# ICF/MR Program in West Virginia:
# A Study Project Report

REPORT AND RECOMMENDATIONS

DECEMBER 9, 2010

A PROJECT OF THE WEST VIRGINIA COMMUNITY VOICES INC. FUNDED BY THE CLAUDE WORTHINGTON BENEDUM FOUNDATION.

## WORKING GROUP MEMBERS

**CORE WORKING GROUP**
**Jim Cremeans**, Planner, West Virginia Developmental Disabilities Council
**Linda Higgs**, Program Specialist, West Virginia Developmental Disabilities Council
**Tina Maher**, Coordinator, West Virginia Olmstead Office, Office of Inspector General
**Steve Wiseman**, Executive Director, West Virginia Developmental Disabilities Council and Chair of the Working Group

**MEMBERS**
Members of the West Virginia Developmental Disabilities Council and the West Virginia Olmstead Council reviewed without objection to the following recommendations and next steps. ***Appendix A*** contains the membership list for the West Virginia Developmental Disabilities Council. ***Appendix B*** contains the membership list for the West Virginia Olmstead Council.

## ISSUE OVERVIEW

The West Virginia Developmental Disabilities Council (WVDDC) and the West Virginia Olmstead Council (WVOC) partnered to implement a project 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.

This study was funded in part by the West Virginia Long Term Care Partnership, the West Virginia Developmental Disabilities Council, and the West Virginia Olmstead Council.

The state and federal laws have changed the terminology used whereas "mental retardation" is now referred to as "intellectual disability." Due to the historical and current reference, the terms mental retardation/developmental disability (MR/DD) and intellectual disability/developmental disability (ID/DD) may be found throughout this report.

The project has amassed considerable information concerning the ICF/MR program both from national and West Virginia sources. The project focuses on complex issues with many different viewpoints which require more detailed examination and careful analysis. The project will be completed in two phases. The first phase is to be completed through the West Virginia Long Term Care Partnership grant, and the second phase is an expansion on those issues that requires more time than the grant period provided. Comprehensive and specific recommendations will be made in the final project report that will be issued once the second phase is completed.

Some questions are important to address before proceeding with this project. These questions are: What is an "institution?" What is the "community?" What is a "home?"

There are different definitions of institution. Some definitions focus on the purpose or services, some on size, and some on a specific characteristic(s) of the setting. ICF/MR is an institution defined by its purpose and services with a restriction for 4 or more beds. An ICF/MR is defined as (42CFR 435.1009) an institution for persons with mental retardation (or distinct part of an institution) that 1) is primarily for the diagnosis, treatment, or rehabilitation of the mentally

retarded or persons with related conditions; and 2) provides, in a protected residential setting, ongoing evaluation, planning, 24-hour supervision, coordination, and integration of health or rehabilitative services to help each individual function at his greatest ability.

The American Association of Mental Retardation (now American Association of Intellectual and Developmental Disabilities or AAIDD) states the community is not a place where you are isolated, deprived of the rights and experiences of other citizens when you have committed no crime. Community is a place where there are unlimited opportunities, not a place where because you are "different" or "special" you cannot fit in, blend in, participate and contribute, give and receive. Community is where all people belong, disability or not, in need of a lot of supports, or some or none. Community is possibility and opportunity and hope for the future. It is not a program, or services, or an alternative (AAMR, 2004).

Everyone needs a home. A home is where we get our sense of belonging and a sense of family. Home is where we can be free to be more independent; control our surroundings; choose who, if anyone we live with; and where we have privacy. Home is where we should feel safe and secure.

Michael Kendrick, Ph.D., authored an article, *The Choice Between a Real Home and a Program*. He cites the following thirteen (13) points for consumers, families and staff to consider as they strive towards building a proper and rich sense of "home" into their residences.

1. The individuals served should assist in the selection and location of the home.
2. The individuals served should help to decorate and furnish their home environment.
3. The individuals served should decide who they want to live with.
4. The individuals served should have a voice in staff selection.
5. Agencies should hire staff whose personal orientation, commitment, and attributes are targeted towards helping people make a home for themselves.
6. Programming, treatment, and related practices are either kept out of the home setting or, if necessary, blended carefully into the home-life so they do not disturb the home setting.
7. Agencies should not bring their bureaucracy into the home. This means agency materials, meetings, offices, or equipment.
8. Home sites should be integrated into their neighborhoods. The houses should be attractive, well cared for, and similar in appearance to neighboring households.
9. The home should be close to work, family, recreation and convenient to other interests of the people who live there.
10. Intimacy, sharing, personal ownership and possessions should be encouraged.
11. Regulatory concerns of funding agencies should be addressed in such a way that the home remains a home.
12. The house is at all times, legally and otherwise, the home of the residents and not the staff or the agency.
13. The agency should stress in its mission and in its communication to staff, consumers and families that the concept of home in its residences is a worthy and preeminent goal of the organization.

These thirteen points are difficult to implement within the structure and confines of an ICF/MR, but can be obtained under the flexibility of an MR/DD waiver program.

The MR/DD Waiver Program is West Virginia's home and community-based services program for individuals who have mental retardation and/or developmental disabilities. It is administered by the Bureau for Medical Services (BMS) in collaboration with APS Healthcare.

The MR/DD Waiver Program is a health care coverage program that reimburses for services to instruct, train, support, supervise, and assist individuals who have mental retardation and/or developmental disabilities in achieving the highest level of independence and self-sufficiency possible in their lives. The MR/DD Waiver Program provides services in natural settings, homes and local communities where the individual resides.

