

Choice of Residential Services and Olmstead: A Virginia Example

**By Patricia Bennett
VOR Representative**

**July 12, 2006
Medicaid Commission Meeting
Arlington, Virginia**



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with Mental Retardation

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INTRODUCTION

My name is Patricia Bennett. I am the parent of a severely multiply-disabled daughter, Ginny, who is now 39 years old and a resident of Northern Virginia Training Center, a state operated Medicaid Intermediate Care Facility for Persons with Mental Retardation.

I am here today as a representative of VOR, a national advocacy organization. I'm very grateful for the opportunity to participate in the vital work that you are doing. For many of our most fragile and vulnerable citizens, Medicaid is critical to their survival and quality of life.

As is required for me to say, I do NOT have any financial involvement related to any services being discussed.

In 1979, I founded Parents and Associates of the Institutionalized Retarded of Virginia, a statewide advocacy organization that represents the residents of Virginia's five training centers for people with mental retardation. I'm a former two-term president and currently serve as vice president. I'm a Board Member of Central Fairfax Services, Inc., a sheltered workshop program, Parent and Associates of the Northern Virginia Training Center, and a former Board Member of the Northern Virginia Association of Retarded Citizens. Appointed by Governor Mark Warner to the Virginia Olmstead Community Integration and Advisory Committee in 2004, this group has been designated a Commission by the Virginia General Assembly and I continue to serve on this Commission

PAIR of Virginia has consistently advocated for increasing community capacity while maintaining the appropriate level of services for her most fragile and vulnerable citizens with mental retardation, most of whom reside in the training centers.

I will take this opportunity to share information about recent developments in Virginia that balance choice, quality, expansion and sustainability of Medicaid services for people with mental retardation in community and facility settings. I will conclude my comments with a brief overview of Virginia's response to the Olmstead decision, and some background on the decision itself.

THE VIRGINIA RESTRUCTURING PLAN¹

In the Commonwealth of Virginia, we are working hard to develop, fine-tune and support a comprehensive continuum of services that meet the individual needs of each person. One way Virginia is doing that is through the expansion of Community Resource Centers, a model program that extends the health care and other training center clinical expertise to people living in the surrounding community.

It is with great pride that I report that the Northern Virginia Training Center is already operating a Community Resource Center², and the Commonwealth of Virginia recently recommended expansion of the NVTC model to the other Virginia Training Centers.

The recommendation came about after the Commonwealth of Virginia studied the cost and feasibility of various proposals regarding the mix of residential and supports available to Virginians with developmental disabilities.

After much deliberation that included a broad spectrum of stakeholders, the study concluded that the most feasible, cost effective option for Virginia is the combination of expanding community options and reducing (but not closing) Virginia's Training Centers, and re-focusing the role of Training Centers to provide services to residents and people in the community along with residential care for those who need it.

Advocates for training center residents especially appreciate the expressed respect for "individual/family preferences" recognizing that "some individuals may choose to live in the state training centers" and that training center residents must "continue to receive quality, high intensity care." Although we will watch carefully how the downsizing objective is carried out, we find great comfort in the other aspects of the Virginia plan, including more and better reimbursed community providers and continued access in most regions to the health care and other services at the state's training centers.

THE OLMSTEAD DECISION

In the original Olmstead Task Force Final Report of August 28, 2003, Governor Mark Warner stated in the Executive Summary:

¹ See, <http://www.dmhmrzas.virginia.gov/documents/OMR-HouseDocument76.pdf>, for the complete report.

² The program at Northern Virginia Training Center is called a Regional Community Support Center (RCSC). It provides specialized services in dentistry, medical specialty areas, and behavioral therapies both on-site and through satellite clinics. RCSCs also provide staff training and linkages with universities for the "next generation" of service providers for people with mental retardation."

The Task Force has identified over 20 State agencies responsible for implementing the recommendations of this Report. Sustained inter-agency collaboration and coordination are critical to the successes of all implementation efforts some individuals with disabilities lack the capacity to make some or all decisions and choices for themselves. Every such individual should have a means by which decisions and choices may be made on his or her behalf. In order to assure choices to individuals with disabilities, we recognize and have developed an Olmstead report that reflects the importance of Virginia's full continuum of care, from self-care through institutional care.

As a member of Virginia's Community Integration Advisory Commission, I am proud of this outcome in support of choice, which is fully compliant with the Olmstead decision itself. Securing such favorable language, surprisingly, however, was, at times, a hard fought battle. I have often found it necessary to clarify just what Olmstead said and didn't say.

What it didn't say is "close all institutions."

What it does say squarely supports choice and I quote:

"We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." Olmstead v. L.C., 119 S. Ct. 2176, 2187 (1999).

The Justices did hold that **unjustified** institutionalization is discrimination. 119 S. Ct. at 2185 (emphasis added). The often quoted 3 part ruling to determine if community placement is appropriate includes as its second prong the choice of the individual to be moved to the community.

Olmstead planning in Virginia and in other states seems predominantly focused on getting people out of institutions, rather than on the spirit of choice contained within the decision itself. I always found this focus perplexing and a bit concerning. Since 1975, 6,936 people have been discharged from the training centers. There have been very few admissions. I found it odd that I was constantly trying to move the discussion away from "getting people out" to focusing on preparing the community to provide more people, including individuals waiting for services, with quality community services. After much deliberation and a lot of hard work by a lot of people, I am pleased to report that Virginia got it right.

CONCLUSION

In closing, I would like to remind everyone that among people with mental retardation, developmental disabilities, or brain injuries, there can be very large discrepancies between mental age and chronological age, often with little or no correlation between the two.

My daughter, Ginny, is 39 years old, yet her functioning level is that of an infant. She has no self-help skills, is medically fragile and requires 24-7 nursing and/or medical supervision. She is complicated and not just any physician in an emergency room without specialized training and skills can treat her appropriately. We certainly wouldn't expect a two-year old to live independently, make decisions for herself as to what services she needs and how she should live, yet some advocates expect these things of people with mental retardation who are discharged from safe, accountable environments to "community living" or nursing homes. In either case, it isn't compassionate, logical, or appropriate. It doesn't make sense.

Any service system must be about investing, because no system can be all things to all people all of the time. Service systems require that sound management practices be applied so that it can be accountable for what, when, where and how our tax dollars are spent. The original intent of Congress when the Medicaid program was originally designed was to provide a safety net for the poorest, most severely or profoundly disabled citizens and underwrite this small, but expensive, population.

Commissioners, I can't express strongly enough how much we appreciate your effort to carefully consider every aspect of this very serious debate.

Thank you very much for this opportunity. I am happy to answer any questions you may have.

AN INVITATION TO VISIT A
MEDICAID INTERMEDIATE CARE FACILITY
FOR PEOPLE WITH MENTAL RETARDATION
(ICF/MR)



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AN INVITATION TO VISIT A MEDICAID INTERMEDIATE CARE FACILITY FOR PEOPLE WITH MENTAL RETARDATION (ICF/MR)

TO: Medicaid Commission Members

FROM: Mary McTernan, Ph.D., President

RE: Invitation to visit an ICF/MR

DATE: June 26, 2006

VOR has had the pleasure of attending the recent Medicaid Commission Hearings in Atlanta, Georgia and Irving, Texas. We will be attending the Arlington, Virginia hearing. We appreciate very much the opportunity to provide public comment at these deliberations.

We would like to invite you to a visit an ICF/MR. If your schedule allows, there is an excellent facility in Fairfax, Virginia, not far from the July Medicaid Commission Hearing. The Northern Virginia Training Center provides residential care and other supports to residents with severe and profound mental retardation, as well as a myriad of health care and other services to individuals living in the surrounding communities.

VOR would be happy to arrange for a tour (contact Tamie Hopp at 605-399-1624; vor@compuserve.com), or you could contact Northern Virginia Training Center directly at 703-323-4000 (Facility Director, Mark Diorio) (<http://www.nvtc.dmhmrzas.virginia.gov/contacts.asp>).

Our comments have focused on three primary themes:

- (1) The People Served:** People with severe and profound mental retardation and the specialized, Medicaid-supported services they require.
- (2) Choice in Medicaid Long Term Care Options:** The importance of a full spectrum of Medicaid services to meet the full spectrum of support needs, as supported by Federal law (Medicaid, Olmstead, etc.).
- (3) The Community Resource Center Model:** A model that allows individuals living in community settings to access health care services at existing Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR), on an outpatient basis.

