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Annual *Olmstead* Report

July 1, 2010 – June 30, 2011

Building Inclusive Communities, Keeping the Promise

October 6, 2011

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The Olmstead Council would like to dedicate this annual report in memory of Mr. John Russell a devoted Council member from 2003 – 2011. John passed away on April 20, 2011.

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EXECUTIVE SUMMARY

On June 22, 1999, the U. S. Supreme Court ruled in the case *Olmstead v. L.C.* that the "integration mandate" of the *Americans with Disabilities Act* requires public agencies to provide services "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." The Supreme Court stated in its ruling that "states should have a comprehensive effectively working plan." *Olmstead* has been called the *Brown v. Board of Education* for people with disabilities. And like *Brown*, it is forcing change very slowly, and then only through determined and vigorous advocacy.

On October 12, 2005, Governor Manchin signed *Executive Order 11-05* formally approving and ordering the implementation of the *West Virginia Olmstead Plan: Building Inclusive Communities*.

West Virginia has been proactive to address implementation of the Olmstead decision by establishing an *Olmstead* office and *Olmstead* Council. In addition, West Virginia has a comprehensive Olmstead Plan, but the question of how effectively it is working is still an issue.

West Virginia continues to struggle with the level of institutional bias in its long term care programs and services. While some steps have been taken to eliminate institutional bias, there has been no real reduction on the reliance of institutional facilities.

On the national level, the federal government continues to provide opportunities to assist states in implementing the *Olmstead* decision. In addition to grant funding and technical assistance, the Department of Justice has dramatically stepped up enforcement activities.

The West Virginia *Olmstead* Council continues to work diligently to advocate for full *Olmstead* implementation. In addition, the West Virginia *Olmstead* Office continues to monitor and implement the States *Olmstead* activities and initiatives. The Olmstead Office received 374 contacts from public entities and private citizens for Olmstead-related assistance. The requested assistance is in the form of information and referral to complaint investigations to funding assistance.

The West Virginia Transition Navigator Program supported 50 to transition, and 101 people to be diverted from institutional settings. The program has provided support to 414 people in the past three (3) years.

Olmstead priorities for 2012 include:

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THE *OLMSTEAD* CASE

In 1995, the landmark case now known as *Olmstead* was brought by the Atlanta Legal Aid Society on behalf of Lois Curtis and Elaine Wilson, who were confined in a state psychiatric hospital in Georgia. Hospital staff agreed that both women should be discharged to supportive community programs. But no such placements were available. The state of Georgia offered nursing facility placements. Ms. Curtis and Ms. Wilson believed this violated their rights under *Title II of the Americans with Disabilities Act* (ADA).

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Olmstead v. L.C. went through the judicial process with the plaintiffs successful at all judicial levels. The Georgia Department of Human Resources appealed to the United States Supreme Court the lower court's decision that the State had violated the ADA's integration mandate by segregating Ms. Curtis and Ms. Wilson.

On June 22, 1999, the U.S. Supreme Court issued their ruling that such segregation is discriminatory both because it "perpetuates unwarranted assumptions" that people with disabilities "are incapable or unworthy of participating in community life" and because "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."

Olmstead has been called the *Brown v. Board of Education* for people with disabilities. And like *Brown*, it is forcing change very slowly, and then only through determined and vigorous advocacy.

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The memories of living in institutional settings since the age of 13 will remain with Lois Curtis. Her story did not end after the landmark Supreme Court decision. Ms. Curtis lived in staffed residential settings after her discharge from the institution. She now rents a beautiful home in Stone Mountain, Georgia with a fellow artist and friend. Ms. Curtis is a successful artist. When asked what her artwork means to her, she responded, "My art been around a long time. I came along when my art came along. Drawing pretty pictures is a way to meet God in the work like it is."

On June, 20, 2011, Lois Curtis presented President Obama with a gift of one of her original paintings in the Oval Office. The "Girl in Orange Dress" is one in a series of three pastel self-portraits Ms. Curtis created since she has no photographs to mark her childhood.

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INTRODUCTION

Six years ago, a public signing ceremony was held on December 14, 2005 to commemorate the October 12, 2005 signing of Executive Order 11-05. It has been 12 years since the United States Supreme Court ruling in *Olmstead v. L.C.*

> *"Confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."*
>
> *-U.S. Supreme Court*
> *Olmstead v. L.C.*

Olmstead v. L.C. upheld the rights of people with disabilities to live and receive supports in the most integrated setting in their community. *Title II of the Americans with Disabilities Act* (ADA) was the basis for this landmark decision. *Title II of the ADA* applies to state and local government entities and the programs funded and administered by them. Two regulations under Title II were fundamental to the *Olmstead* decision:

1. The **integration regulation** mandates that states "shall administer services in the most integrated setting appropriate to the needs of individuals with disabilities." The **most integrated setting** is "a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible."

2. The **reasonable modifications regulation** mandates that states "shall make reasonable accommodations in its policies, practices, or procedures when necessary to avoid discrimination, unless modifications would fundamentally alter the nature of the services, programs, or activities." The Supreme Court stated that, "…if the State were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons…in [most integrated] settings, and a waiting list that moved at a reasonable pace, not controlled by the State's endeavors to keep institutions fully populated, the **reasonable modification standard** would be met."

On October 12, 2005, *Executive Order 11-05* was signed formally approving and directing the implementation of the *West Virginia Olmstead Plan: Building Inclusive Communities*. *Executive Order 11-05* directs:

1. the implementation of the *West Virginia Olmstead Plan*;

2. the cooperation and collaboration between all affected agencies and public entities with the *Olmstead* Office to assure the implementation of the *Olmstead* decision within the budgetary constraints of the State; and

3. the submission of an annual report by the *Olmstead* Office to the Governor on the progress of the implementation of the *Olmstead Plan*.

Appendix A provides a list of the 10 goal mission statements of the *West Virginia Olmstead Plan*.

OLMSTEAD ON THE NATIONAL LEVEL

In 2009, President Obama launched "The Year of Community Living," a new effort to assist Americans with disabilities. In the time since this new initiative was initiated, the Department Housing and Urban Development, and the Department of Health and Human Resources (DHHS) released $40 million in Housing Choice vouchers for 5,300 people over 12 months. DHHS created the "Community Living Initiative" to coordinate the efforts of Federal agencies and underscored the importance of the ADA and *Olmstead*. The Money Follows the Person Rebalancing Demonstration Program, through grant funding awards to States, has helped almost 12,000 individuals transition from institutions to the community. This program was extended for current State participants and opened up for additional States to apply. West Virginia applied and received an MFP Rebalancing demonstration grant under this program.