## ARGUMENTS FOR KEEPING INSTITUTIONS OPEN

Five basic arguments typically are cited for keeping institutions open for people with developmental disabilities. These same arguments are used by state officials and providers for keeping ICFs/MR open in West Virginia. The five basic arguments are that institutions are needed to serve **people with challenging behavior and/or psychiatric disabilities**; **people with significant and complex medical needs**; **people who have aged or lived most of their lives in the institution**; the need for **safeguards** and the issue of related **costs**.

## RESPONSES TO THOSE ARGUMENTS

### People with Challenging Behavioral Needs

People with challenging behavioral needs live in the community, some never being institutionalized. The states that have closed their public institutions for people with developmental disabilities have also learned how to support people with psychiatric disabilities in the community. In fact, far more people with both diagnoses are living in communities all over the country than in public institutions. States need not rely on institutions to serve people with both psychiatric and developmental disabilities (AAMR, 2004).

### People with Complex Medical Needs

People who rely on feeding tubes and ventilators, who have difficult-to-control diabetes or seizures or other potentially dangerous conditions, who need suctioning and frequent positioning, or who have other medical conditions requiring sophisticated medical expertise and technology, are living in the community. For every person with such needs in institutions, there are many with the same or more complex needs living in the community, going to school, going on family vacations, going to a workplace, and generally having as normal a life as possible. Their medical services are provided by community doctors, nurses, personal care assistants, provider agency staff persons, and trained family members. At times, specialized medical services must be created or packaged in order to meet needs: medical equipment might be brought into a home, or round-the-clock nursing assistance, to enable the person to live as normally as possible (AAMR, 2004).

## People of Advanced Age or Lengthy Institutionalization History

It is sometimes said that people who have grown old in a public institution should not be moved into a home in the community, because "the institution is the only home they have ever known." However, individuals who have moved out after growing old in institutions are frequently very happy with the move, living fulfilling and active lives in the community. States need not keep institutions open just for the older residents of such institutions (AAMR, 2004).

## Safeguards

Some proponents of ICFs/MR argue that people with developmental disabilities are more at risk in the community, and that institutionalization is the best safeguard. These proponents cite mortality studies as evidence, and use this as grounds to oppose deinstitutionalization. This "evidence" is highly disputed within the research community. Instead, researchers assert the focus should be on identifying and addressing the specific circumstances that create risk in the community (AAMR, 2004).

In order to address risk, systems tend to impose more and more regulations. Regulations alone cannot guarantee the safety of people inside or outside of the institution. In addition, regulations should never be used as a rationale for institutionalizing people. As with all bureaucracy, there are problems and limitations with regulations (Taylor, 1993) (AAMR, 2004):

1. Regulations in the field of developmental disabilities represent the bureaucratization of values.
2. Regulations reflect the abuses of the past, and sometimes the present, but limit the potential of the future.
3. Regulations encourage investment in unnatural environments.
4. Regulations foster ritualistic compliance and not fulfillment of their spirit.
5. Regulations place control and power in the hands of regulators, and not the people with developmental disabilities and their families.
6. Regulations direct attention to concrete and tangible things, and trivialize the most important things in life.

It should not be inferred that all regulations are bad, but careful thought should be employed prior to implementing regulations in the name of safeguards. Generally, having caring personal relationships, appropriate and responsive supports, common sense and careful planning are the best tools to ensure the safety and well-being of vulnerable people.

## Costs

A number of factors complicate the direct comparisons of the costs of ICF/MR and home and community-based services (HCBS) approaches to financing residential services. Several research articles were reviewed that discussed the issue of comparing costs of institutional care and HCBS. It was noted that the question "Which is less expensive, institution or community?" is the wrong question. The questions that need to be asked revolve around the individual and what they need and desire. Some of these complicating factors are (Lakin K. L., 2009) (Walsh, 2003):

1. Disproportionately higher expenditures for ICF/MR recipients may be explained by artificially inflated institutional costs resulting from deinstitutionalization.

2. The consistent pattern of relatively lower expenditures for HCBS recipients in some states in an intended and controlled program goal.
3. In almost all states substantial numbers of HCBS recipients live in the family home (an estimated 48.2% nationally), reducing the costs by the relative value of the supports provided by family members and other non-paid support providers.
4. Federal regulations require both HCBS and ICF/MR recipients to meet the same eligibility criteria and level of care needs, in actual practice some states HCBS tend to be less intensive than ICF/MR, making HCBS in some states, almost by definition, less costly.
5. Medicaid law specifically prohibits HCBS financing of room and board costs, HCBS recipients pay for such cost through their own funds, typically from Social Security benefits. These individual "contributions" to room and board may represent up to $6,700 per HCBS recipient per year, and can be even higher because of state supplements.
6. There is an intrinsic lack of comparability between institutions and community settings. Community services include a diverse array of service types, and institutions traditionally offer an established package of services.

Between 1993 and 2008 average per person annual ICF/MR expenditures increased from $62, 180 to $126,130 (103%), and the average per person HCBS expenditures increased from $25,176 to $43,464 (73%).

## SUPPORTIVE INFORMATION AND DATA

### BACKGROUND AND HISTORY

The University of Minnesota issued the publication, *Residential Services for Persons with Developmental Disabilities: Status and Trends through 2008* that details the history of the ICF/MR program development. In 1965, Medical Assistance, Title XIX of the Social Security Act was enacted to provide federal participation in long term care for persons with developmental disabilities. Depending on per capita income for states, federal matching funds from 50 to 83 percent would be provided for medical assistance, including Skilled Nursing Facilities (SNF), for people in the categories of elderly, blind, disabled, and dependent children and their families.