If your schedule will not allow for a visit of NVTC in July, VOR is able to suggest other ICFs/MR to visit near your homes at your convenience. To arrange a tour, please contact Tamie Hopp at 605-399-1624; or vor@compuserve.com.

We feel strongly that your long term care discussions will be enhanced by an onsite review. Seeing is believing. Thank you for your consideration.

TO: Medicaid Commission Members
 FROM: Mary Matman, Ph.D., President
 RE: Invitation to visit an ICFMR
 DATE: June 28, 2008

THE OLMSTED DECISION

VOR has had the pleasure of attending the recent Medicaid Commission Hearing in Virginia and living Texas. We will be attending the Michigan, Virginia Hearing. We appreciate very much the opportunity to provide public comment at these deliberations.

We would like to invite you to visit an ICFMR. If your schedule allows, there is an excellent facility in Fairfax, Virginia, that is on the July Medicaid Commission Hearing. The Virginia Training Center provides residential care and other supports to residents with serious and ongoing mental illness, as well as a variety of health care and other services to individuals living in the surrounding communities.

VOR would be happy to arrange for a tour. Contact Jamie Hopp at 602-388-1824 (jhop@victor.virginia.gov) or you could contact Northern Virginia Training Center directly at 703-323-4600 (Pamela Director, Mark Giron) (<http://www.vic.virginia.gov/vic/visit.asp>).

Our comments have focused on three primary themes:

- (1) The People Serve: People with severe and profound mental illness and the associated Medicaid-supported services they require.
 - (2) Choice in Medicaid Long Term Care Options: The importance of a full spectrum of Medicaid services to meet the full spectrum of support needs, as supported by the Medicaid (Medicaid) Act.
 - (3) The Community Resource Center Model: A model that allows more care to be provided in the community to access health care services at existing Intermediate Care Facilities for Persons with Mental Retardation (ICFMR) or an outpatient clinic.
- If your committee will not allow for a visit to VICTOR in July, VOR is able to supplement ICFMR to visit your facility if you are unable. To arrange a tour, please contact Jamie Hopp at 602-388-1824 or jhop@victor.virginia.gov.
- We believe strongly that your ongoing work and our dialogue will be enhanced by an onsite visit. We are delighted to thank you for your consideration.



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Olmstead requires choice of residential settings

The Supreme Court, in its Olmstead ruling, recognized the need for a range of services which respond to the varied and unique needs of the entire disability community:

- (1) Unjustified institutionalization is discrimination based on disability. 119 S. Ct. 2176, 2185 (1999).
- (2) The Supreme Court held that community placement is only required and appropriate (i.e., institutionalization is unjustified), when –
 - (a) the State's treatment professionals have determined that community placement is appropriate;
 - (b) the transfer from institutional care to a less restrictive setting is not opposed by the affected individual; and
 - (c) the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities." 119 S. Ct. at 2181.
- (3) A majority of Justices in Olmstead recognized an ongoing role for publicly and privately-operated institutions: "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." 119 S. Ct. at 2187.
- (4) A plurality of Justices noted: "As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk... 'Each disabled person is entitled to treatment in the most integrated setting possible for that person — recognizing on a case-by-case basis, that setting may be an institution'[quoting VOR's *Amici Curiae* brief]." 119 S. Ct. at 2189.
- (5) Justice Kennedy noted in his concurring opinion, "It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that states had some incentive, for fear of litigation to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision." 119 S. Ct. at 2191.

VOR is dedicated to supporting a full range of quality residential options to meet the full spectrum of needs, desires, choices and abilities of all people with mental retardation.

THE COST AND FEASIBILITY OF ALTERNATIVES TO THE STATE'S FIVE MENTAL RETARDATION TRAINING CENTERS

Submitted to the Governor and
the General Assembly of Virginia

House Document No. 76
2005

**REPORT OF THE
DEPARTMENT OF MENTAL HEALTH, MENTAL
RETARDATION AND SUBSTANCE ABUSE SERVICES**

**The Cost and Feasibility of
Alternatives to the State's Five
Mental Retardation Training Centers**

**TO THE GOVERNOR AND
THE GENERAL ASSEMBLY OF VIRGINIA**



HOUSE DOCUMENT NO. 76

**COMMONWEALTH OF VIRGINIA
RICHMOND
2005**

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EXECUTIVE SUMMARY

The Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) has studied the cost and feasibility of: i) developing community-based alternatives to the state's five mental retardation training centers, (ii) renovating the state's five mental retardation training centers, or (iii) a combination of both to meet the future care and housing needs of these individuals, as required by Item 330 P of the 2005 Appropriation Act for the Chairmen of the Senate Finance and House Appropriations Committees. The feasibility study report includes an overview of Virginia's mental retardation system: its vision, values, progress, and challenges, the process used for completing the study, a description of the findings, and the identification of the most feasible and cost effective option, with strategies and related costs.

The study reinforced that the Commonwealth's mental retardation system is underfunded, many Virginians with mental retardation are underserved or unserved, and the "dual system" that exists (state training centers and community services) is difficult to coordinate and is not the most efficient or effective approach to support. **The most feasible, cost-effective option for Virginia is the combination of developing community alternatives, reducing the size of the state training centers by re-focusing their purpose and function, and making needed renovations to these centers necessary for the maintenance of safety standards and increased efficiency.**

The strategies for developing community alternatives, while refocusing the role of the state training centers include:

- **Increase Mental Retardation (MR) and Day Support (DS) Waivers' Rates**

Creating community alternatives will not be possible until the Waiver rates are increased to a level that enables providers of services to stabilize their workforce through competitive pay rates and provide assurances that all standards of sound business and safety practices are maintained.

1. Increase the MR and DS Waivers' reimbursement rates 20% across all services in the next four biennia.
2. Make an annual cost of living adjustment (COLA) for all MR and DS Waiver rates.
3. Have an additional 17% rate differential for Northern Virginia programs.
4. Create an additional 10% differential for all congregate residential services that are 4 beds or less (except for sponsored residential) and for In-Home Residential Support.

- **Develop Community Alternatives for Residents of Virginia's Five State Training Centers**

Develop community alternatives for 100 residents of the five state mental retardation training centers per year for the next 4 biennia.

1. Modify the Mental Retardation (MR) Waiver to allow reimbursement for therapeutic behavioral consultation to a wider range of persons practicing behavioral interventions, as qualified Waiver providers, (PBS, ABA, etc.) thereby offering more options to support individuals in the community.
 2. Provide for increased personnel costs for DMAS and DMHMRSAS staff associated with the large volume of new community services.
 3. Provide Community Investment Grants in the form of one-time grants to Community Services Boards and Behavioral Health Authorities (CSBs/BHAs) and private providers to make modifications as needed designed to establish the necessary supports for community living alternatives for individuals choosing to leave the state training centers.
 4. Increase the Medicaid Waiver rate for skilled nursing to allow for more competitive reimbursement of nursing services in the community system enabling more persons to remain in their home communities.
- **Increase Efficiencies in the MR and DS Waivers that Promote Greater Service Satisfaction with More Efficient Use of Dollars.**
 1. Increase flexibility in the MR Waiver through consumer direction and personal budgets.
 2. Increase the rate for Supported Employment to equal the average rate currently offered by the Department of Rehabilitation Services (DRS).
 3. Develop a Supports Waiver, with personal budgets, consumer direction, and individual capitation of dollar amounts for persons on the waiting list for MR Waiver services.
 - **Develop the Community Infrastructure to Better meet the Needs of Individuals Whose Only Current Option Is Readmission or New Admission to a State Training Center.**
 1. Approve 1,000 slots (over the next four biennia) for the MR Waiver.
 2. Increase Family Support funding.
 3. Establish public guardianship programs.
 4. Train providers of services and families.
 5. Develop a system to administer grants for non-waiver services for people with mental retardation.
 - **Reduce the Size of the State Mental Retardation Training Centers, Refocus their Purpose and Function, and Make Renovations Necessary To Maintain Safety and Meet the Needs For the New Purpose and Function**

Respecting individual/family preferences and providing choice, some individuals may choose to live in the state training centers. It will be necessary for the Commonwealth to ensure individuals that choose to live in the state training centers continue to receive quality, high intensity care.

