted for geographic distribution as well as the intensity of services needed by waiver participants. The broad review of IPPs found that for all plans reviewed, the actual amount billed to Medicaid was 44 percent less than what was projected by the IPPs. The service review focused on three main services, agency residential habilitation, day habilitation, and respite care. These services were chosen because the majority of waiver recipients receive at least one of these services and the focus group sessions suggested the importance of these services to waiver recipients. Lewin analysis revealed that services were delivered in an amount less than authorized in 77 percent of the service categories. In 20 percent of the categories, services were delivered in excess of the amount authorized in the assessment and 3 percent matched what was assessed (*Table 4*).

**Table 4. Billed Services**

Service	Number of times provided	Number below authorized	Percent below authorized	Number over authorized	Percent over authorized	Number billed at authorized level	Percent billed at authorized level
Agency Res Hab 1:1	74	51	69%	22	30%	1	1%
Agency Res Hab 1:2	34	22	65%	11	32%	1	3%
Agency Res Hab 1:3	26	17	65%	9	35%	0	0%

<sup>27</sup> Cooper, R., Smith, G. (2000) Medicaid Case Management for Persons with Developmental Disabilities. National Association of State Directors of Developmental Disabilities Services (NASDDDS).

Service	Number of times provided	Number below authorized	Percent below authorized	Number over authorized	Percent over authorized	Number billed at authorized level	Percent billed at authorized level
Agency Res Hab 1:4+	11	8	73%	3	27%	0	0%
Day Hab 1: 6+	7	7	100%	0	0%	0	0%
Day Hab 1:1	86	63	73%	23	27%	0	0%
Day Hab 1:2/3	60	49	82%	11	18%	0	0%
Day Hab 1:4/5	47	39	83%	7	15%	1	2%
Respite Care Level 1	81	65	80%	5	6%	11	14%
Respite Care Level 2 agency	49	40	82%	6	12%	3	6%
<b>Total</b>			<b>77%</b>		<b>20%</b>		<b>3%</b>

Source: Lewin analysis

The average monthly cost of services not billed at the maximum authorized was \$2,850. As *Table 4* shows, of the services studied respite care and day habilitation had the highest levels of billings under the authorized levels. Respite care was under authorized levels an average of 72.17 hours a month per recipient, for Levels 1 and 2 (see *Table 5* below). Although families can carry over respite care service hours from month to month, the high level of respite care underutilization (81 percent of claims under authorized levels) in two different months, October and April, suggests that there may be a lack of access to respite care givers. Underutilization of respite care was consistent across providers, irrelevant of their location. The data was supported by the consumer and family focus groups in which a common theme was the lack of available respite care. Consumers and families urged the state to reconsider respite care reimbursement rates, to reinstitute an administrative fee cap (the amount a provider can take from a respite care worker’s salary for administrative expenses), and to reduce respite workers’ tax paying responsibilities.

Day habilitation was underprovided an average of 34.86 hours a month per recipient. This may be due to geographic differences in the availability of day habilitation as well as limitations in day habilitation slots. Lewin’s analysis found that day habilitation was provided below authorization by providers across the state, irrespective of the location and the area population density. West Virginia is, however, a predominately rural state. Of West Virginia’s 55 counties, 38 are either entirely or partially designated as primary medical care Health Professional Shortage Areas by the Health Resources and Services Administration (HRSA). There is likely a shortage of other service providers in the state, similar to the shortage of health professionals.

**Table 5. Hours Below Authorization per Month**

Service	Average Hours Below Authorized Per Month
Agency Res Hab 1:1	-39.43
Agency Res Hab 1:2	-32.76
Agency Res Hab 1:3	-18.92
Agency Res Hab 1:4+	24.27
Day Hab 1: 6+	-40.14
Day Hab 1:1	-22.01
Day Hab 1:2/3	-29.8
Day Hab 1:4/5	-47.47
Respite Care Level 1	-72.81
Respite Care Level 2	-71.53
Grand Total	-35.06

Source: Lewin analysis

Consumers and providers expressed concern over provider rates in the West Virginia MR/DD program. Providers may be unwilling to provide services that are not financially sound due to low rates, for example 1:1 services in an apartment setting. *Table 6*, below, provides an overview of typical rates from a sample of other neighboring state MR/DD waiver programs.