Soon after the establishment of this federal reimbursement for skilled nursing care government officials noted a "rapid growth" in the number of patients in SNFs. It was further documented that "many of these individuals were receiving far more medical care than they actually needed, at a greater cost than was needed, largely because of the incentives of placing people in facilities for which half or more of the costs were reimbursed through the federal Title XIX program."

As a result of these findings, in 1967, a less medically oriented and less expensive "Intermediate Care Facility" (ICF) program for elderly and disabled adults was authorized under Title XIX of the Social Security Act.

The SNF and ICF programs were combined under Title XIX in legislation enacted in 1971. Within the legislation combining the two programs was a little noticed, scarcely debated amendment that for the first time authorized federal financial participation (FFP) for "intermediate care" provided in facilities specifically for people with ID/DD. Three primary outcomes of the new ICF/MR legislation appear to have been intended by proponents of this legislation: 1) to provide substantial federal incentives for upgrading the physical environment and the quality of care and habilitation being provided in large public ID/DD facilities; 2) to neutralize incentives for states to place persons with ID/DD in non-state nursing homes and/or to certify their large state facilities as SNFs; and 3) to provide a program for care and habilitation ("active treatment") specifically focused on the needs of persons with ID/DD rather than upon medical care.

During this time of rapid facility growth, support for community residential services was growing and was used by a growing number of critics that the ICF/MR program 1) had created direct incentives for maintaining people in large state facilities by providing federal matching funds; 2) had diverted funds that could otherwise have been spent on community programs development into facility renovations to obtain FFP; 3) provided the development of large private ICFs/MR for people leaving large state facilities; and 4) promoted organizational inefficiency and individual dependency by promoting a single uniform standard for care and oversight of the ICF/MR residents irrespective of the nature or degree of their disabilities and/or their relative capacity for independence.

In 1991, New Hampshire closed the Laconia State School and became the first state to close all of its public institutions. Since that time, the District of Columbia, Vermont, Rhode Island, Alaska, New Mexico, West Virginia, Hawaii, Minnesota, and Oregon have also closed all of their public institutions.

In addition to closing public facilities, Alaska and Oregon do not operate any private ICF/MR facilities. Vermont only operates one 6-bed private ICF/MR facility.

## OVERVIEW OF WEST VIRGINIA'S ICF/MR PROGRAM

In 1981, West Virginia established the first ICF/MR facility in Charleston with 10 beds. West Virginia once operated 2 large institutions specifically for people with developmental disabilities, and had specialized units in 3 large psychiatric hospitals. The first state-operated facility for people with developmental disabilities to close was Greenbrier Center, which opened in 1973 and closed in 1993. Colin Anderson Center, which opened in 1921, closed in 1998 making West Virginia the sixth state to close all of its public institutions which were ICFs/MR.

In 1989, a court order was established to place a moratorium on "the construction or development of new ICF/MR facilities in the state." This was a matter in the Hartley class action suit that remains active today. The court order states the agreement with the parties that "new

resources should be used to develop small individualized residences and home-based programs." The court ordered moratorium was also added to the State Code §16-2D-5.

The West Virginia Health Care Authority (WVHCA) follows ICF/MR Standards that were approved by the Governor on October 5, 1992. These standards state:

1. The supply of ICF/MR group homes exceeds the needs of the population served.
2. Applications for the establishment, replacement, or addition of ICF/MR beds by any provider shall not be approved under the certificate of need program.
3. Capital expenditures made on behalf of an existing or proposed provider of ICF/MR group home services which are in excess of the expenditure minimum shall not be approved by the certificate of need program.

According to the West Virginia Bureau for Medical Services (BMS), ICFs/MR are part of the long term care continuum that provides care for individuals with mental retardation and/or developmental disabilities. The BMS provides reimbursement for allowable services and an eligibility process for recipients. BMS establishes the medical and financial eligibility for the ICF/MR Program. The ICF/MR Program and the MR/DD Waiver Program both have the same eligibility criteria.

Although the eligibility criteria are the same, applicants are more likely to be accepted for ICF/MR placement than for home and community-based waiver services. During calendar year 2009, 58 percent of the eligibility applications for MR/DD Waiver services were denied, while only 2 percent (one applicant) of the eligibility applications for ICF/MR were denied. Compared to 2005, 53 percent and 2006, 58 percent of the eligibility applications for MR/DD Waiver services were denied, while 0 percent were denied for ICF/MR.[1]

The Office of Health Facility Licensure and Certification (OHFLAC) certifies that ICF/MR programs meet requirements with relevant State and Federal regulations. The ICF/MR must maintain standards necessary for licensure and certifications. Reviews are conducted, at a minimum, annually for licensure and certification. After completion of a certification survey, OHFLAC will report any deficiencies found during the survey to the ICF/MR and the BMS. The facility is responsible for the development and implementation of a plan of correction of any identified deficiency.

### Demographics of the West Virginia ICF/MR Program

According to OHFLAC, there are 66 ICFs/MR with 511 certified beds operating privately across the State. ICFs/MR range from four beds to 24-beds, with an average of eight beds, scattered geographically across West Virginia. Six providers operate ICF/MR facilities in West Virginia. Res-Care, Inc. operates 70 percent of the ICF/MR beds in West Virginia, and was ranked the ninth largest private employer in the state in March 2010.