1. Reduce census at the state training centers by 100 people per year for the next 4 biennia.
2. Refocus the specialized services at the training centers to become Regional Community Support Centers (RCSC). Each RCSC will offer specialized services in dentistry, medical specialty areas, and behavioral therapies both on-site and through satellite clinics. RCSCs also provide staff training and linkages with universities for the “next generation” of service providers for people with mental retardation.
3. Change the role of state training centers to Intensive Support Centers (ISC), which are residential, for individuals with the highest levels of support need. Options include:
 - Short-term residential options for persons in need of intensive support due to behavioral or high medical support issues before returning to the community placement.
 - Temporary emergency support for persons with specialized needs due to mental retardation during periods of natural or man-made disasters or individual crisis when other community options are exhausted.
 - Long-term residential specialized support for persons with mental retardation who have the highest level of long-term medical needs or behavioral needs that are preventing successful community living.

The vision for the future of Virginia’s MR services is to offer a “seamless” system of supports that provides individuals with mental retardation with a choice of options to support their quality of life and keep them involved with their families and communities, offering only the level of support needed to be successful. The blending of the “dual system” to a “seamless system” of supports will improve coordination, collaboration, and management of MR services. Virginians with mental retardation and their families will have easier access within the supports and services offered to have their needs met, and not be restricted by the types of funding, programmatic definitions, or other restrictions that currently exist. The anticipated outcome is a well-balanced system of supports that offers an array of service options while ensuring the health and safety of all Virginians with mental retardation.

The well-balanced system of supports, however, cannot be a reality without significantly increased funding. The findings of this report, and other recent reports, such as the recent JLARC study on the Medicaid Waiver rates, the DMHMRSAS report on the capital improvement needs of the state training centers to meet safety standards, and the DMHMRSAS Comprehensive State Plan, 2006 – 2012 all provide documentation that the

MR system is largely underfunded. Additional indicators, such as the steady climb of the number of people on the waiting list for MR Waiver services to nearly 3,000 Virginians and the significant numbers of individuals with mental retardation who need services, but who are not eligible for Waiver services shows clearly the situation will only get worse without additional resources. Transforming the MR system and properly addressing the recommended strategies in this report will require an investment of Virginia resources over a period of time. This plan lays out an eight-year effort that will put Virginia back on course to more fully addressing the needs of its citizens with mental retardation. Over the next eight years, this plan will:

- Establish a means of providing some level of support to individuals who are on the waiting list for full Waiver services while waiting for a slot to become available.
- Provide for an appropriate community alternative for most persons whose only current option for services is to live in a state mental retardation training center.
- Increase the total number of Virginians with mental retardation who are being served by 4,000 individuals, addressing underserved and unserved individuals.
- Develop a more efficient system of supports for all persons served.
- Change the role of the state training centers to a state operated support service for those persons requiring the highest level of intensive supports while supporting community placement alternatives through consultation and direct provision of off-site specialized support teams (RCSC).

I. INTRODUCTION

Item 330 P of the 2005 Appropriation Act directs the Commissioner of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS), to "prepare a report to the Chairmen of the Senate Finance and House Appropriations Committees by October 15, 2005 (extended to December 15) on the cost and feasibility of (i) developing community-based alternatives to the state's five mental retardation training centers, (ii) renovating the state's five mental retardation training centers, or (iii) a combination of both to meet the future care and housing needs of these individuals. The report includes an overview of Virginia's mental retardation system, the methodology used for the study, and the findings of the study.

The DMHMRSAS, through its Office of Mental Retardation (OMR), has created this report with statewide representation of Virginians with mental retardation, their family members, The Mental Retardation Special Populations Work Group, with representation from The Arc of Virginia and local Arc chapters, state mental retardation training centers, state mental health hospitals, private providers, Community Services Boards/Behavioral Health Authorities (CSBs/BHAs), Virginia Department of Medical Assistance Services (DMAS), Virginia Board for People with Disabilities (VBPD), Partnership for People With Disabilities, Virginia Commonwealth University (VCU), Parent to Parent, Parents and Associates of the Institutionalized Retarded (PAIR), Virginia Autism Resource Center, DMHMRSAS Central Office staff, and all interested citizens, participated in studying the options and developing the cost and feasibility study (Participants Roster, Appendix A). The cost and feasibility study used current information from national and state studies, statewide data, and costs of services. The findings of this feasibility study support the vision of the DMHMRSAS, *"of a consumer-driven system of services and supports that promotes self-determination, empowerment, recovery, resilience, health, and the highest possible level of consumer participation in all aspects of community life including work, school, family and other meaningful relationships."*

II. OVERVIEW OF VIRGINIA'S MENTAL RETARDATION SERVICE DELIVERY SYSTEM

A. Vision, Values, and Goals of Virginia's Mental Retardation (MR) System

Improving the lives of Virginians with mental retardation has been, and continues to be a high priority for the DMHMRSAS, mental retardation service providers, people with mental retardation, their families, and advocates. Over the past 30 years, changes have occurred in the mental retardation service delivery system that better support people with mental retardation. DMHMRSAS has followed its vision and national trends to build and enhance the availability of individualized services and supports, which create opportunities for greater choice, and improve cost-effectiveness of services. These improvements in serving and supporting Virginians with mental retardation were realized in part, due to the legislative support of the State's policy makers and revisions made to federal and state policies, allowing for greater flexibility and innovation in the development of community supports and services.

To continue the process for improvement, Commissioner Reinhard, DMHMRSAS created the Mental Retardation Special Populations Work Group to draft a transformation plan for Virginia's MR system. The Work Group identified "guiding values" for the transformation of the mental retardation system. The values include:

- The individual with mental retardation is at the center of the support system.
- Elimination of a dual system of supports in favor of a more "seamless" system of support options available to all persons with mental retardation.
- Persons are supported according to their level of need.
- Choice of service options is real and meaningful.
- Support options are offered in safe environments.
- Service options available to anyone are available to all.
- Service and support options are available at a reasonable cost.

B. Challenges of Virginia's MR System

Despite improvements, Virginia's mental retardation services, provided through the State's five training centers, 40 CSBs/BHA, and over 650 private providers, remains an under-funded system, with many underserved and unserved individuals. At the same time, court decisions such as *Olmstead*¹, and the self-direction movement have supported the development of community alternatives to institutional placements. In Virginia, the *Olmstead* Task Force's final report, *One Community, Final Report of the Olmstead Task Force, 2003*, included 201 recommendations for improving the state's ability to provide community alternatives to individuals residing in all state facilities (not just the five state mental retardation training centers), as required by the *Olmstead* decision. Many of the *Olmstead* Task Force recommendations related to the need for additional community

¹ *Olmstead v. L.C.*, 119 S. Ct. 2176 (1999)

services, supports, and funding for people with mental retardation.² The challenges of Virginia's MR System include:

- Many Virginian's with Mental Retardation are Unserved or Underserved
It is estimated there are 67,477 Virginians (age 6 and older) with mental retardation.³ In FY 2004, 23,925 people with mental retardation received services through the CSBs, 1,517 more individuals lived and received services in the state training centers, 762 people with mental retardation were in nursing homes, and 5,174 people were on CSB Waiting Lists for MR Waiver and Non-Waiver Services (DMHMRSAS, 2005). Based on this data, there may be a significant number of Virginians with mental retardation who have not requested services, and some are likely unknown to the system.

Community services for Virginians with mental retardation are filled to capacity, waiting lists exist and are getting longer, and specialized services are difficult, if not impossible to find in areas of the state. There are some people with mental retardation who are getting an array of supports while many others, living at home and in the state training centers, wait (sometimes for years) for the support they need to live a life of their choosing. Current numbers of individuals living in a variety of residential settings (Table 1) again show that a significant number of people with mental retardation are living at home and have not requested or are not receiving mental retardation services.

The large number of Virginians with mental retardation living in their families' or their own homes is similar to national data. "The National Health Interview Survey on Disability and the Residential Information Systems Project data show that an estimated 92% of all Americans with developmental disabilities (including mental retardation) live with family members, spouses or alone, 6% live in community-supported living arrangements, while 1% live in the state institutions, and 1% live in nursing homes. Clearly, many people with extensive support needs, similar to or more intensive than the needs of those now living in institutions, are living in the community today." ⁴ The individuals living at home in Virginia could have a huge impact on the mental retardation system if their needs for residential placement changed. Consideration of the people living at home is an important factor while examining the feasibility of community alternatives for individuals currently living in the state training centers.