**Table 6. Comparison of Some 2004 MR/DD Waiver Rates**

Service	State	Rate/Unit
Respite Level I	West Virginia	\$2.50/15 minutes
	Virginia	\$11.36/hour (\$2.84/15 minutes)
	Ohio	\$200 maximum/day
	Kentucky	\$2.77/15 minutes
Day Habilitation Level I	West Virginia	\$3.25/15 minutes
	Virginia	\$23.99/unit*
	Ohio	N/A
	Kentucky	\$2.66/15 minutes

Service	State	Rate/Unit
Supported Employment	West Virginia	\$3.63/15 minutes
	Virginia	\$16/hour (\$4.00/15 minutes)
	Ohio	\$24 maximum/hour (\$6.00/15 minutes)
	Kentucky	\$5.54/15 minutes

Source: Personal communication with Kentucky and Ohio state staff.

\*In Virginia, one unit equals 1-3.99 hours, two units equals 4-6.99 hours. Virginia Department of Medical Assistance Services website, [http://www.dmas.virginia.gov/downloads/pdfs/wvr-2005\\_MR\\_rate\\_increase.pdf](http://www.dmas.virginia.gov/downloads/pdfs/wvr-2005_MR_rate_increase.pdf).

Table 6 shows that West Virginia’s rates for respite care, day habilitation, and supported employment are not unreasonably low compared to neighboring states. Kentucky, Virginia, and Ohio have higher respite care and supported employment rates, but West Virginia’s day habilitation rate is higher than Kentucky’s. Ohio negotiates waiver rates with providers individually, but puts upper limits on the amount that can be charged. In 2000 in West Virginia, rates were increased on several service codes, but the entire rate structure was not addressed at that time. Currently, many services in West Virginia are measured in 15 minute increments, increasing the administrative burden of providers and families who provide services. Other states, such as Minnesota, Pennsylvania, and Maryland, use a per diem rate structure at least for residential services, day programming, and respite care. Virginia’s unit for day habilitation, one unit corresponding to one to 3.99 hours, also offers more flexibility and decreases the administrative burden. The current West Virginia requirement of recording services at the specific times the services occurred may create additional paperwork that increases indirect costs for providers, while reducing time available for delivery of support services.

Many states have moved to systems that reimburse providers based on an individual’s service needs – i.e., the more disabled an individual, the more the provider is reimbursed. For example, a provider would receive a higher rate for serving someone with MR and who also has schizophrenia, than for someone with Downs Syndrome. Currently West Virginia offers levels of services, such as Respite I and Respite II, but does not reimburse based on support intensity.

Finally, providers who participated in the town hall meeting and sent written comments expressed concern about the lack of ongoing training available to providers. They discussed confusion about the application process, plan approval, and the new quality process. While several forums for trainings and interactions have been instituted over the last few years, it appears that providers are requesting a more in-depth level of education. The annual waiver conference and provider workshops tend to be larger group settings and may not offer the level of interaction or direction that the providers may desire. The new QA/QI system, however, was designed to provide technical assistance around specific areas of need. This focused, in-

depth training and technical assistance for providers could additionally lead to better outcomes for waiver participants.

### **Recommendations for Service Improvement**

Many states have added a Family Supports benefit to their HCBS waiver programs. Such benefits can increase the likelihood that families will be able to maintain their relatives at home for longer and preclude or delay the need for costly residential placement. The only family support service currently in the waiver is respite care. West Virginia should consider adding such a benefit and using some or all of the general fund revenue in the existing State Family Support Program to fund a waiver service and, subsequently, draw down federal matching dollars.

Additionally, West Virginia's waiting list protocol currently only enrolls individuals on a first-come, first-served basis. If someone on the waiting list goes into crisis, they are served using State General Fund dollars until enrolled in the waiver. The state also should consider adding a crisis intervention benefit to the waiver to: a) support individuals in crisis who will soon be enrolled in the waiver, reducing the use of state-only dollars by receiving federal matching dollars; and b) to offer crisis services to families to stabilize the care environment and preclude out-of-home placement.