In 2009, one 6-bed facility was de-certified through the licensure review process.

[1] Data provided by the WV Bureau for Medical Services

West Virginia has a four bed, a five bed and a 24 bed ICF/MR for children with developmental disabilities. The 24 bed Potomac Center, located in Romney, is a transitional facility or short-term (6-24 month) residential placement designed to assist children, ages 5 to17 years, with developmental disabilities and behavioral issues. The five bed facility is located in Terra Alta, a very rural and isolated location, and the four bed facility is located in Charleston.

***Appendix C*** lists the ICF/MR facilities operating in West Virginia.

**Reimbursement**

The Medicaid State Plan for the ICF/MR program defines the reimbursement methodology. The BMS pays an all-inclusive per diem rate for all services and items that are required to be provided by the ICF/MR. The Inventory for Client & Agency Planning (ICAP) assesses adaptive and maladaptive behavior and gathers additional information to determine the type and amount of assistance a person will need. The level of care an individual needs is based upon the results of the ICAP assessment. The service level determines the rate of reimbursement for the individual.

Based on the ICAP score an individual may fall into one of four possible levels of care. The four reimbursement levels are Intermittent, Limited, Extensive, and Pervasive. The most recent ICF/MR rates range from $268.12 to $468.22 per diem with the average rate being $353.43.

Reported allowable costs are grouped into one of the following cost centers: Direct Care and Nursing Staff; Medical and Other; Day Programming and Supportive Employment; and Room and Board; and Administration. The following is considered non-allowable costs: bad debt, charity, penalties and fines, and courtesy allowances.

An annual standard appraisal value (SAV) and an inflation factor are included in the ICF/MR rate. According to BMS, the per diem rates include the SAV and inflation factor, which range from $74.43 - $144.53.

Individuals who meet the ICF/MR level of care receive Social Security benefits and a portion of each individual's Social Security payment also is paid to the facility. The individual retains $50 per month from their Social Security.

In 2009, the ICF/MR Program operated 511 beds at a cost of $62,324,645 and served 568 people. This total includes state dollars and federal matching payments. According to BMS, from 1999 to 2009, ICF/MR expenditures have increased by approximately 37 percent without the total number of certified beds changing. The last time the total number of ICF/MR beds had a significant change was in August of 1998 when Colin Anderson Center closed. The total number of ICF/MR beds has remained stable since August of 1998.

The average ICF/MR per person cost in 2009 was $109,726, and the average cost in 1999 was $88,096. These costs do not include acute care which cost a total of $3,497,225 or an average of $6,158 per person in 2009. Therefore, in 2009 the average cost of ICF/MR services including acute care costs was $115,884 per person.

### Leave of Absence Policy for ICF/MR

Reimbursement is generally limited to the actual days in the facility. However, payment may be authorized to reserve a certified bed when the ICF/MR resident is absent for temporary periods. Payment for days of authorized absence shall be at the full rate of the facility's approved default per diem (not adjusted for acuity). A day of absence from the ICF/MR is defined as an absence when the resident spends the night away from the facility.

Reimbursement will be paid for an ICF/MR resident who must be transferred to an inpatient hospital for care and treatment that can only be provided on an inpatient basis. The maximum bed reservation for such authorized medical absences shall be limited to 14 consecutive days, provided the resident is scheduled to return to the ICF/MR facility following discharge from the hospital. If the bed is used during the client's absence for emergency or respite care, it will in no way jeopardize or delay the return of the hospitalized resident to the facility.

Reimbursement will be paid to an ICF/MR facility for non-medical leave of absence for therapeutic home visits and for trial visits to other facilities. Such visits are encouraged, and the policies of the ICF/MR should facilitate rather than inhibit such absences. Non-medical absences shall be initiated as a part of the resident's individual plan of care at the request of the resident, his parent(s), or his guardian. The Medicaid agency will pay to reserve a bed for up to 21 days per calendar year for a resident residing in an ICF/MR when the resident is absent for therapeutic non-medical leave. If the bed is used during the client's absence for emergency or respite care, it will in no way jeopardize or delay the resident's return to the ICF/MR. No additional payment is allowed for such short-term use of the bed for emergency or respite care.

## WEST VIRGINIA STUDIES AND REPORTS

Four studies and/or reports completed on behalf of the West Virginia Department of Health and Human Resources (DHHR) have included information regarding the ICF/MR program.

1. **Public Consulting Group (PCG) Money Follows the Person.** In 2006, the West Virginia Olmstead Office contracted with the Public Consulting Group to study the long term care system and make recommendations for rebalancing strategies. The report contained an analysis of the ICF/MR program with recommendations and cost projections for downsizing ICFs/MR. PCG stated that West Virginia's ICFs/MR are an outdated model of service delivery that has been abandoned in many states.

2. **The Lewin Group MR/DD Waiver Report.** In October 2004, the Bureau for Medical Services contracted with the Lewin Group to conduct an independent evaluation of its MR/DD Waiver for the 2005 renewal application to the Centers for Medicare and Medicaid Services. Lewin stated that home and community-based services and waiver program were 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.