² Virginia Olmstead Task Force, 2003

³ A 1993 study of mental retardation prevalence rates, *State Specific Rates of Mental Retardation - United States, 1993*. MMWR Weekly (Jan. 26, 1996), 45, #3: 61-65, used data from the U.S. Department of Education for children with mental retardation who were enrolled in special education programs and data from the Social Security Administration (SSA) to estimate an overall mental retardation prevalence rate of 1 percent, or 7.2 cases per 1,000 persons. This rate was applied to Virginia's population, using 2003 Final Estimated Population data to estimate that 67,477 Virginians age 6 and over have mental retardation.

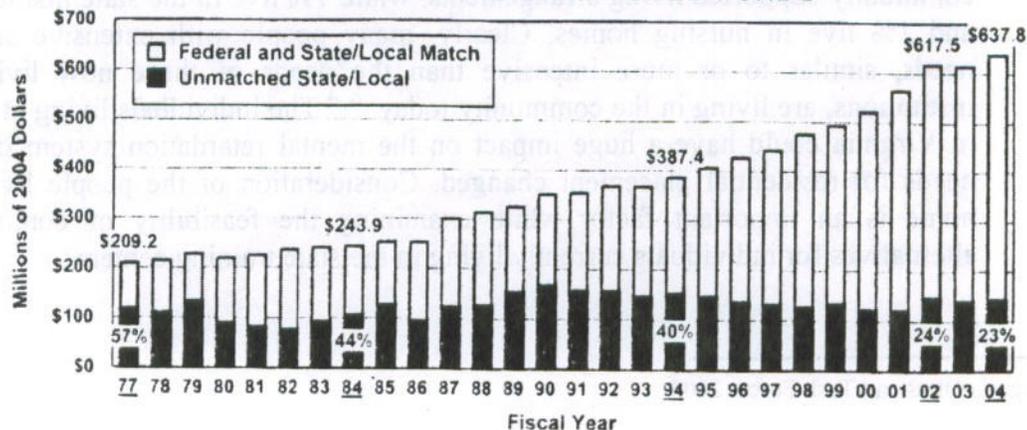
⁴ Larson, Doljanac, & Lakin, in press

Residence	Number	VA percentage
Community-supported (group homes, apartments, sponsored placements, etc.)	4,929	7%
MR Training Centers	1,517	2%
Small Intermediate (ICF/MR)	302	.04%
With family members, spouses or alone	59,990 (possible)	88.9%
Nursing Home	762	1%
Total	67,477	100%

- The MR System in Virginia is Underfunded**

Although Virginia ranks 12th among states in per capita income, it ranks 48th nationally in its funding of community services and 28th for state training centers.⁵ The MR system as a whole in Virginia is underfunded. In an effort to be efficient with state funds, more mental retardation funds have been matched to Federal Medicaid Funds. Since its inception in 1991, Virginia's Home and Community-Based Mental Retardation Medicaid Waiver has funded most of the support services to people with mental retardation and their families. Medicaid has increasingly become the funding source for Virginia's services in its CSBs/BHA and state training centers (Figure 1). Virginia continues to increase the percentage of matched funds, yet the waiting list grows. At the same time, the percentage of unmatched funds, which are used for people with mental retardation who do not meet Medicaid eligibility, are decreasing.

Figure 1 - Virginia
TOTAL MR/DD SPENDING:
MATCHED AND UNMATCHED FUNDS



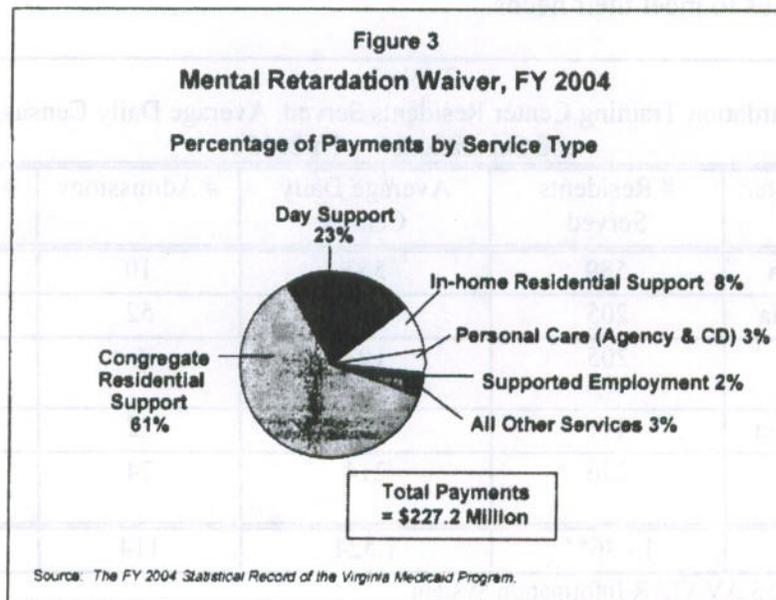
254 Source: Braddock, Hemp, & Rizzolo, Coleman Institute and Department of Psychiatry, University of Colorado, 2005

⁵ Braddock, 2005

Virginia's mental retardation system (community alternatives and the state training centers) is becoming increasingly dependent on Medicaid funding, which creates several challenges:

- a. Not every Virginian with mental retardation is eligible for Medicaid. People with mental retardation who are not Medicaid eligible have few options for services and supports in the Commonwealth.
- b. Virginia spends less per capita on long-term care services as compared to most other states. "When per-capita long-term care expenditures are disaggregated by institutional care and community-based care services, Virginia still ranks relatively low compared to other states across all services."⁶

In FY 2004, the largest percentages of Medicaid Waiver payments were made for residential support and day support. Together, these two services made up 84 percent of MR Waiver payments. The remaining 16 percent of payments were split between in-home residential support services and all other MR waiver services, including personal assistance and supported employment. The more flexible, inexpensive services in the Waiver are not being used as often as the more costly residential and day support options, as shown in Figure 3 of the JLARC study.⁷



- Virginia has a "Dual System" (State Training Centers and Community Services)
Virginia's increase in community options has resulted in a cumulative reduction in the population of the state training centers. The population in the training centers has gone from a high of 5,874 individuals in 1975 to a current population

⁶ JLARC, 2005

⁷ JLARC, 2005

of 1,517 individuals.⁸ The reduction in the training center size has improved the ability of the training centers to offer more individualized supports for the persons living there. As supports have improved, the costs of supporting the residents of the state training centers have increased, while the physical plants of the state training centers are deteriorating and outdated (not appropriate to serve the changing needs of some residents). In addition, as the number of residents in state training centers has decreased, the number of unused or underused buildings has increased. The buildings have maintenance issues although they are empty.⁹

Nationally, closing state training centers and moving to community alternatives has been the goal of many states. Virginia remains one of 13 states that have not closed any public institutions.¹⁰ Table 2 shows that all the state training centers continue to have admissions, and some have as many admissions as separations (includes discharges, transfers, and deaths). At the same time, CSBs/BHA continue to rely on the supports provided through the state training centers for emergency placements of individuals with mental retardation and challenging behaviors, and for individuals with mental retardation and significant health care needs. Finally, some residents choose (or their families choose for them) to stay in the state training centers, because of the lack of appropriate community alternatives to meet their needs.

MR Training Center	# Residents Served	Average Daily Census	# Admissions	# Separations*
Central Virginia	589	564	10	32
Northern Virginia	205	182	52	53
Southeastern Virginia	205	193	6	10
Southside Virginia	411	371	22	49
Southwestern Virginia	236	214	24	30
Total MR	1,646**	1,524	114	174

Source: DMHMRSAS AVATAR Information System

* Separations include discharges, transfers, and deaths

** Unduplicated count for by state facility type.

An imbalance currently exists in Virginia's funding of a dual system of support, (state training centers and community services), which is not based solely on individual needs. A challenge in a dual system is the expense of the state training centers (36% of the total

⁸ DMHMRSAS, 2005

⁹ DMHMRSAS, 2005

¹⁰ Braddock, 2005

MR funding) serves 2% of Virginians with mental retardation. In addition, funding for an individual in the state training center is not transferable to the community to create alternatives, creating a "dual system" of funding. This imbalance is increasing as CSBs/BHA are now opting to create smaller Intermediate Care Facilities for People with Mental Retardation (ICF/MR) in response to the need that is not being answered through sufficient Waiver funding (Waiver slots and rate adjustments).