> *"The Olmstead decision recognized the rights of individuals with disabilities to live the lives they choose, but its promise has not yet been fully realized. Far too many people remain segregated in institutions when they would rather be thriving in their communities."*
>
> *-Thomas E. Perez, Assistant Attorney General for the Civil Rights Division*

The United States Department of Justice, Civil Rights Division's Disability Rights Section, which enforces Title II and Title III of the ADA, and Special Litigation Section which enforces the *Civil Rights of Institutionalized Persons Act* (CRIPA), have made *Olmstead* enforcement a top priority. The first year of the Obama Administration proved to be a landmark year, with a record number of amicus briefs, lawsuits, and intervention into state *Olmstead* cases.

Since "The Year of Community Living" was announced the DOJ has joined or initiated litigation in the following 5 states in 6 cases: Arkansas, Delaware, Georgia, New Hampshire, and New York. The DOJ has filed amicus briefs in the following 16 states in 27 cases: Alabama, California, Connecticut, Florida, Georgia, Illinois, Louisiana, Mississippi, Missouri, New Jersey, North Carolina, Pennsylvania, Tennessee, Texas, Virginia and Washington. In addition, "findings letters" were issued following DOJ investigations in the following 6 states and 1 territory: California, Delaware, Nebraska, New Hampshire, North Carolina, Virginia, and Puerto Rico.

In addition to stepping up enforcement, investigatory work under the CRIPA authority has significantly changed. In the past the first question asked was whether the institutions under investigation are safe, and whether conditions of confinement are constitutional. This is now the second question asked. The first question is whether there are individuals in those institutions who could appropriately receive supports in a more integrated setting.

The DOJ released a new technical assistance document describing public entities' obligations and individuals' rights under the integration mandate of Title II of the ADA and the *Olmstead* decision.

STATE OF THE STATE

This section will discuss the state of West Virginia's *Olmstead* implementation. First, examples of institutional bias will be identified with recommendations for reducing our reliance on institutional care. Then accomplishments and barriers to the implementation of the *West Virginia Olmstead Plan* will be outlined.

It is important to note that there are at least 14,000 people institutionalized in nursing facilities, ICFs/MR, and assisted living facilities across West Virginia. Both ICFs/MR and nursing facilities have moratoriums on new development, but this has not stopped the construction or expansion of these programs. West Virginia has continued to increase its reliance on institutional settings in the past 12 years since the *Olmstead* decision. ICFs/MR have been constructed to replace older or larger structures. Nursing facilities have been permitted to be developed at critical access hospitals. Both State-owned and operated psychiatric facilities have expanded (or have plans to expand) their bed capacity. This reverses downsizing that occurred for both facilities in the 1990s.

One achievement that will hopefully have a profound impact on the long term care system is the Money Follows the Person Rebalancing grant that West Virginia received from the Centers for Medicare and Medicaid Services in 2011.

Institutional Bias

One of the major barriers to achieving compliance with the *Olmstead* decision is the institutional bias of federal and state Medicaid and long term care regulations. Historically, Medicaid has covered long term care supports more readily when an individual resides in an institutional setting. Federal Medicaid law requires states to provide institutional care to all eligible individuals as a mandatory benefit, and permits (but does not require) states to make services available in the community as an optional benefit.

> *"Power yields nothing without demand. It never did and it never will. Find out what any people will quietly submit to and you have found the exact measure of injustice and wrong that will be imposed upon them."*
>
> *-Fredrick Douglass*

In response to the *Olmstead* decision, the Centers for Medicare and Medicaid Services (CMS) have offered various opportunities to states for clarification, guidance, increased flexibility, modifications to rules, and demonstration grant funding with the goal to assist states to implement the *Olmstead* decision and reduce the reliance on institutional care. While West Virginia has taken advantage of some of this federal assistance, we have lagged behind other states in moving to balance the long term care system.

Forty-four (44) states have been actively engaged for decades in formal statewide activities to balance their long term care system. This includes legislation, institutional closure initiatives, transition initiatives, streamlining eligibility criteria and processes, and CMS Money Follows the Person Rebalancing grants.

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In February 2011, West Virginia received a grant from CMS for the Money Follows the Person Rebalancing Demonstration Grant. This program will begin in late 2011. This is the biggest step West Virginia has taken to actively reduce the reliance on institutional settings, since the last institutional closure in 1998.

The *Olmstead* Office and Council have identified the following eleven (11) examples of institutional bias in West Virginia:[1]

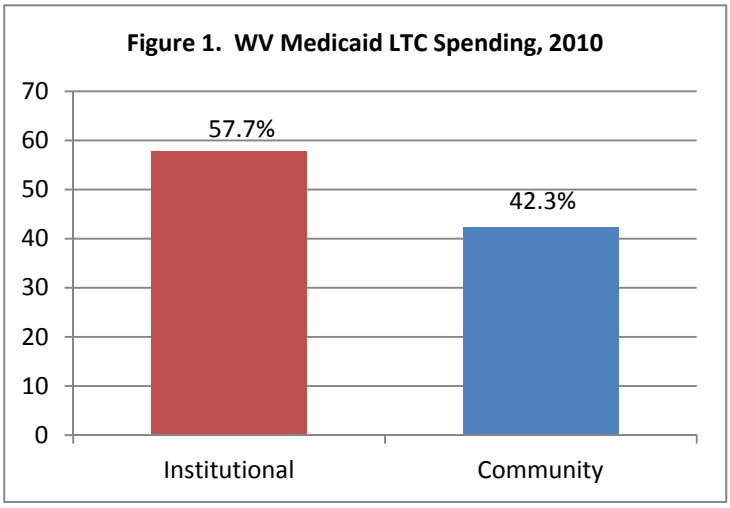
1. West Virginia spends a greater percentage of its overall Medicaid long term care funding for institutional care when compared to community-based supports.
2. West Virginia's Aged and Disabled Waiver Program does not provide a comparable or functional alternative to nursing facility care.
3. West Virginia restricts access to Medicaid Personal Care services to all recipients of the Aged and Disabled Waiver Program.
4. West Virginia utilizes waiting lists for eligible applicants of the I/DD Waiver Program, and (historically with) the Aged and Disabled Waiver Program.
5. West Virginia does not provide an adequate education (informed choice) on support options for home and community-based services prior to institutional placement.
6. West Virginia implements a complicated and lengthy eligibility process for the I/DD Waiver Program when compared to the ICF/MR program.
7. West Virginia implements a complicated and lengthy eligibility process for the Aged and Disabled Waiver Program when compare to the nursing facility program.
8. West Virginia incentivizes institutional care through a cost-based reimbursement methodology.
9. West Virginia has a fragmented and inadequate service system for people with mental illness and co-occurring disabilities.
10. West Virginia does not effectively use unlicensed, trained personnel to administer medications in the community through exemption and delegation methods.
11. West Virginia does not effectively use case management services to support people in transitioning from institutional care to the community.