3. **Costs and Services, Olmstead Task Force.** In 1999, the Olmstead Task Force was created through an Executive Order by Governor Cecil Underwood. The Task Force implemented committees to work on targeted areas. These committees were co-chaired

by a state agency representative and a disability advocacy representative. The "Costs and Services Subcommittee" was co-chaired by Steve Mullins, BMS and Steve Wiseman, WVDDC. The Subcommittee used 2001 Medicaid data to make cost methodology and projections for transitioning people from institutional settings to community-based settings. One of the Subcommittee recommendations was to "*Reduce the number of ICF/MR facilities*." This recommendation addresses the Olmstead most integrated setting mandate and potential cost savings.

4. **Cooper/Hill MR/DD Waiver Report.** In 2000, BMS purchased consulting services to study the program and make recommendations as a part of their renewal process with the Centers for Medicare and Medicaid Services (CMS). Robin Cooper of the National Association of State Directors of Developmental Disability Services (NASDDDS) and Marilyn Hill of Hill Associates conducted the study for West Virginia. The July 10, 2000 report included an analysis of the ICF/MR program with recommendations. Cooper/Hill stated, "As has been clearly demonstrated, many individuals with similar needs are well served through the waiver. As a means to offer more choice and flexibility and achieve potential cost savings that could be used to add new individuals to the waiver, West Virginia may wish to review the role of these settings in the overall services system."

All four (4) reports identified the cost effectiveness of the MR/DD Waiver in comparison to the ICF/MR program. Three (3) of the reports identified the ICF/MR program as outdated and recommended people receive home and community-based services supported through the MR/DD Waiver.

## STATE AGENCY INPUT

The working group members of the WVDDC and the WVOC interviewed representatives of the following state agencies: BHHF; BMS; and OHFLAC. WVHCA submitted answers to questions in lieu of a meeting.

***Appendix D*** lists the questions asked of state agencies related to the ICF/MR program. Not all the requests for information have been received. The following is a sample of the responses received thus far from state agencies:

1. The BHHF does not track "emergency placements" in ICFs/MR. Other residential crisis sites are used for this type of placement need.
2. The BHHF does not track ICF/MR admissions and discharges to and from state psychiatric facilities.
3. The BMS reported some individuals did not utilize their waiver slots due to a lack of available waiver providers for those individuals.
4. The BMS stated they do not track data for occupancy rates in the ICF/MR program.
5. The BMS stated the information from the required Admittance/Discharge/Transfer form is reported to them by the facilities, but if the form is not turned in regularly the numbers may be inaccurate.
6. Inconsistent information on the ownership status of the facilities and/or properties was received.

7. Inconsistent information on current plans for downsizing or replacement of ICF/MR beds was received.
8. The OHFLAC does not issue an annual report regarding ICFs/MR, but does have an extensive and comprehensive database of information from reviews, surveys, and complaint investigations.
9. The BHHF stated the need for independent review before admission for more consistency and adequacy of screening.

**PROVIDER INPUT**

Two methods were used to gather input from providers: 1) a provider survey was mailed to all ICF/MR home managers; and 2) a meeting was held with ICF/MR program administrators. ICF/MR home managers are responsible for the management and oversight of a specific facility, and ICF/MR program administrators are responsible for the management and oversight of a specific agency or region which includes ICF/MR programs.

When asked what aspects of the ICF/MR make them a positive option for people, program administrators stated:

1. People living in ICF/MR facilities have spending money to pay for community activities. People living in waiver settings have very little to no money to pay for community activities.
2. Adequate and accessible housing is provided by the ICF/MR facilities. People living in waiver settings have poor choice for adequate, safe, and accessible housing in the community.
3. Reimbursement rates cover the individual needs in ICF/MR. If a client needs a piece of equipment the ICF/MR provider purchases it with little wait time. Waiver recipients do not have the same access to purchase needed equipment.
4. Less risk of abuse because more staff are present.
5. The funding stream allows for things the MR/DD Waiver cannot provide to meet individual needs.
6. Single person waiver homes are too risky for the individual.

When asked what aspects of the ICF/MR make them a negative option for people, program administrators stated:

1. Persons’ services are linked to a bed.
2. ICFs/MR are owned/operated by service providers.
3. You can’t choose or kick out your roommate.
4. You can’t always go where you want, whenever you want.
5. You can make a reasonable case that 6 or 8-bed homes are too large.
6. Utilization of ICF/MR beds as emergency placement options for people with behavioral needs is a disruption to the people living in the home.

Additionally program administrators reported on other advantages of the ICF/MR program:

1. ICF/MR has a sensible, dependable, predictable funding stream.
2. There have been by far more rate increases for ICF/MR than for MR/DD Waiver.
3. The paperwork requirements are not as burdensome as for MR/DD Waiver.
4. Staffing is more stable with fewer turnovers in an ICF/MR when compared to waiver.

5. Transportation is provided by the facility, and personal staff vehicles are not used or put at risk.
6. People with significant health and equipment needs would be very difficult to serve in a typical home without significant renovations.
7. ICF/MR has a predictable survey/licensure process. You know what is expected and waiver is much more onerous. This has totally flipped over time.
8. The State recognized that the MR/DD Waiver reimbursement was inadequate and made the decision to allow Green Acres to build ICF/MR facilities in the community as opposed to the original plan for waiver services.
9. ICF/MR funding lets the provider increase or decrease staffing ratios as the individual support needs dictate. Waiver does not have this same flexibility.

There have not been enough responses received to date to report the findings. Efforts will continue to obtain this information during the second phase of the project.

***Appendix E*** is a copy of the provider survey. ***Appendix F*** is a copy of the questions asked of ICF/MR program administrators.