II. METHODOLOGY OF THE FEASIBILITY STUDY

A. Mental Retardation Special Populations Work Group

The DMHMRSAS utilized wide-based input, review of statewide and national data, and review of relevant literature to ensure a balanced and accurate assessment of the options identified in the requested feasibility study. Most influential in the review process has been the Mental Retardation Special Populations Work Group (Appendix B), which was originally given the assignment by DMHMRSAS Commissioner Reinhard of drafting a transformation plan for Virginia's MR system. The Mental Retardation Special Populations Work Group created the Sub-Committee on Levels of Need and Support Options for Virginia to develop strategies for transformation of the MR system, including the role of state training centers and community-based services.

The Mental Retardation Special Populations Work Group met multiple times during the past year to create a transformation plan, which included guidance in the development of the feasibility study. Drafts of the feasibility study were shared with the participants of the Work Group twice, giving opportunity for input and including comments, prior to completion.

B. Sub-Committee on Levels of Need and Support Options for Virginia and Level of Support Model

The Sub-Committee on Levels of Need and Support Options for Virginia developed a Level of Support Model which defines 5 levels of support that assist in determining the general needs of an individual with mental retardation, and what might be required of the system to support that person. The Level of Support Model is also designed to promote flexibility, choice, and independence, and identifies the required investment of resources to build community services and supports capacity. The implementation of the Level of Support Model will require the development of more community alternatives to meet the needs of individuals moving from the state training centers to their chosen community, at a time when the process of creating additional community services and supports in Virginia's mental retardation system has slowed considerably due to systemic challenges and limited resources (funding, services, etc.).

III. FINDINGS OF THE FEASIBILITY STUDY

A. Most Cost Effective and Feasible Option

The most feasible, cost-effective option for Virginia is the combination of developing community alternatives, reducing the size of the state training centers by re-focusing their purpose and function, and making needed renovations to these centers necessary for the maintenance of safety standards and increased efficiency.

This option most effectively addresses the vision of the DMHMRSAS, the Level of Support Model, and the challenges of the mental retardation system in Virginia, and is the most feasible option in addressing existing challenges to the MR system by ensuring:

- More individuals who are unserved or underserved will be assisted through the development of additional community residential options;
- Additional funding will be dedicated to the mental retardation system, and existing resources will be used efficiently; and
- The “dual system” will be eliminated, and emphasis will be placed on creating options not eliminating them.

B. Cost Prohibitive and Not Feasible Options

The options; i) developing community-based alternatives to the state’s five mental retardation training centers, and (ii) renovating the state’s five mental retardation training centers at the current size, are cost prohibitive and not feasible at this time. It is unrealistic to believe that the needed community alternatives to replace state training centers, will be funded, planned, and developed quickly. The transformation of the state training centers to use existing resources effectively and efficiently, while at the same time preserving their specialized supports, is challenging.

The option of renovating/replacing the state’s five mental retardation training centers to their current level is both cost prohibitive and unnecessary. National research has found that “the high costs of institutional care have made it more difficult for states to support institutional services.”¹¹ It is anticipated that the number of people at the five state training centers will continue to decline as community alternatives increase. Maintaining the existing buildings and grounds of Virginia’s state training centers is very costly, but it is also incongruent with the values, trends, and best practices of mental retardation services.

C. Strategies and Costs for Developing Community Alternatives and Reducing the Size of the Five State Training Centers.

The DMHMRSAS proposes the following strategies for improving and expanding community-based services and supports for people with mental retardation, while

¹¹ Lakin & Prouty, 1995/96

changing the role and size of existing training centers. The strategies provide a plan of action that is feasible, while ensuring the health and safety of people with mental retardation, and respecting their personal preferences and choice. Critical strategies, which include a combination of developing community-based alternatives to the state's five mental retardation training centers and renovating the training centers, are as follows:

- **Increase Mental Retardation (MR) and Day Support (DS) Waivers' Rates**

Creating community alternatives will not be possible until the Waiver rates are increased to a level that enables providers of services to stabilize their workforce through competitive pay rates and provide assurances that all standards of sound business and safety practices are maintained. The recent JLARC study on Medicaid Wavier reimbursement rates in Virginia, found that Waiver rates are too low and generally have not risen with inflation" (JLARC, 2005). The overall increase in the MR and DS Waivers' rates will initiate self-directed quality improvements in all waiver services to include improved hiring, training, and retention of qualified staff and development of additional capacity in the community for services and supports. The increases to the MR Waiver rates include:

1. Increase the Waiver reimbursement rates 20% over the next 3 biennia and an annual COLA each FY thereafter across all MR and DS Waiver services.

Each Budget Addition Will Continue in Succeeding Years

FY 2007-08	FY2009-10	FY 2011-12	FY 2013-14
\$34,461,681	\$10,850,657	\$4,361,180	\$2,907452

2. Have an additional 17% rate differential for Northern Virginia programs.

Each Budget Addition Will Continue in Succeeding Years

FY 2007-08	FY2009-10	FY 2011-12	FY 2013-14
\$4,000,000	0	0	0

3. Create an additional 10% differential for all congregate residential services that are 4 beds or less (except for sponsored residential) and for In-Home Residential Support.

Each Budget Addition Will Continue in Succeeding Years

FY 2007-08	FY2009-10	FY 2011-12	FY 2013-14
0	0	\$8,000,000	0

- **Develop Community Alternatives for Residents of State Training Center**

Develop community alternatives for 100 residents of the five state mental retardation training center residents per year for the next 4 biennia.

1. Modify the current MR Waiver to allow reimbursement for therapeutic behavioral consultation to a wider range of persons practicing behavioral interventions, as qualified Waiver providers, (Positive Behavior Support (PBS), Applied Behavioral Analysis (ABA), etc.) thereby offering more options to support individuals in the community. Many individuals leaving the state training centers will need behavioral support, but there are not enough providers.

Each Budget Addition Will Continue in Succeeding Years

FY 2007-08	FY2009-10	FY 2011-12	FY 2013-14
Cost Neutral	Cost Neutral	Cost Neutral	Cost Neutral

2. Provide for increased personnel costs for DMAS and DMHMRSAS staff associated with utilization review, licensing, human rights, community resource consultation, and service pre-authorization for monitoring the access, compliance, and quality of the large volume of new community alternatives. This is figured at 8 staff for every 400 new community beds created.

Each Budget Addition Will Continue in Succeeding Years

FY 2007-08	FY2009-10	FY 2011-12	FY 2013-14
\$529,600	\$529,600	\$529,600	\$529,600

3. Provide Community Capacity funds in the form of one-time grants of \$4,000 each person to make modifications as needed to community alternatives individuals from the state training center will be moving into or to purchase or assist in the purchase of any necessary items of equipment, furnishings, or properties required for community living.

These figures represent the **only** amount that will be spent each biennium

FY 2007-08	FY2009-10	FY 2011-12	FY 2013-14
\$800,000	\$800,000	\$800,000	\$800,000

4. Increase the Medicaid Waiver rate for skilled nursing to allow for more competitive reimbursement of nursing services in the

community system enabling more persons to remain in their home communities.

Each Budget Addition Will Continue in Succeeding Years

FY 2007-08	FY2009-10	FY 2011-12	FY 2013-14
0	\$1,700,000	\$200,000	\$200,000

- **Increase Efficiencies in the MR and DS Waivers that Promote Greater Service Satisfaction with More Efficient Use of Dollars.**

1. Increase flexibility in the MR Waiver through consumer direction and personal budgets to be developed during the second biennium. Budget reflects costs associated with the fiscal intermediary. Other costs of services may, in fact, be reduced through the process of consumer direction as reflected in the experience of some states following conversion.

Each Budget Addition Will Continue in Succeeding Years

FY 2007-08	FY2009-10	FY 2011-12	FY 2013-14
0	\$3,000,000	\$3,000,000	\$1,000,000

2. Increase the rate for Supported Employment to equal the average rate currently offered by DRS to provide an incentive for greater use of that service (People moving from 500 units of day support annually with an annual cost of \$12,595 (regular intensity at \$25.19 per unit) to supported employment for up to 200 hours a year at \$48 per hour at an annual cost of \$9,600 plus the added benefit of earning wages).

Each Budget Addition Will Continue in Succeeding Years

FY 2007-08	FY2009-10	FY 2011-12	FY 2013-14
Increased Efficiency	Increased Efficiency	Increased Efficiency	Increased Efficiency

3. Develop a Supports Waiver to address community waiting list needs (Approval of 2,000 slots under this waiver at a capped cost of \$25,000, including case management and transportation for a total general fund (GF) expenditure of \$25,000,000). It would have the following features:
 - a. Completely consumer directed;
 - b. Allow for personal budgets with a capitation of \$25,000 per person;

- c. Available to be used to purchase any Waiver service except congregate residential;
- d. Available to anyone on the current waiting list for a MR Community Waiver slot as a method of providing some service options while waiting for a slot to become available;
- e. Slots approved each year to reflect the number of new persons on the waiting list.