The *Olmstead* Office and Council have identified recommendations to eliminate or reduce the institutional bias that results in the costly overuse or inappropriate use of institutional settings.

[1] This is not an all-inclusive list.

1. ***West Virginia spends a greater percentage of its overall Medicaid long term care funding for institutional care when compared to community-based supports.***

In 2010, West Virginia spent 57.7% of Medicaid long term care funding on institutional care, and 42.3% on community-based supports.[2] West Virginia has slowly decreased this gap in spending over the last 5 years by 4.6%. ***Figure 1*** shows the comparison of institutional and community-based spending for 2010.



However, West Virginia's national ranking continues to remain the same or even decline in some cases. Thomson Reuters is under contract with the Centers of Medicare and Medicaid Services to issue an annual report on Medicaid long term care spending and state rankings. Since 2004, West Virginia has dropped in the national rankings from 17th in the nation to 21st in 2009. The lowest ranking during this time period was 24th. It is important to note that the 2009 rankings did not include 11 states due to insufficient data. Ten out of these 11 states have historically ranked higher than West Virginia. Therefore, this could place West Virginia much lower that 21st in the national rankings.

Recommendation: West Virginia should take advantage of the State Balancing Incentive Payments Program. In combination with the West Virginia MFP grant these are two excellent ways to increase the percentage of funding for home and community-based services.

The *Patient Protection and Affordability Act* includes Medicaid options and incentives to expand long term care services and supports. The State Balancing Incentive Payments Program offers opportunities for states to receive increases in Federal Medicaid Assistance Program (FMAP). States in which less than 50 percent of Medicaid long term care spending was for non-institutional supports and have a target of 50 percent on home and community-based services by 2015 would receive FMAP incentive payments of two percentage points. All incentive payments received by states must be used to expand the availability of Medicaid home and community-based services. This program goes into effect October 1, 2011.

If you apply the two percentage points to the home and community-based expenditures for fiscal year 2009, this would equate to an additional $7,188,133 in federal match.

[2] West Virginia Bureau for Medical Services report issued on 05/06/2010. Institutional care includes nursing facility and ICF/MR care. Community-based supports include the Aged and Disabled Waiver, I/DD Waiver, home health and personal care services.

2. ***West Virginia's Aged and Disabled Waiver (ADW) Program does not provide a comparable or functional alternative to nursing facility care.***

West Virginia Bureau for Medical Services defines the Aged and Disabled Waiver Program "as a long term care alternative that provides services that enable an individual to remain at or return to home rather than receiving nursing facility (NF) care."[3]

The traditional model of the ADW Program offers eligible members 62 to 155 hours per month of in-home support based on an assessed level of care that is defined by the BMS. This equates to an average of only 2 to 5 hours a day of in-home direct support.

West Virginia is one of only 4 states that does not provide respite care under their aging and disability waiver. The other states are Louisiana, Rhode Island, and Washington.

Nursing facilities are staffed 24 hours per day, seven days per week.

Recommendation: West Virginia needs to assess the waiver program to better meet the needs of people it serves and those that cannot access it due to an inadequate service package. Aggressive planning needs to take place to develop a long range plan to enhance the service package to offer a responsive and functional alternative to nursing facility care.

3. ***West Virginia restricts access to Medicaid Personal Care services to all recipients of the Aged and Disabled Waiver Program.***

Medicaid Personal Care services may only be accessed by members who are receiving ADW services at level of care D. Medicaid Personal Care services are not available to ADW members receiving level of care A through C. This restriction is not based on individual need, but on arbitrary levels of service for the ADW program established by the State. The eligible ADW member is fit into a level of service as opposed to the level of service being defined by the eligible member's needs.

Personal Care services can provide an additional 2 – 7 hours of direct in-home support per day.

Recommendation: The Bureau for Medical Services needs to eliminate this restriction, especially in light of the fact that the ADW program does not have an equitable service or benefits package when compared to nursing facility level of care. Due to this and the level of burden placed on informal supports, the addition of personal care services is necessary to support people from being institutionalized.

[3] West Virginia Bureau for Medical Services, Aged and Disabled Waiver Manual, Section 501.1

4. ***West Virginia utilizes waiting lists for eligible applicants of the I/DD Waiver Program, and (historically with) the Aged and Disabled Waiver Program.***

The I/DD Waiver Program has had a waiting list for services since 2005. As of June, 30, 2011, 473 people were on the waiting list and 383 have been waiting longer than 90 days. During this same time period, the longest period of time any one individual has been on the waiting list was 532 days.[4]

In 2009, the average cost for per I/DD Waiver member was $61,794, and the average cost per resident in an ICF/MR was $115,884.[5]

West Virginia has 66 ICF/MR facilities with 511 beds. There is a moratorium on adding ICF/MR beds and facilities in West Virginia. However, the State continues to rely, redistribute, and reconstruct facilities under the current system. BMS reported that data for occupancy rates are not collected by the Bureau for the ICF/MR program.

BMS plans to add 300 unduplicated slots to the I/DD Waiver Program over the next 5 years (through 2015). In addition, unused slots from discharges throughout the year are reallocated every July 1st.

The ADW Program does not currently have a waiting list for services. It has used them as recently as 2009. When long term care budgets are cut or reductions are made these rarely affect institutional supports for nursing facilities or ICF/MR care.

In 2010, the average cost for per ADW member was $22,788, and the average cost per Medicaid patient in a nursing facility was $46,667.[6]

BMS plans a reduction of 2,301 unduplicated slots to the ADW Program over the next 5 year (through 2015). As of June 30, 2011, the average occupancy rate for West Virginia nursing facilities was 88.3%.[7]

Waiting lists result in eligible individuals being unable to access services at a reasonable pace. Often, eligible individuals are forced to wait extensive periods of time, which results in inappropriate institutionalization or undue stress on family and informal supports.