## WORKING GROUP RECOMMENDATIONS

From what has been learned thus far, 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.
2. Issue a final report on the project findings and recommendations, including input from national experts by, Spring 2011.

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## APPENDICES

Appendix A: West Virginia Developmental Disabilities Council Membership

Appendix B: West Virginia Olmstead Council Membership

Appendix C: West Virginia ICF/MR Facilities

Appendix D: State Agency Questions

Appendix E: ICF/MR Home Manager Survey

Appendix F: ICF/MR Administrator Questions

## Appendix A: West Virginia Developmental Disabilities Council

Christy Black
Milton, WV

Sarah Brown
Shinnston, WV

Robert Cain
Paden City, WV

Joyce Church
Beverly, WV

Richard Covert
Madison, WV

Ronald Dean
Charleston, WV

Jeannie Elkins
Ashford, WV

Virginia Gattlieb
Charleston, WV

Sandy Haberbosch
Shinnston, WV

Betty Holliday
Oak Hill, WV

Ann Hubbs
Morgantown, WV

Stephanie Jackson
Wayne, WV

Clint Martin
Summersville, WV

Kelly Miller
Sweetland, WV

Richard Perry
Dunbar, WV

Clark Queen
Vienna, WV

Jerry Ramsey
Huntington, WV

Karen Robinson
Charleston, WV

Tina Tanner
Parkersburg, WV

Stacey Thomas
Hedgesville, WV

Amber Hinkle
Lewisburg, WV

Carlos E. Lucero, MD
Beckley, WV

Julie McClanahan, Director, Medicaid Program Operations
Bureau of Senior Services

Pat Winston, Director, DD Division, BHHF

Christina Mullins, Director, Maternal, Child & Family Health
Division of Infant, Child & Adolescent Health

Patricia Nisbet, Program Manager, MR/DD Waiver
Bureau for Medical Services

John David Smith, JD, Concord University
Higher Education

LuAnn Summers, Rehabilitation Program Manager
Division of Rehabilitation Services

Jane McCallister, Director
Office of Social Services
Bureau for Children and Families

Karen Ruddle, Coordinator, Adolescent Education
Office of Special Programs, Department of
Education

Clarice Hausch, Executive Director, West Virginia
Advocates

Janice Holland, Associate Director
Center for Excellence in Disabilities at WV University

## Appendix B: West Virginia Olmstead Council Membership

Cindy Beane
Bureau for Medical Services

Elliott Birckhead
Bureau for Behavioral Health and Health Facilities

Karen Davis
Charleston, West Virginia

Jan Derry
Northern WV Center for Independent Living

Jeannie Elkins
Ashford, West Virginia

Darla Ervin
ADAPT WV

Laura Friend
WV Council of Home Care Agencies, Inc.

Nancy Fry
Legal Aid Behavioral Health Project

Clarice Hausch
WV Advocates

Brenda Hellwig
Job Squad, Inc.

Roy Herzbach
Legal Aid, Long Term Care Ombudsman Program

Cathy Hutchinson
Mountain State Centers for Independent Living

Ted Johnson
Charleston, West Virginia

Linda Maniak
Charleston, West Virginia

Ann McDaniel
WV Statewide Independent Living Council

Suzanne Messenger
Morgantown, West Virginia

John Russell
WV Behavioral Health Providers Association

David Sanders
WV Mental Health Consumers Association

Christine Shaw
Res-Care, Inc.

Kevin Smith
Vienna, West Virginia

Vonda Spencer
Bureau of Senior Services

David Stewart
Fair Shake Network

Vanessa VanGilder
Charleston, West Virginia

Steve Wiseman
WV Developmental Disabilities Council

**Appendix C. West Virginia ICF/MR Facilities**

Information was obtained from www.wvdhhr.org/ohflac/FacilityLookup/default.aspx on August 17, 2010 and November 3, 2010.