Each Budget Addition Will Continue in Succeeding Years

FY 2007-08	FY2009-10	FY 2011-12	FY 2013-14
0	\$25,000,000	\$12,500,000	0

• **Develop Community Infrastructure to Better meet the Needs of Individuals Whose Only Current Option Is Readmission or New Admission to a State Training Center.**

1. Approve 1,000 slots for the MR Waiver for persons living in the community over the course of the next four biennia that would be distributed by need across the mental retardation system of care.

Each Budget Addition Will Continue in Succeeding Years

FY 2007-08 (200 slots)	FY2009-10 (200 slots)	FY 2011-12 (200 slots)	FY 2013-14 (400 slots)
\$4,851,100	\$5,275,489	\$5,514,061	\$11,529,125

2. Increase Family Support funding provides flexible dollars to be spent on behalf of families for needs that exist related to the care of a family member with mental retardation that are not met through the Waivers or other funding.

Each Budget Addition Will Continue in Succeeding Years

FY 2007-08	FY2009-10	FY 2011-12	FY 2013-14
\$10,521,300	\$4,200,000	\$2,000,000	\$2,000,000

3. Establish public guardianship programs around the state designed to protect the rights of individuals with limited or no family involvement who cannot make their own decisions regarding medical, financial, or programmatic decisions.

Each Budget Addition Will Continue in Succeeding Years

FY 2007-08	FY2009-10	FY 2011-12	FY 2013-14
\$12,300,000	\$10,800,000	\$900,000	\$900,000

4. Train providers of services and families in practices to enhance the quality of services available in the community.

Each Budget Addition Will Continue in Succeeding Years

FY 2007-08	FY2009-10	FY 2011-12	FY 2013-14
\$80,000	\$40,000	\$40,000	\$40,000

5. Develop a system to administer grants for non-waiver services to persons with mental retardation of \$200 per month each to go toward room and board expenses. These grants would be administered through the DMHMRSAS and would be used to enhance the Supplemental Security Income (SSI) benefits to pay for room and board expenses for adults with mental retardation who are living in the community.

Each Budget Addition Will Continue in Succeeding Years

FY 2007-08	FY2009-10	FY 2011-12	FY 2013-14
0	\$10,614,240	\$720,000	\$720,000

- **Reduce the Size of the State Mental Retardation Training Centers, Refocus their Purpose and Function, and Make Some Renovations**

State training centers will be more cost-effective with a focus on service to only the individuals requiring the highest level of support, reductions in overall population size, and replacement of older buildings through one-time capital expenditures. The state training centers will evolve and refocus by:

- a. Reduce census at the state training centers by 100 persons per year for the next 4 biennia. These figures also reflect cost reductions in facility operations through downsizing and more efficient physical plants added to community costs of supports

Each Budget Addition Will Continue in Succeeding Years

FY 2007-08	FY2009-10	FY 2011-12	FY 2013-14
\$4,246,448	\$4,656,738	\$7,373,166	\$7,373,166

- b. Refocus the specialized services at the training centers to become Regional Community Support Centers (RCSC). Each RCSC will offer specialized services in dentistry, medical specialty areas, and behavioral therapies both on-site and through satellite clinics. RCSCs also provide staff training and linkages with universities for the “next generation” of

service providers for people with mental retardation. RCSC development can also be associated with community hospitals and universities.

Each Budget Addition Will Continue in Succeeding Years

	FY 2007-08	FY2009-10	FY 2011-12	FY 2013-14
	\$400,000	\$200,000	\$200,000	\$200,000

c. Change the role of state training centers to Intensive Support Centers (ISC), residential options that fit the criteria for individuals with the highest levels of support need. Options include:

Short-term residential options for persons in need of intensive support due to behavioral or high medical support issues before returning to the community placement.

Temporary emergency support for persons with specialized needs due to mental retardation during periods of natural or man-made disasters or individual crisis when other community options are exhausted.

Long-term residential specialized support for persons with mental retardation who have the highest level of long-term medical needs or behavioral needs that are preventing successful community living.

IV. CONCLUSIONS

Our challenge in providing community alternatives to state training centers is to individualize the care while the system changes. There must be a balance between available resources, program development, and personal satisfaction with the care received. The proposed changes to the MR system will also need to maintain a balance between individual planning, fiscal resources, and the necessary renovations at the state training centers. Replacing state training centers with community alternatives will not occur before some of the renovations to the training centers will need to be completed. Some renovations to the state training centers will need to be completed as people with mental retardation continue to reside there. In addition, respecting individual/family preferences and providing choice, some individuals may choose to live in the state training centers. It will be necessary for the Commonwealth to ensure individuals that choose to live in the state training centers receive quality, high intensity care.

The vision for the future of Virginia's MR services is to offer a "seamless" system of supports that provides individuals with mental retardation with a choice of options to support their quality of life and keep them involved with their families and communities, offering only the level of support needed to be successful. The blending of the "dual system" to a "seamless" system of supports will improve coordination, collaboration, and management of MR services. The anticipated outcome is a well-balanced system of supports that offers an array of service options while ensuring the health and safety of all Virginians with mental retardation.

The well-balanced system of supports, however, cannot be a reality without significantly increased funding. The findings of this report, and other recent reports, such as the recent JLARC study on the Medicaid Waiver rates, the DMHMRSAS report on the capital improvement needs of the state training centers to meet safety standards, and the DMHMRSAS Comprehensive State Plan, 2006 – 2012 all provide documentation that the MR system is largely underfunded. Additional indicators, such as the steady climb of the number of people on the waiting list for MR Waiver services to nearly 3,000 Virginians and the significant numbers of individuals with mental retardation who need services, but who are not eligible for Waiver services shows clearly the situation will only get worse without additional resources. Transforming the MR system and properly addressing the recommended strategies in this report will require an investment of Virginia resources over a period of time. This plan lays out an eight-year effort that will put Virginia back on course to more fully addressing the needs of its citizens with mental retardation. Over the next eight years, this plan will:

Over the next eight years, this plan will:

- Establish a means of providing some level of support to individuals who are on the waiting list for full Waiver services while waiting for a slot to become available.

- Provide for an appropriate community alternative for most persons whose only current option for services is to live in a training center.
- Increase the total number of persons who are being served by 4,000 individuals.
- Develop a more efficient system of supports for all persons served.
- Change the role of the state training centers to a state operated support service to those persons requiring the highest level of intensive supports while supporting community placement alternatives through consultation and direct provision of off-site specialized support teams (RCSC).

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Appendix A
Mental Retardation Special Population Work Group
Participant Roster

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 * Howard Cullum, The Arc of Virginia
 * Nita Grignol, The Arc of Virginia
 Paul Steele, The Arc of Virginia
 * Jessica Burmester, The Arc of Northern Virginia, The Arc of Virginia
 * Ray Burmester, The Arc of Northern Virginia, The Arc of Virginia
 * Kathy May, The Arc of Northern Virginia
 Nancy Mercer, The Arc of Northern Virginia
 * Donna Martinez, The Arc of Virginia
 * Ben Kaplan, Consumer
 * Liu-Jen Chu, Family member
 * Lana Hart, Family member
 * Herk Latimer, NOVA Coalition for the Mentally Disabled
 Dr. Carol Schall, Virginia Autism Resource Center
 Kimberly Jones
 Tracy Self
 Joseph Iacuele
 Suzanne Klaas, Department of Medical Assistance Services (DMAS)
 Teja Stokes, DMAS
 Terry Smith, DMAS
 Diana Thorpe, DMAS
 Tammy Whitlock, DMAS
 Katherine Lawson, Virginia Board for People with Disabilities (VBPD)
 * Norma Draper, VBPD
 * Sandy Herman, VBPD

* Family member or consumer

Levels Of Support Needs

The model recommended by the Mental Retardation Special Populations Work Group creates levels of support needs for individuals with mental retardation. The levels serve to determine the general needs of the individual and what might be required of the system to support that person. The levels do not take away the personal preference and choice of individuals with mental retardation. The *Supports Intensity Scale*, developed by AAMR is recommended to become the tool the Virginia adopts statewide as an assessment of the level of support needed by persons with mental retardation. The Levels of Support Needs include:

Level 1 – Requires some basic supports that are not 24-hour in nature. Respite care may be all that is needed or some skill training for more independent living. “Drop-in” services may be appropriate, or a basic level of supported employment services.