West Virginia has a moratorium on adding nursing facility beds and facilities. However, this did not prevent the legislature from passing a law during the 2011 regular legislative session to permit the development and operation of a nursing facility on the grounds of a critical access hospital. This law not only exempts the moratorium, but exempts the requirement to obtain a certificate of need from the WV Health Care Authority. This is the second time legislation of this type has been enacted.

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[4] Data Source: APS Healthcare
[5] Data Source: WV Bureau for Medical Services
[6] Data Source: WV Bureau for Medical Services
[7] American Health Care Association based on CMS OSCAR data. http://www.ahcancal.org/research_data/oscar_data/Nursing%20Facility%20Operational%20Characteristics/OperationalCharacteristicsReport_Jun2011.pdf

Recommendation: West Virginia needs to develop a long range plan to meet the needs of people seeking community-based waiver services. Historical (monthly and yearly) data exists on the number of people applying and determined eligible for the waiver programs. This data could be used to project future need. Money Follows the Person and other rebalancing techniques should be utilized.

In addition, the Balanced Incentive Program could be used to apply enhancing federal match to eliminate the reliance on waiting lists.

5. ***West Virginia does not provide an adequate education (informed choice) on support options for home and community-based services prior to institutional placement.***

Benefits or options counseling is not required prior to any institutional placement in West Virginia for nursing facility or ICF/MR care.

The BMS uses the Pre-Admission Screening Assessment (PAS-2000) tool for determining eligibility for the ADW Program, personal care services, and nursing facility care.

Question 17 on the PAS-2000 states:

"Has the option of Medicaid Waiver been explained to the applicant?"

This question only requires a "yes or no" response. This results in people being intentionally or unintentionally steered towards institutional care without being fully informed of their options.

Individuals being admitted to an ICF/MR sign an informed consent document stating they are choosing ICF/MR services over home and community-based waiver services. There is no requirement to provide information to support individuals in making an informed choice.

Recommendation: The process for nursing facility and ICF/MR services should be modified to eliminate require a benefits or options counseling process for every applicant prior to institutionalization.

6. ***West Virginia implements a complicated and lengthy eligibility process for the I/DD Waiver Program especially when compared to the ICF/MR program.***

The I/DD Waiver Program has a mandated (court ordered) 90 day eligibility determination process. However, West Virginia has a waiting list which significantly impacts the time an eligible individual must wait before services can be provided.

BMS policy permits ICF/MR services to be provided prior to the eligibility determination being made. This is known as presumptive eligibility. To establish eligibility, a completed packet of the required information must be submitted within 30 days after placement in the ICF/MR facility. For those

admitted after their eligibility has been determined, the ICF/MR manual states that eligibility determinations will be made as quickly as possible (a maximum of 45 days).[8]

During calendar year 2009, 58% of the eligibility reviews for I/DD Waiver services were denied, and 2% of the eligibility reviews (or one applicant) for ICF/MR were denied.[9]

West Virginia has one of the most restrictive eligibility criteria in the nation for its I/DD Waiver Program.

Recommendation: West Virginia needs to redesign the eligibility and enrollment process to ensure equitable processes for ICF/MR and I/DD Waiver programs. The I/DD waiver should redefine its eligibility criteria to use the federal definition and national standards used my nearly every other state in the nation. There needs to be equal access to community-based and institutional care.

7. West Virginia implements a complicated and lengthy eligibility process for the Aged and Disabled Waiver Program especially when compare to the nursing facility program.

Like the I/DD Waiver, the ADW has a lengthy and cumbersome eligibility and enrollment process. This process has numerous steps and takes months to complete. In comparison, the nursing facility process takes an average of 24-48 hours to complete.

During calendar year 2009, 53% of the initial eligibility reviews for ADW were denied, and 4% of nursing facility eligibility reviews were denied.[10]

Recommendation: West Virginia needs to redesign the eligibility and enrollment process to ensure equitable processes for nursing facility and ADW programs. There needs to be equal access to community-based and institutional care.

8. West Virginia incentivizes institutional care through a cost-based reimbursement methodology.

Institutional services for ICF/MR and nursing facility care are paid for through a cost-based reimbursement methodology.[11] I/DD Waiver and the ADW programs are paid for on a fee-for-service basis.

For nursing facilities, the cost-based reimbursement methodology results in a comprehensive per diem rate that is recalculated every six months. These per diem rates are cost related and not developed based on acuity. Case mix is an add-on to the rate.

[8] BMS ICF/MR Manual, Section 513.5.3
[9] Data source: WV Bureau for Medical Services
[10] Data source: WV Bureau for Medical Services 7/13/2010
[11] The I/DD Waiver Program uses a managed care style algorithm to set individual budgets.

For ICF/MR programs, the cost-based reimbursement methodology is based on actual costs and client specific needs assessments. In addition, per diem rates reimburse for allowable cost for room and board, laundry, housekeeping, administrative costs, cost of capital and cost of inflation.

This creates an incentive to provide institutional care over home and community-based services. Some examples of this are:

- Institutional care is reimbursed for services that are also required of home and community-based waiver programs. These are required but not reimbursed under the fee-for-service model of the waiver programs. For example, training, supervision, cost of living increases, cost of inflation.
- Documentation requirements are typically more extensive under a fee-for-service model. For example, fee-for-service documentation is typically required for every 15 minute to one hour unit. Cost-based reimbursement is billed on a daily basis as opposed to a per unit basis.

Recommendation: West Virginia should fund programs in a manner that does not give incentives or advantages for institutional care.

9. West Virginia has a fragmented and inadequate service system for people with mental illness and co-occurring disabilities.

As evidenced by the long-standing court action under the *Hartley* consent decree the mental health system continues to struggle with meeting the mental health needs of West Virginians. In addition, the findings of the national President's New Freedom Commission on Mental Health identified the following findings for West Virginia's mental health system:[12]

a. children with emotional disturbances are unnecessarily and precipitously being sent out of state for services;
b. families are split because of a perceived need to place children in custody before providing services;
c. psychiatric hospitals are overcrowded, with millions of dollars expended on inpatient services for people who could and should be served in community programs;
d. there is a severe lack of safe, affordable housing for people with psychiatric disabilities;
e. apathy about jobs for people with disabilities fosters an inappropriate and disproportionate reliance on expensive and restrictive treatment services.