| LEGAL NAME | COUNTY | PROVIDER | BEDS |
|---|---|---|---|
| 1204 S. Kanawha Group Home | Raleigh | Res-Care, Inc. | 8 |
| 6th Street West Group Home | Cabell | Res-Care, Inc. | 4 |
| 811 S. Kanawha Group Home | Raleigh | Res-Care, Inc. | 8 |
| Accoville Group Home | Logan | Res-Care, Inc. | 8 |
| Adamston Group Home | Harrison | Res-Care, Inc. | 8 |
| Amherstdale Group Home | Logan | Res-Care, Inc. | 8 |
| Arc Group Home | Kanawha | Arc of Three Rivers | 4 |
| Barbour Street Group Home | Upshur | Res-Care, Inc. | 8 |
| Betsy Broh House | Cabell | Autism Services Center | 6 |
| Birch Lane Group Home | Hampshire | Res-Care, Inc. | 6 |
| B-U Group Home | Upshur | Res-Care, Inc. | 6 |
| Chafin Hall | Cabell | Res-Care, Inc. | 9 |
| Church Lane Group Home | Mercer | Res-Care, Inc. | 8 |
| Cornell Street Group Home | Mineral | Res-Care, Inc. | 8 |
| Cross Lanes Group Home | Kanawha | Res-Care, Inc. | 8 |
| Davis Street Group Home | Grant | Res-Care, Inc. | 6 |
| East End Group Home | Kanawha | Res-Care, Inc. | 8 |
| Eighth Avenue Group Home | Cabell | Res-Care, Inc. | 8 |
| Fairmont Group Home | Marion | Res-Care, Inc. | 8 |
| Fowler Group Home | Harrison | Res-Care, Inc. | 8 |
| Franklin Group Home | Pendleton | Res-Care, Inc. | 8 |
| Gaboya Place Group Home | Berkeley | Res-Care, Inc. | 8 |
| Gihon Road Group Home | Wood | Res-Care, Inc. | 8 |
| Guyandotte Group Home | Cabell | Res-Care, Inc. | 8 |
| Hansford Street Group Home | Kanawha | Res-Care, Inc. | 8 |
| Hudson Street Group Home | Kanawha | Res-Care, Inc. | 6 |
| Jackson Avenue Group Home | Boone | Res-Care, Inc. | 8 |
| Judyville Group Home | Greenbrier | Res-Care, Inc. | 8 |
| Kenova Group Home | Wayne | Res-Care, Inc. | 8 |
| Lakeview Group Home | Wood | Res-Care, Inc. | 8 |
| Lifestart Group Home | Kanawha | Res-Care, Inc. | 10 |
| Main Street Group Home | Harrison | Res-Care, Inc. | 8 |
| Mcghee Hall | Cabell | Res-Care, Inc. | 14 |
| Mcveigh Avenue Group Home | Cabell | Res-Care, Inc. | 4 |
| Monroe Avenue Group Home | Cabell | Res-Care, Inc. | 4 |
| Montvue Group Home | Greenbrier | Res-Care, Inc. | 8 |
| Northside Group Home | Berkeley | Res-Care, Inc. | 6 |
| Nutter Fort Group Home | Harrison | Res-Care, Inc. | 8 |
| Oak Hill Group Home | Fayette | Res-Care, Inc. | 8 |
| Old Bluefield Group Home | Mercer | Res-Care, Inc. | 8 |

| LEGAL NAME | COUNTY | PROVIDER | BEDS |
|---|---|---|---|
| Potomac Center | Hampshire | Potomac Center | 24 |
| Raven Avenue Group Home | Ohio | Northwood Health Systems | 6 |
| Brookhaven Road Group Home | Monongalia | REM WV, Inc. | 8 |
| Curtis Avenue Group Home | Monongalia | REM WV, Inc. | 8 |
| Flynn Avenue Group Home | Ohio | REM WV, Inc. | 8 |
| G. C. & P. Road Group Home | Ohio | REM WV, Inc. | 8 |
| Moundsville Group Home | Marshall | REM WV, Inc. | 8 |
| New Martinsville Group Home | Wetzel | REM WV, Inc. | 8 |
| Rockdale Road Group Home | Brooke | REM WV, Inc. | 8 |
| White Avenue Group Home | Monongalia | REM WV, Inc. | 7 |
| Woodcrest Drive Group Home | Brooke | REM WV, Inc. | 8 |
| Riverview Group Home | Marshall | Northwood Health Systems | 6 |
| Russell Nesbitt Apartments | Ohio | Northwood Health Systems | 8 |
| Salem Group Home | Harrison | Res-Care, Inc. | 8 |
| Sixteenth Street Group Home | Wood | Res-Care, Inc. | 6 |
| Southside Group Home | Berkeley | Res-Care, Inc. | 8 |
| Spring Street Group Home | Wood | Res-Care, Inc. | 8 |
| Stonewood Group Home | Harrison | Res-Care, Inc. | 8 |
| Summersville Group Home | Nicholas | Res-Care, Inc. | 8 |
| Temple Street Group Home | Raleigh | Res-Care, Inc. | 8 |
| Terra Alta Children's Home | Preston | Res-Care, Inc. | 5 |
| Thompson Group Home | Mercer | Res-Care, Inc. | 8 |
| Valley View Group Home | Mercer | Res-Care, Inc. | 8 |
| Virginia Avenue Group Home | Cabell | Res-Care, Inc. | 8 |
| Washington Street Group Home | Hampshire | Res-Care, Inc. | 8 |
| Woodward Children's Home | Kanawha | Res-Care, Inc. | 4 |
| **TOTAL (66 Facilities)** | | | **511** |

**Appendix D: State Agency Questions**

The following questions were asked of the relevant agency: BHHF, BMS, OHFLAC, and the WVHCA.

1. How many emergency placements have occurred annually from 2005 – 2009? For the purposes of this question an emergency placement is defined by the "DHHR Change of Residence Policy." "Change of Residence Policy" cites an emergency placement is 1) due to a medical or family emergency; 2) due to a psychiatric or behavioral emergency; or 3) natural disaster.
    a. Why were these emergency placements requested? What were the circumstances of the individual to warrant the need for an emergency placement in an ICF/MR?
    b. How long did each person remain in this emergency placement?
    c. Where were the persons residing prior to the emergency placement?
    d. Did individuals have MR/DD Waiver services prior to the emergency ICF/MR placement?
    e. Did individuals have access to a crisis placement prior to or in place of the emergency ICF/MR placement?
    f. What other alternatives were pursued prior to the emergency ICF/MR placement?
2. How many people are discharged to ICF/MR facilities from state psychiatric facilities annually from 2005 – 2009?
3. How many people were admitted to state psychiatric facilities from ICF/MR facilities annually from 2005 – 2009?
4. What happened to the "Re-Deployment Plan" developed by BHHF in 2006?
5. Do any providers have plans to downsize current ICF/MR facilities during 2010 and 2011? If yes, what are those plans?
6. Is there a plan to make capital improvements to facilities that are in need of repairs and updates during 2010 and 2011? If so, what are these plans? Will the state incur the costs?
7. How many ICF/MR residents on the MR/DD Waiver Wait list are transitioned when a "slot" is allocated or becomes available? How many ICF/MR residents on the MR/DD Waiver Wait list are NOT transitioned when a "slot" is allocated or becomes available? Data requested for 2005 – 2009.
8. Copy of the final Colin Anderson Center monthly report submitted to the legislature. Copy of the fiscal reports submitted to the legislature.
9. What is the average (annual) occupancy rate for ICF/MR facilities in West Virginia for 1999 – 2009?
10. How many ICF/MR residents on the MR/DD Waiver Wait list are transitioned when a "slot" is allocated or becomes available? How many ICF/MR residents on the MR/DD Waiver Wait list are NOT transitioned when a "slot" is allocated or becomes available? Data requested for 2005 – 2009.