One factor potentially contributing to the under provision of services authorized for waiver recipients, as demonstrated in the Lewin analysis, could be that IPPs are not appropriately assessing the needs of consumers. One step West Virginia could take is to incorporate a Level of Supports assessment such as the previously mentioned Supports Intensity Scale (SIS) developed by the American Association on Mental Retardation. This would assist with resource allocation and financial planning while taking the desires and needs of the consumer into consideration. West Virginia could also address this issue by moving toward the increasingly used "consumer directed" models. In the past three years, CMS and the Bush Administration have signaled their interest in facilitating the inclusion of consumer direction in state waiver programs. CMS has developed "Independence Plus" 1915(c) and 1115 waiver templates to enable consumer directed waiver services, as well as provided policy guidance in the form of State Medicaid Directors' letters from the CMSO Administrator. Based upon the national trend, CMS's encouragement and data showing high levels of consumer satisfaction, it would be in West Virginia's best interest to consider a consumer-directed component that would also address concerns from families and consumers regarding their level of direction of day to day services.

### **C. Quality**

West Virginia has made great strides in its Quality Assurance/Quality Improvement (QA/QI) system in the past year. Given the recent implementation of the QA/QI system in West Virginia, Lewin was not able to conduct a full review of the implementation of the system.

However, the design of the system appears to be in accordance with protocol laid out by CMS.<sup>28</sup> CMS waiver design QA/QI protocol includes reviews of:

- Structural features of the state’s QA system;
- State QA related to waiver participants;
- State QA related to waiver providers;
- Other quality enhancing activities related to the state’s QA program.

The state has clearly laid out the frequency of provider reviews as well as review sample methodologies. The state has increased consumer, family, and provider involvement through the Quality Improvement Council as well as annual MR/DD state conferences. Through the waiver renewal process, consumers and families were able to participate in focus groups to provide direct input on waiver access, services, quality, and cost effectiveness. The state should consider additional consumer focus groups or regional meetings to ensure continued consumer feedback and compliance with CMS protocol.

West Virginia could also consider enhancing its incident reporting and tracking system. Currently, “major and unusual incidents” are reported to Adult Protective Services, Child Protective Services, OHFLAC, or directly to the state waiver unit. The organizations have a partnership in which the three non-waiver offices report all incidents involving waiver recipients to the waiver office, which is then responsible for tracking and investigating incidents. The State of Ohio provides a model for West Virginia to consider. Ohio’s MR/DD department has developed and implemented a more efficient process for reporting and tracking incidents. The system is internet-based and can be used by the state to follow up on investigations and remediations related to incidents, as well as analyze patterns and trends related to incidents. Since implementation in 2001, there has been a significant increase in the reporting of major and unusual incidents. This is due to more reliable reporting and tracking (electronic rather than fax), more specificity about incident reporting in state rules, and more clarity about state expectations. Ohio’s incident reporting system is county-based, but could be adapted to fit West Virginia’s needs.<sup>29</sup>

#### **D. Cost Effectiveness and Financing**

States report waiver expenditures and service utilization to CMS annually by means of the CMS 372 Report. *Table 7*, below, provides a summary of West Virginia’s MR/DD waiver spending by service and number of unduplicated users for the current waiver renewal period to date.

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<sup>28</sup> CMS Regional Office Protocol for Conducting Full Reviews of State Medicaid Home and Community-Based Services Waiver Programs. Version 1.2. December 20, 2000.

<sup>29</sup> Center for Medicare and Medicaid Services and Thomson Medstat. Ohio’s Incident Reporting and Tracking System. HCBS Quality, 1 (2), May 2003. <http://www.cms.hhs.gov/promisingpractices/datareadinessOH.pdf>.

**Table 7. West Virginia Annual Number of Participants and Monthly Average Costs**

	1999-2000		2000 – 2001		2001-2002		2002-2003	
	Participants	Cost/ Participants	Participants	Cost/ Participants	Participants	Cost/ Participants	Participants	Cost/ Participants
<b>Total Served (Unduplicated) /Spent</b>	1,879	\$3,626	2,320	\$3,517	2,788	\$3,320	2,962	\$3,529

Source: Lewin Analysis of CMS 372 reports submitted by BMS

CMS uses 372 reports to ensure that states are maintaining HCBS waiver programs in accordance with cost effectiveness requirements. In state fiscal year 2003, the West Virginia MR/DD waiver average monthly cost person was approximately \$3,528, while the average ICF/MR monthly cost was \$6,400. Based on these reports, the waiver is well within cost effectiveness requirements and has been during the term of the Waiver (see Table 3 above).