Examples of Level 1 are:

1. *An individual living at home whose basic support needs are met through regular periods of respite care.*
2. *An individual living at home or in an apartment whose basic support needs are met through in-home residential supports aimed at certain skill development or maintenance issues for independent living.*
3. *An individual living at home who's basic support needs are met through regular intensity day support or supported employment services.*

Level 2 – Some combination of in-home supports and a day support program could meet most needs. Some training or assistance to maintain activities of daily living could be indicated. Support needs could also be met through personal care services. Others at this level could have medical needs met through a limited level of home-based skilled nursing. Could require access to twenty-four hour general supervision.

Examples of Level 2 are:

1. *In-Home supports to provide training and/or assistance with some self-care along with assistance during the day through school system or formal day support to maintain safety and enhance skills of independent living would provide basic support needs.*
2. *An individual living in a group home with a service plan that addresses some ADL needs through monitoring as well as independent living skill needs through training. Day supports or supported employment would also most likely be indicated. Overnight staff would not necessarily be required to be awake, but available if needed.*

Level 3 – Requires 24-hour supervision. Individuals at this level are typically involved with more complex issues of need such as behavioral interventions, medical monitoring, or skill training/ maintenance in basic activities of daily living.

Examples of Level 3 are:

1. *May be an individual living in natural home who requires moderate levels of supervision most of the time to maintain safety. Training and assistance supports are needed for ADLs, behavioral issues, medical monitoring, or a combination. Day supports or school involvement combined with an in-home service to train and or maintain skills would be needed. Could have a behavioral or other therapeutic intervention plan.*
2. *An individual living in a group home that requires awake, overnight supervision to maintain safety in conjunction with formal day activity that involves training or supervision.*

Level 4 – Requires 24-hour supervision, much of which is intensive in nature. At times, some level of one-on-one supervision or therapeutic intervention is necessary to protect self, others, or to maintain minimum acceptable standard of life quality.

Examples of Level 4 are:

1. *An individual who has a history of frequently wandering away from the home or other environment where supports are present into areas that can present hazards to personal safety. This individual may possess poor social skills that can place hem/her at risk if supports are not in place.*
2. *An individual whose medical treatment requires close monitoring by a trained professional so as to maintain his/her safety. Monitoring may be by non-professional staff in direct support with access to trained medical professionals for review and drop-in visits as needed.*
3. *An individual whose behavior is prone to escalate to outbursts that endanger self or others under certain conditions. Maintenance of safety is dependent on support levels being provided by persons trained in the specifics of the behavior plan written for the individual.*

Level 5 – Requires 24-hour medical (to include skilled nursing), behavioral, or other specialized supervision to maintain a minimum acceptable standard of quality of life. A high level of training is required for the staff involved in the supports. Individuals must have 24-hour access to professionals in medical or other specialty areas related to the mental retardation/ developmental disability population.

Appendix C Glossary of Services

Applied Behavior Analysis: the design, implementation, and evaluation of modifications to an individual's environment with the purpose of increasing socially acceptable behavior. ABA includes the use of direct observation, measurement, and functional analysis of the relations between environment and behavior. ABA is based on the belief that an individuals' behavior is determined by past and current environmental events in conjunction with organic variables such as genetics. Thus, it focuses on explaining behavior in terms of external events that can be manipulated rather than internal constructs that are beyond our control.

Assistive Technology: specialized medical equipment and supplies to include devices, controls, or appliances, which enable individuals to increase his/her abilities to perform activities of daily living, or to perceive, control, or communicate with the environment in which he/she lives. This service also includes items necessary for life support, ancillary supplies and equipment necessary to the proper functioning of such items, and durable and nondurable medical equipment.

Case Management: assessing and planning of services; linking the individual to services and supports identified in the consumer service plan; assisting the individual directly for the purpose of locating, developing or obtaining needed services and resources; coordinating services and service planning with other agencies and providers involved with the individual; enhancing community integration; making collateral contacts to promote the implementation of the consumer service plan and community integration; monitoring to assess ongoing progress and ensuring services are delivered; and education and counseling that guides the individual and develops a supportive relationship that promotes the consumer service plan.

Congregate Residential: Training, assistance or specialized supervision provided primarily in a licensed or approved residence to enable an individual to acquire, retain, or improve the self-help, socialization, and adaptive skills necessary to reside successfully in home and community-based settings. This service is provided to enable individuals to maintain or improve their health, to develop skills in activities of daily living, to adapt their behavior to community and home-like environments, to develop relationships, and participate as citizens in the community. In order to qualify for this service in a congregate setting, the individual has a demonstrated need to continuous training, assistance, and supervision for up to 24 hours per day.

Consumer-Directed Services: Services, such as personal assistance, respite and companion, for which the individual or family/caregiver is responsible for hiring, training, supervising, and firing of the staff.

Day Support: Training, assistance, and specialized supervision in the acquisition, retention, or improvement of self-help, socialization, and adaptive skills, which typically take place outside the home in which the individual resides. Day support services focus on enabling the individual to attain or maintain his maximum functional level.

In-Home Residential: Support provided in the individual's home by a DMHMRSAS-licensed residential provider to supplement that provided by a primary caregiver. This service includes training, assistance or specialized supervision that is provided to enable individuals to maintain or improve their health, to develop skills in activities of daily living, to adapt their behavior to community and home-like environments, to develop relationships, and participate as citizens in the community. It is typically not a 24-hour/day service.

Intermediate Care Facility for Persons with Mental Retardation (ICF/MR): a facility or distinct part of a facility certified by the Virginia Department of Health, as meeting the federal certification regulations for an Intermediate Care Facility for the Mentally Retarded and persons with related conditions. These facilities must address the total needs of the residents, which include physical, intellectual, social, emotional, and habilitation, and must provide active treatment.

Intensive Support Center (ISC): will be the new designation for a training center for persons with mental retardation.

Intensive Support Home (ISH): a small (up to 6 bed) community home located in close proximity to an Intensive Support Center. These may be operated by training centers, CSBs or private providers and may be ICFs-MR or MR Waiver group homes.

Personal Assistance: assistance with activities of daily living, instrumental activities of daily living, access to the community, self-administration of medication, or other medical needs, and the monitoring of health status and physical condition.

Positive Behavior Support: an empirically validated, function-based approach to eliminate challenging behaviors and replace them with pro-social skills. It acknowledges that all behaviors serve a purpose and that understanding the purpose is the first step to changing the behavior. Use of PBS decreases the need for more intrusive or aversive interventions (i.e., coercion or punishment) and can lead to both systemic as well as individualized change.

Regional Community Support Centers (RCSC): a program operated by and located at a training center with the purpose of providing individuals with mental retardation living in the community who have complex medical and behavioral needs with specialized medical, behavioral, nutritional, dental, and other clinical therapies/services. RCSCs may also have regionally-based satellite clinics, both on-site and through satellite clinics.

Respite services: services provided to individuals who are unable to care for themselves, furnished on a short-term basis because of the absence or need for relief of those unpaid persons normally providing the care.

Self-direction: a means of supporting people with disabilities that gives the person with a disability more control in planning for and running his/her own life and makes the voice of the person with a disability paramount in making choices about his/her life.

Skilled Nursing: services that are ordered by a physician and required to prevent institutionalization, and that are provided by a licensed registered professional nurse, or by a licensed practical nurse under the supervision of a licensed registered professional nurse.

Supported Employment: Work in settings in which persons without disabilities are typically employed. It includes training in specific skills related to paid employment and the provision of ongoing or intermittent assistance and specialized supervision to enable an individual with mental retardation to maintain paid employment.

Therapeutic Consultation: Activities to assist the individual, family/caregiver, and any other provider staff in implementing an individual service plan.

For Dianne's Sake:

**Maintain the choice of
Medicaid Intermediate Care Facilities
for Persons with Severe and Profound
Mental Retardation**

**By Nancy Ward
VOR Immediate Past President**

**May 18, 2006
Medicaid Commission Meeting
Irving, Texas**

For Dianne's Sake:

Maintain the choice of Medicaid Intermediate Care Facilities for Persons with Severe and Profound Mental Retardation

INTRODUCTION

My name is Nancy Ward.