11. How many people have been admitted/discharged/transferred annually to ICF/MR facilities from 2005 – 2009? What was the reason cited for the transfer/discharge?
12. What is required for discharge planning for ICF/MR residents?
13. How often are rates re-based?
14. What are the most recent per diem rates for each ICF/MR facility?
15. Does the per diem rate include durable medical equipment (DME) and provider taxes?
16. What is the most recent individual (assessed) level of care for each resident for each ICF/MR facility?
17. Does the State of West Virginia own any of the facilities or the land/property of the facilities? If so, which facilities?
18. Do any providers have a plan to downsize current ICF/MR facilities during 2010 and 2011?
19. What is the plan to make capital improvements to facilities that are in need of repairs and updates during 2010 and 2011?
20. Have any ICF/MR facilities made capital improvements through the certificate of need (CON) process per year for 2005 - 2009? If so:
    a. Why were the capital improvements made?
    b. Which facilities had capital improvements?
    c. How much did the capital improvements cost?
    d. How much did the per diem rate increase due to these capital improvements?
21. Is there a process for paybacks when ICF/MR providers are out of compliance with individual program plans, training requirements, etc?
22. Does OHFLAC do an annual report with a summary of licensure surveys or reviews for ICFs/MR? If so, please provide copies for the past 5 years. If not, how many facilities had their license suspended or revoke (or had immediate jeopardy issues), how many received a provisional license, how many were re-certified without major problems? Please provide this information for 2005-2009 or the most recent previous 5 years.
23. Does OHFLAC do an annual report on compliant investigations for ICFs/MR? If so, please provide copies for the past 5 years. How many investigations were completed due to death, abuse (verbal, physical, sexual, emotional), neglect, financial exploitation, medication errors, and use of restraints.
24. Does the State of West Virginia own any of the facilities or the land/property of the facilities?
25. Do any providers have plans to downsize current ICF/MR facilities during 2010 and 2011?
26. Is the current facility lookup function on the OHFLAC website up-to-date for ICF/MR facilities? If not, what changes exist?

**Appendix E: ICF/MR Home Manager Survey**

ICF/MR providers had two opportunities to confidentially submit answers to the suvey.

1. How many licensed beds does your facility have?
2. What is the length of stay for current residents? Average? Longest? Shortest?
3. How many residents do you currently have in the following age categories? (17 or younger, 18-29, 30-39, 40-49, 50-59, 60-69, 70-79, and 80+)
4. How many residents have been discharged in the past 12 months to the following settings? (another ICF/MR, nursing facility, waiver setting, family home, specialized family care)
5. How many residents have a discharge plan to an MR/DD Waiver setting? Other?
6. How many residents are currently on the MR/DD Waiver wait list?
7. Do you currently have a waiting list for admission? If yes, how many?
8. Do you currently have any vacancies? If yes, how many? How long?
9. How many current residents could have their service needs met through the MR/DD Waiver Program?
10. How many residents have at least one person in their life who is both: not paid nor a family member?
11. How many emergency admissions have you accepted in the past 12 months?
12. Who referred the individual for emergency placement?
13. What amount of pressure do you receive to discharge residents to community-based settings?
14. What amount of pressure do you receive to fill vacant ICF/MR beds?
15. How many residents have DHHR as their legal representative?
16. How many residents have family members as their legal representatives?
17. How do residents spend their time during the day? How many residents participate in the following? (day program, community day habilitation, volunteer, sheltered workshop, supported employment, competitive employment)
18. What is the hourly rate of pay for direct staff? Starting? Maximum?
19. What is the number of current full-time direct care staff? FTE vacancies?
20. What is the number of current part-time direct care staff? PTE vacancies?
21. What is the maximum length of employment? Minimum?
22. How many employees have left in the past 12 months?
23. How many hours of pre-service training are provided to employees?
24. How many hours of on-the-job training are provided to employees?
25. What aspects of the ICF/MR make them a positive residential setting for people?
26. What aspects of the ICF/MR make them a negative residential setting for people?

**Appendix F: ICF/MR Administrator Questions**

The following questions were asked of ICF/MR Program Administrators: Autism Services Center, Potomac Center, REM WV, Inc., and Res-Care, Inc.

1. What is the role(s) of ICFs/MR for supporting adults and children?
2. What aspects of the ICF/MR make them a positive/negative option for people relying on them for services?
3. What aspects of the MR/DD Waiver make it a positive/negative option for people transitioning from ICF/MR?
4. What changes, renovations, or movement are being planned for current facilities/beds?
5. What properties/facilities are owned by the State of West Virginia?