In 2008, the West Virginia Mental Health Planning Council issued a report entitled, *Synopsis of Current Recommendations for Mental Health and Substance Abuse Services in West Virginia, with a Blueprint for Transformation.* This report identified 14 recommendations for systems change.

[12] New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003.

Recommendation: Recommendations made in study, commissions or councils on behalf of the West Virginia behavioral health system need to be implemented. Some examples are:

a. Re-design Medicaid reimbursement to support effective community-based services.
b. Develop and implement a true performance-based contract for Community Behavioral Health Centers.
c. Create a policy to achieve integration of physical health care and behavioral health care.
d. Develop a plan, in collaboration with the Housing Development Authority, to expand availability of a variety of safe, affordable housing.
e. Increase the qualifications for entry-level positions in community-based mental health services.
f. Develop a system to provide quicker access to services and enable consumers to obtain services better matched to their needs at the beginning of treatment.
g. Create an annual process to identify and support with State funds services and programs that have achieved desired outcomes for at least two years, using "demonstration funding" from sources like the Community Mental Health Services Block Grant.
h. Develop and implement a plan to assure cultural competence that includes addressing issues of rurality in the State, including better use of technology.

10. West Virginia does not effectively use unlicensed, trained personnel to administer medications in the community through exemption and delegation methods.

Medication administration is a regular service provided to patients of nursing facilities, and residents of ICF/MR programs.

ADW members are required to self-administer medications or have informal supports to perform this function. Medication administration by unlicensed personnel (AMAP) is not permitted within the ADW Program as a matter of policy, not statute.

I/DD Waiver Program permits the use unlicensed personnel to administer medications, but this service is severely underutilized. In addition, the statute is in need of revision to include the lessons learned of the past decade to better address the needs of people living in their community.

Recommendation: The following recommendations would better support people to live and be supported in the most integrated setting: 1) West Virginia should develop and implement a program for unlicensed personnel to administer medications for the ADW program. 2) West Virginia should support legislation to increase the flexibility of the AMAP program for the I/DD Waiver to increase its utilization and decrease the overall costs of the program.

11. ***West Virginia does not effectively use case management services to support people in transitioning from institutional care to the community.***

The BMS states the following about Targeted Case Management (TCM): "A Medicaid eligible individual over age 20 who have been determined in need of discharge, disposition, placement and after care follow up from a long term care facility may access TCM services to assist with transition planning, In this capacity, TCM is not permitted to exceed 30 days prior to the estimated date of discharge."[13]

The Centers for Medicare and Medicaid Services permits case management services under Medicaid to be provided for transition or discharge planning 180 consecutive days prior to discharge date from an institutional facility.[14]

The I/DD Waiver Program permits service coordination to be used for discharge or transition planning 30 day prior to the date of discharge.

Recommendation: West Virginia should review states that use TCM more effectively to cover a wider range of support and increase utilization. Once this review is completed, West Virginia should develop a plan to enhance its TCM services to better serve Medicaid members.

Olmstead Plan Implementation Accomplishments and Barriers

There continues to be a general lack of urgency to implement the *Olmstead Plan, Building Inclusive Communities*.

[13] West Virginia BMS Targeted Case Management Manual, Section 523.2
[14] State Medicaid Directors Letter, Olmstead Update No. 3, July 25, 2000

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OLMSTEAD INITIATIVES IN WEST VIRGINIA

Since August 2003, West Virginia has had a full-time Olmstead Coordinator. The Olmstead Coordinator assembled an Olmstead Council in November 2003. The Olmstead Office and Council oversee and advise four initiatives during state fiscal year 2011.

> *"To live in my own home, well I feel very grateful to all the people who helped me to get my own home and I feel very good about my home. I have a great life and I can make my own decisions. And I can handle my own business, and I feel good about myself."*
>
> *-Elaine Wilson, from an interview published by ILRU#*

The *Olmstead* Information, Referral and Assistance Program provides West Virginia citizens with information or referral needs concerning the long term care system. In addition to information and referral, the *Olmstead* Office provides citizens with assistance on Olmstead-related complaints or grievances.

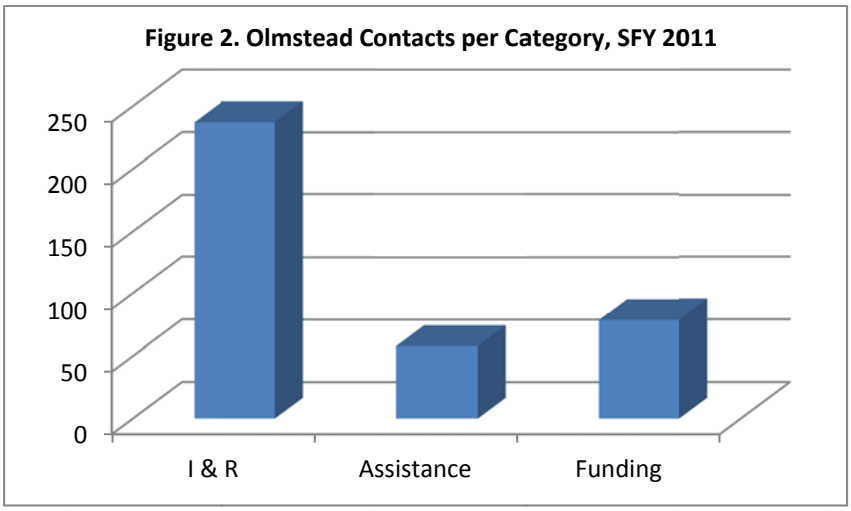
The second initiative is the West Virginia Transition Navigator Program. This program provides assistance to people wishing to return to or remain in their home and community. This program will be going through much change during state fiscal year 2012.

The third initiative is the SAMHSA *Olmstead* grant. This program provides federal grant funds to community organizations to implement specific and targeted *Olmstead*-related goals.