Lewin’s review of claims and IPP data validated the CMS 372 reports. Of the 300 recipient claims studied, only 19 exceeded the \$6,400 ICF/MR monthly cost, and all were pre-approved by BMS. In Lewin’s sample, the average amount billed per month was \$3,445 while the average amount suggested by the IPPs was \$5,784, a difference of \$2,339. This again suggests that while West Virginia’s MR/DD waiver is cost effective, consumers are either not receiving needed services or IPPs are not written to reflect consumer needs.

As part of a broader effort to add elements of consumer direction and person centered planning, and to serve additional individuals, West Virginia should explore strategies to reimburse based on levels of consumer need. For example, Wisconsin reimburses MR/DD providers based on a rate calculated by an automated assessment tool. In Wyoming, the DOORS program calculates an individualized budget. First the state determines the level of support the consumer needs by analyzing factors including living arrangements, work setting, services received in the past, and functional and medical assessments. Using these factors, the state then uses a regression formula to calculate individual budgets. Wyoming also sets aside a portion of each waiver’s overall state budget for people who need more funding than their original budget predicted. Since implementation of individualized budgets, the state has seen fewer requests for additional funding and the amount of funding requested per person has decreased.<sup>30</sup>

<sup>30</sup> Centers for Medicare and Medicaid Services Promising Practices in Home and Community-Based Services. Wyoming – Individual Budgets for Medicaid Waiver Services. Updated 12/16/2004. <http://www.cms.hhs.gov/promisingpractices/wyib.pdf>

## **VI. CONCLUSION**

The assessment of West Virginia's waiver found a number of strengths and weaknesses within the program. The waiver offers a wide range of services to address the needs of recipients. During the period under review, the state added a number of new services. The state is also implementing a new quality assurance system, which closely models CMS recommendations and will better ensure the health and welfare of the participants. It has devoted considerable time and effort to design and improve this new system with consistent input from stakeholder groups. Additionally, the waiver is extremely cost effective in comparison with ICF/MR costs, operating at a cost almost \$3,000 per month less per recipient than recipient costs in facilities. There are, however, improvements that could be made to the waiver.

Access to the waiver and developing a consumer-centered plan of care are areas for potential improvement. The assessment process is time-consuming and may not give the most accurate description of what a participant may need to be supported for community living. Lewin recommends that the state review the Supports Intensity Scale assessment as well as North Carolina's SNAP assessment tool. Both of these instruments focus on a consumer-driven, outcomes-based plan of care.

West Virginia should also review the use of providers as access points to the waiver. While the objective of using providers to afford easier access to waiver application and services was laudable, it has created a system where the same providers who deliver vital service coordination functions also deliver other needed services. This creates an apparent conflict of interest, as service coordinators should have no allegiance other than to create the best service plan for a participant and everything possible to ensure that the participant gets the services required by the plan. West Virginia must address this issue and change its system to ensure the objectivity of its plan of care process and the delivery of the highest quality services.

The state should also consider the implementation of a more consumer-directed waiver model which could improve access, quality, service provision, and cost effectiveness of the waiver. Increased consumer participation in the creation of IPPs as well as control over caregivers and budgeting could help ensure consumers are receiving the services they want and need.

Lewin's review of services provided (claims data) compared with services authorized revealed that a large majority of participants are not receiving important authorized services. This could be due to a number of reasons including inaccurate needs assessments and/or lack of service providers. The state needs to examine this issue more closely to ensure that participants are receiving necessary services.

Provider retention could be enhanced by compensating for services based on a participant's service needs, paying more for participants who have more intense service needs. West Virginia could also consider a change in their rate structure to increase billing increments. This would decrease providers' administrative burden. In addition, providers expressed the desire for the availability of more in-depth training.

The state should consider adding a Family Support service to the waiver to support families in crisis who are waiting for waiver enrollment. West Virginia could use some or all of the state

resources it currently uses in its state-funded program and receive federal matching funds for these important services.

While Lewin did not find fault with the existing incident-tracking system, the system could certainly be enhanced by an electronic reporting and management system. With many entities involved in the process, this would be a good improvement to the current system.