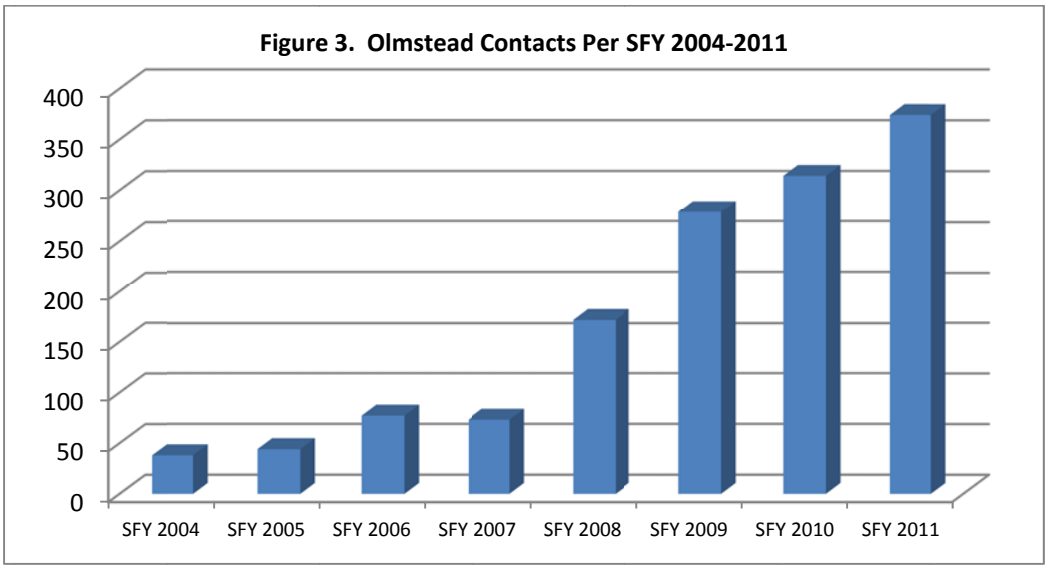
The last initiative is the West Virginia Long Term Care Partnership grant. *Olmstead* Office and Council partnered with the West Virginia Developmental Disabilities Council and the Fair Shake Network to apply for grant funding offered by the West Virginia Long Term Care Partnership. The grant project was to study Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR) and best practices for serving people in the community. The study focuses on the ICF/MR program's current and future role as a long term care option in West Virginia.

Olmstead Information, Referral and Assistance Program

The *Olmstead* Office provides information, referral and assistance to West Virginia citizens with disabilities and their families concerning Olmstead-related issues. In state fiscal year 2011, the *Olmstead* Office received 374 documented (and unduplicated) contacts for information, referral and assistance. ***Figure 2*** shows the number of contacts per category for the fiscal year. Information and referral means the typical contact is providing basic information with no further contact needed. Assistance means the typical contact is requesting help that requires additional time and contact to the individual. Assistance includes help with Olmstead-related grievances, complaints, and requests for funding to return to or remain in the home.



The *Olmstead* Office has been tracking *Olmstead*-related contacts since the office was established in August 2003. ***Figure 3*** shows the number of contacts for state fiscal years 2004 through 2011.



The biggest barrier to providing assistance is the need for systems change to decrease the institutional bias and make community-based services and supports more readily available and accessible.

Transition Navigator Program

Since 2007, the purpose of the Transition Navigator Program is to assist West Virginians with disabilities residing in institutional facilities (or at-risk of institutionalization) to be supported in their home and community. As a pilot program, direct transition assistance is provided in 22 counties through two (2) full-time Transition Navigators. Transition Navigators are employed through grant funding by Community Access, Inc. and Northern West Virginia Center for Independent Living.

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The remaining 33 counties can access start-up funding through the *Olmstead* Office, however, direct transition services are not provided in these counties.

Transition Navigators assist people residing in nursing facilities (and their representatives), who want to leave the facility and return to their home and community. Navigators provide: direct transition services; information and referral; outreach and education; assessment and planning; and advocacy.

During state fiscal year 2011, the program supported 151 people through the transition and diversion process. ***Figure 4*** identifies the number of people the program supported for transition and diversion for state fiscal years 2011 compared to 2010 and 2009.

Figure 4. Transition and Diversion Totals, SFY 2009 - 2011

	SFY 2011	%	SFY 2010	%	SFY 2009	%
Total # People Transitioned	50	33%	38	28%	28	22%
Total # People Diverted	101	67%	96	72%	101	78%
TOTAL	**151**		**134**		**129**	

In SFY 2011, 50 people were transitioned and 101 were diverted from institutional care..

The program has helped support 414 people in three years to return to or remain in their home and community.

Each participant is eligible to receive up to $2,500 to pay for reasonable and necessary one-time start-up costs. One-time start-up costs included: security deposit for housing; set-up fees for utilities; moving expenses; essential home furnishings and supplies; and home accessibility modification. ***Figure 5*** details the funding allocated for participants during state fiscal year 2011 as compared to 2010 and 2009.

Figure 5. Transition Navigator Start-Up Funding, SFY 2009 - 2011

Transition Navigator Start-Up Funding	SFY 2011	%	SFY 2010	%	SFY 2009	%
Housing Security Deposit	$12,990.12	5%	$9,030.85	3%	$3,748.58	1%
Utility Set-Up Fees or Deposits	$5,148.20	2%	$3,420.53	1%	$5,005.34	1%
Essential Home Furnishings and Supplies	$80,598.20	3%	$59,441.17	22%	$125,802.34	31%
Moving Expenses	$2,394.20	<1%	$5,680.13	2%	$8,027.33	2%
Home Modifications	$171,405.41	63%	$196,832.00	72%	$266,887.02	65%
TOTAL	**$272,536.15**		**$274,404.68**		**$409,470.61**	
PER PERSON AVERAGE	**$1,804.88**		**$2,063.19**		**$2,844.00**	
NUMBER SERVED	**151**		**134**		**129**	

The average start-up funding allocated per participant was 1,804.88. This is an overall decrease from previous years. The program has worked to effectively use the funding available and to serve the most people possible. In addition, the program was able to leverage resources to supplement start-up funding. Some examples of these leveraged resources:

- An apartment manager provided some furniture.
- Veteran's administration providing $2,000 towards home modifications.
- Secondary insurance covered partial costs for equipment.
- The Center for Independent Living provided supplemental funds through the Community Living Services Program for at least 10 participants.
- Family provided funding to pay for home furnishings.
- Neighbors donated labor to build a ramp.
- Contractor lowered the cost of project by $600 to stay at the program funding cap.
- Family paid $401 of the project to stay at the program funding cap.
- Family, friends, and neighbors donated labor to build ramps and/or complete bathroom modifications for at least 6 different participants.
- The Center for Excellence in Disabilities Funds for YOU Program provided $2,500 in supplemental funding to pay for a bathroom modification.
- The health care supply vendor lowered the cost by $450 to stay at the program funding cap.
- A USDA grant was received to supplement funding to pay for a bathroom modification and a ramp.

Due to the program starting late in SFY 2008, unused funding were carried over to 2009 and accounts for the higher funding allocated in 2009.

The Transition Navigators collected data and information for each participant to track trends and monitor for quality improvement needs.

The following lists some of the data and information tracked for participants of the Transition Navigator Program:

- The youngest person served by the program was 22 years old.
- The oldest person served by the program was 105 years old.
- The average age of all participants was 74 years old, with 53% being female and 47% being male.
- Twenty-one percent (21%) of participants received Medicaid only, 28% received Medicare only, and 42% received a combination of Medicare and Medicaid.
- Nine percent (9%) of participants did not receive either Medicare or Medicaid.
- The average transition time from intake to transition was 2.8 months.
- The average diversion time from intake to diversion was 3.6 months.
- Eighty percent (80%) of participants were transitioned from a nursing facility.
- Twenty percent (20%) of participants were transitioned from a state psychiatric facility, rehabilitation facility, or some other type of institutional setting.
- Thirty-four percent (34%) of participants had a diagnosed mental illness, 10% had a diagnosed intellectual disability, and 8% had a diagnosed dementia-related illness.

- Sixty-seven percent (67%) of participants were institutionalized due to or after a hospitalization.
- Thirty-three percent (33%) were institutionalized due to: lack of community-based supports, lack of informal supports, or a significant health status change.
- The average length of institutional stay prior to transition was 12 months.
- Ninety-two percent (92%) off all transition and diversion participants had informal supports available to them in the community.
- Fifty-five percent (55%) of participants received only informal supports post-transition, 39% received paid in-home supports post-transition, and 6% did not receive any formal or informal supports post-transition.
- Ninety-four percent (94%) of all participants resided in their own home or apartment post-transition, and 6% resided within a family home post-transition.

Transition Navigators have identified barriers that prevent or hinder people returning to or remaining in their home and community. As a result of these barriers, many people are forced to leave their home to receive more costly institutional care. The *Olmstead* Office tracks, monitors and reports on identified barriers to the *Olmstead* Council and other appropriate entities. **The following lists some of these barriers:**

1. The waiting list for the Aged and Disabled Waiver Program makes it very difficult for people to transition from nursing facilities to their home. The wait list also places more stress on informal caregivers and family.
2. Lack of affordable and accessible housing remains the most critical barrier for people. This includes waiting lists for federal and/or state housing vouchers or lack of adequate funding for housing programs.
3. Lack of funding and programs to meet the needs of people requiring home modifications or home repairs that are essential to remaining at home in the community. Bathroom modifications, access modifications to multi-levels of a home, and ramps are expensive one-time costs. However, they are significantly less costly than nursing facility placements.
4. Lack of community-based supports for people with mental health needs. Waiver, home health and personal care are not always able meet the mental health needs of participants.
5. Lack of comprehensive community-based supports under the Aged and Disabled Waiver Program. The Aged and Disabled Waiver Program is not a functional alternative to nursing facility care.
6. Lack of fast track or presumptive eligibility for home and community-based services results in nursing facility placements often being the only viable option.

7. Lack of timely processing for grant agreements and funding at the state-level creates delays in responsive Transition Navigator services.

SAMHSA *Olmstead* Grant

Since 2000, the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA) have issued state *Olmstead* initiative grants to states and territories every three (3) years in the amount of $60,000. The purpose of this grant funding is to expand resources and opportunities for adults with serious mental illnesses and children with serious emotional disturbances to live in their home communities.

West Virginia Long Term Care Partnership Grant

The *Olmstead* Office and Council partnered with the West Virginia Developmental Disabilities Council and the Fair Shake Network to apply for grant funding offered by the West Virginia Long Term Care Partnership. The grant project was to study Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR) and best practices for serving people in the community. The study focuses on the ICF/MR program's current and future role as a long term care option in West Virginia.

In addition to the West Virginia Long Term Care Partnership, the project was funded and supported by the West Virginia Developmental Disabilities Council and the West Virginia *Olmstead* Council.

The project encompassed two phases. The first phase amassed a large amount of information and data through research and interviews with stakeholders.

From what has been learned in the first phase, it can be said that there is a need for improved data collection and tracking by state agencies related to the people served in the ICFs/MR facilities, and there is a sense of need for independent screening before people are admitted to the facilities. Data collection and tracking for reporting, monitoring, oversight, and admissions/discharges are specific areas that need improvement. There are no specific recommendations for legislative action at this time. However, it is anticipated that specific recommendations will be made in the final report for the following areas to address:

1. The barriers to accessing home and community-based support options, including housing.
2. The future use of ICF/MR services in West Virginia.
3. The processes for relevant data collection and tracking at the state-level.
4. The eligibility criteria for placement and options counseling so that institutional placement becomes a last resort to achieve compliance with the West Virginia Olmstead Plan.
5. The funding and administrative bias towards the ICF/MR program.
6. The need to strengthen the MR/DD Waiver to better support people in their communities.

The following are the major activities planned for the second phase of the project:

1. Contract with a knowledgeable consultant to meet with and produce personal profiles of six people who reside in West Virginia ICFs/MR and six people who receive MR/DD Waiver services in the community.

Issue a final report on the project findings and recommendations, including input from national experts.

West Virginia *Olmstead* Council

The West Virginia *Olmstead* Council was established in 2003 to advise and assist the *Olmstead* Coordinator to develop, implement, and monitor West Virginia's *Olmstead* activities. The mission of the *Olmstead* Council is to assist all West Virginia citizens with disabilities to have the opportunity to receive supports and assistance in the most integrated setting in the community. The Council has the following responsibilities as outlined in the *Olmstead Plan*:

1. Advise the Coordinator in fulfilling the position's responsibilities and duties;
2. Review the activities of the Coordinator;
3. Provide recommendations for improving the long term care system;
4. Issue position papers for the identification and resolution of systemic issues; and
5. Monitor, revise, and update the *Olmstead Plan* and any subsequent work plans.

The Council is a 30-member body consisting of eight (8) people with disabilities and/or immediate family members; eleven (11) advocacy and/or disability organizations; six (6) providers of institutional and community supports; four (4) state agencies; and one (1) housing representative.

Olmstead Council and Office Action Steps

The *Olmstead* Council and Office have taken a number of proactive steps to address the implementation of the *Olmstead Plan*. The following provides some examples of these action steps in state fiscal year:

1. Provided financial and technical support for the Bureau for Medical Services MFP Grant application.

2. Developed a comprehensive work plan to direct and guide the implementation of the *Olmstead Plan*.

3. Administered and monitored the on-going implementation of grant agreements for the Transition Navigator Program.

4. Received grant funding through the West Virginia Long Term Care Partnership to study the current and future uses of the ICF/MR program in West Virginia. This was a collaborative project with the WV Developmental Disabilities Council.

5. Worked collaboratively with the WV Developmental Disabilities Council, WV Fair Shake Network, and the WV Statewide Independent Living Council on legislation to increase the flexibility of medication administration by unlicensed personnel in home and community-based programs.

6. Worked collaboratively with the Bureau of Senior Services and the Bureau for Medical Services to implement the new federal regulation for the MDS 3.0 assessment.

7. Requested an improvement package for additional state general revenue funding to support a statewide transition and diversion program.

8. Monitored the I/DD Waiver Wait list on a monthly basis.

9. Reviewed the I/DD Waiver renewal application and draft manual and provided comments to the Bureau for Medical Services.

10. Reviewed the Aged and Disabled Waiver renewal application and draft manual and provided comments to the Bureau for Medical Services.

11. Monitored the I/DD Waiver program through attending quarterly provider meetings and quarterly Quality Council meetings.

12. Monitored the Aged and Disabled Waiver program through attending quarterly provider meetings and quarterly Quality Council meetings.

13. Participated in the 2011 National Mental Health Block Grant, Data and Olmstead Conference in Washington, DC.

14. Participated and provided funding to support and sponsor the West Virginia Fair Shake Network Disability Advocacy and Training Days.

15. Provided funding to support and sponsor the West Virginia Disability Caucus.

16. Managed an annual budget of $493,709 in state general revenue funds for grant programs.

17. Administered the federal Olmstead grant provided by the U.S. Substance Abuse and Mental Health Services Administration.

18. Participated as a member of the West Virginia Long Term Care Partnership.

19. Participated in the West Virginia Behavioral Health Rules Committee.

20. Analyzed the long term care system and reported on institutional bias in West Virginia.

21. Re-established regular meetings with the DHHR Secretary's Office to discuss on-going Olmstead issues.

22. Participated on the in-home worker credentialing and registry committee.

The *Olmstead* Office tracks and monitors the following systemic issues that impede the successful implementation of the Olmstead Plan:

1. Individuals inappropriately placed at the two (2) state-operated psychiatric facilities.
2. Individuals inappropriately placed at the five (5) state-operated long term care nursing facilities.
3. Waiting list for individuals eligible for the I/DD Waiver Program.
4. Institutional bias in West Virginia's long term care system that support unnecessary reliance on institutional care.
5. Individuals inappropriately placed in out-of-state facilities, due to a lack of in-state supports.
6. Continued use and development of ICF/MR facilities.
7. Medication administration in the community that does not support choice, independence, and safety.
8. Inmate work release program within a state-operated nursing facility.

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PRIORITIES & RECOMMENDATIONS FOR 2012

The goal of these forums was to 1) educate the public about *Olmstead*, and 2) gather input for the 2012 Priorities and Recommendations. The 2012 Priorities and Recommendations will be used to guide our work during the regular legislative session and the *Olmstead* Work Plan.

[Need to complete section.]

> *"Much can be done when we raise our voices and join together. We cannot simply stand by and wait for someone else to take action. We must make our own history."*
>
> *-the late Ken Ervin, ADAPT-WV founder and Olmstead Council member*

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Appendix A: West Virginia *Olmstead* Plan Goals

The *Olmstead* Council through extensive public input developed 10 *Olmstead* goals. Each goal has a series of specific objectives. The following lists these 10 goals:

1. **Informed Choice:** Establish a process to provide comprehensive information and education so people with disabilities can make informed choices.
2. **Identification:** Identify every person with a disability, impacted by the Olmstead decision, who resides in a segregated setting.
3. **Transition:** Transition every person with a disability who has a desire to live and receive supports in the most integrated setting appropriate.
4. **Diversion:** Develop and implement effective and comprehensive diversion activities to prevent or divert people from being institutionalized or segregated.
5. **Reasonable Pace:** Assure community-based services are provided to people with disabilities at a reasonable pace.
6. **Eliminating Institutional Bias:** Provide services and supports to people with disabilities by eliminating the institutional bias in funding and administering long term care supports.
7. **Self-Direction:** Develop self-directed community-based supports and services that ensure people with disabilities have choice and individual control.
8. **Rights Protection:** Develop and maintain systems to actively protect the civil rights of people with disabilities.
9. **Quality:** Continuously work to strengthen the quality of community-based supports through assuring the effective implementation of the Olmstead Plan, and that supports are accessible, person-centered, available, effective, responsive, safe, and continuously improving.
10. **Community-Based Supports:** Develop, enhance, and maintain an array of self-directed community-based supports to meet the needs of all people with disabilities and create alternatives to segregated settings.

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APPENDIX B: *Olmstead* Council Membership

Elliott Birckhead	Bureau for Behavioral Health and Health Facilities
Marcus Canaday	Bureau for Medical Services
Libby Collins	WV EMS-TSN Hartley Medley Advocacy Program
Karen Davis	Charleston, West Virginia
Jan Derry	Northern WV Center for Independent Living
Jeannie Elkins	Ashford, West Virginia
Darla Ervin	Morgantown, West Virginia
Nancy Fry	Legal Aid of WV, Behavioral Health Advocacy Project
Penney Hall	WV State ADA Coordinator
Clarice Hausch	WV Advocates
Brenda Hellwig	Job Squad, Inc.
Roy Herzbach	Legal Aid of WV, Long Term Care Ombudsman Program
Cathy Hutchinson	Mountain State Center for Independent Living
Ted Johnson	WV Mental Health Planning Council
Linda Maniak	Charleston, West Virginia
Ann McDaniel	WV Statewide Independent of Living Council
Suzanne Messenger	Bureau of Senior Services
John Russell	WV Behavioral Health Providers' Association
David Sanders	WV Mental Health Consumers' Association
Christine Shaw	Res-Care, Inc.
Kevin Smith	Parkersburg, West Virginia
David Stewart	WV ADA Coalition
Vanessa VanGilder	Fair Shake Network
Steve Wiseman	WV Developmental Disabilities Council