As is required for me to say, I do NOT have any financial involvement related to any services being discussed.

I am VOR's Immediate Past President. VOR is a national advocacy organization which advocates for people with mental retardation. It is the only national advocacy group that supports a full array of Medicaid residential options, including Intermediate Care Facilities for People with Mental Retardation (ICFs/MR).

As an advocate in Texas, I have more than 33,000 hours of volunteer services in state schools for people with mental retardation and state schools for people with mental illness.

I am also here on behalf of my daughter. Dianne Ward was born 44 years ago. She has an IQ of 8, which means she functions at the level of a 16-month old infant. She stands almost 6 feet tall, is quite mobile, loves hats, loves to hum, and admires her own reflection. She will also run into a busy road, ingest almost anything, can't talk, have no sense of self-protection, and needs help in all aspects of self-care. She also has chronic medical needs.

She is a resident of Denton State School, a state-operated ICF/MR. I feel quite certain that should Denton close, or Dianne be transferred, she would perish. Yet, in Texas, and across the country, families like my own face almost daily challenges to the viability of places like Denton, as deinstitutionalization continues in earnest.

Today, the Medicaid Commission seeks to address this question:

“How do we get the best quality long-term care for our public dollars?”

In an attempt to answer your question, I will focus my comments on the need for ICFs/MR. I will call on this Commission to support the continuation of Medicaid-funded and licensed ICFs/MR. I will conclude my comments by sharing information about a cost-effective solution being used currently in a few states to reduce costs, enhance quality community options by indefinitely preserving the family unit.

MYTHS OF A BYGONE ERA

You will likely hear from advocates who will say that no one needs an institution. They will tell you that people can be served better and for less money in "community" settings. These myths were born from a bygone era, and they no longer hold any truth.

Dianne was first placed in a state institution 1971, before Geraldo Rivera made his name exposing Willowbrook for all its horrors. Families had been lobbying long before Geraldo for federal standards, funding and oversight of these facilities – quality assurances we enjoy to this day.

What was initially our blessing – public awareness -- has become our curse. The image of Willowbrook has stuck in the public's mind. Yet facilities no longer resemble Willowbrook. At Denton and all of the state-operated facilities in Texas, community volunteers and state employees ensure that residents enjoy a variety of community activities, including concerts, sporting events, shows, outings to restaurants, special events, Six Flags, and the Texas State Fair. Within the facilities' communities, the staff, families, friends and volunteers join together to provide parties, holiday celebrations, dances, worship services and other social activities. Neighbors (disabled and not) are invited and participate in these facility-based events. The actual level of activity in these facilities does not match with the vision of some people that living in an institution means being locked in institutional dormitories and being attended to by cold heartless staff.

MY DAUGHTER AND HER PEERS

For my daughter and her peers, this environment is the least restrictive, most appropriate, cost effective, safest and efficient setting according to her unique needs. Everyday she receives training and habilitation to improve her self-help and other skills. She benefits from access to all necessary health care, including physicians, dentists, nurses and therapists. The dedicated, caring and compassionate staff ensures that Dianne remains happy, well-adjusted and continues to grow so that she may reach her full potential.

Dianne is not alone. 79.3% of all people in state operated ICFs/MR have severe and profound mental retardation. A majority of these residents have additional functional limitations associated with walking, communicating, eating, dressing, and/or toileting. A majority have additional disabling conditions, such as cerebral palsy, behavioral or psychiatric disorders¹. Most people living in ICFs/MR also have chronic medical conditions. Because of the severity of their multiple handicaps, especially their significant cognitive disabilities and medical fragility, these folks require access to on site medical and health care services in ICFs/MR around the clock, 7 days a week.

¹ Robert Prouty, Gary Smith, and K. Charlie Lakin (eds.) (2005). *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2004*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institution on Community Integration.

COMMISSIONERS: PLEASE SUPPORT CHOICE

I am an advocate for choice. I support expanding community-based options and I support the preservation of ICFs/MR. As an advocate for choice, I would be the first to stand next to any advocate in a picket line or in the office of a lawmaker supporting the individual's right to choose and receive community-based supports. Choice and need are the operative words. Regrettably, these concepts – in the blind pursuit for community for all – are often abandoned. This vision neglects the needs and choices of some people with profound mental retardation who have very critical health care and support needs.

COMMUNITY RESOURCE CENTERS: THE SOLUTION

At the March Medicaid Commission hearing, you heard from a fellow VOR representative, Irene Welch. Her presentation, "Don't Rob Peter to Pay Paul: Maintaining choice and achieving better outcomes in Medicaid residential facilities for people with mental retardation," included a section on Community Resource Centers.

CRCs are a proven model of cost-effective, high quality community-based long-term care options, including health care. With this model, people residing in the community access ICF/MR-based health care expertise on an outpatient basis. States that provide this option are currently using the existing infrastructure to help families maintain their loved ones in the family home with supports from the expert practitioners based at ICFs/MR. Services offered through this model include respite, dental care, medical and nursing care, equipment modification, communication technology support, speech, recreation, day services, evaluations and assessments, a whole host of therapies (OT, PT, pool, equestrian, sensory, etc.), and much more. By eliminating or delaying the need for full residential care, states save millions of dollars and families stay together.

CONCLUSION

Providing consumers a choice between home and community-based supports and ICFs/MR is supported by federal statutory and case law, including *Olmstead* and Medicaid². The "least restrictive environment" can be a facility setting, where opportunities for inclusion in community events are often abundant.

We can't express strongly enough how much we appreciate your effort to carefully consider every aspect of this very serious debate.

Thank you very much for this opportunity to present our perspective before the Medicaid Commission.

² See e.g., *Olmstead v. L.C.*, 119 S. Ct. 2176, 2185 (1999), in which the Supreme Court held that unjustified institutionalization is discrimination under the Americans with Disabilities Act, with choice of the individual being a required criteria in determining whether community placement was required. To emphasize the importance of choice, and the ongoing role for publicly and privately-operated institutions, the Supreme Court stated: "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." 119 S. Ct. at 2187.

March 2006

Don't Rob Peter to Pay Paul:

Maintaining choice and achieving better outcomes
in Medicaid residential facilities for people with mental retardation

Don't Rob Peter to Pay Paul:

Maintaining Choice and achieving better outcomes in Medicaid residential facilities for people with mental retardation

By Irene Welch
VOR Representative

March 14, 2006
Medicaid Commission Meeting

March 2006

Don't Rob Peter to Pay Paul:

Maintaining choice and achieving better outcomes in Medicaid residential facilities for people with mental retardation

INTRODUCTION

My name is Irene Welch.

As is required for me to say, I do NOT have any financial involvement related to any services being discussed.

I am a VOR member. VOR is a national advocacy organization which advocates for people with mental retardation. I am here in particular on behalf of my niece, Mary Elizabeth, who has profound mental retardation, cerebral palsy, a complex seizure disorder, together with additional disabilities and chronic medical concerns. She and her housemates have never spoken. Some use 2 or three signs such as "eat," "drink," "toilet," or "more."

Mary Elizabeth lives in a state-operated group home in Massachusetts and goes every day to a day program at a state-operated Intermediate Care Facility for People with Mental Retardation – an ICF/MR. Her daily routine, relying on a combination of community and facility supports, mirrors VOR's overall mission in support of a full array of residential and service options for people with mental retardation.

Today, you, the Commission members, are focusing on access, quality and the cost of Medicaid long-term care services by considering the question:

**"How do we get the best quality acute care and
preventive care for our public dollars?"**

In an attempt to answer your question, I will focus my comments first on the people with mental retardation in need of services, second upon the quality of available service systems for this population, and third, upon a cost-effective solution being used currently in a few states to reduce costs, enhance quality community options by indefinitely preserving the family unit.

FIRST: THE PEOPLE BEING SERVED BY ICFs/MR

To fully appreciate the need for ICFs/MR, we need to consider the people being served.

79.3% of all people in state operated ICFs/MR have severe and profound mental retardation. A majority of these residents have additional functional limitations associated with walking, communicating, eating, dressing, and/or toileting. A majority have additional disabling conditions, such as cerebral palsy, behavioral or psychiatric disorders¹. Most people living in ICFs/MR also have chronic medical conditions.

Because of the severity of their multiple handicaps, especially their significant cognitive disabilities and medical fragility, these folks require access to on site medical and health care services in ICFs/MR around the clock, 7 days a week.

SECOND: THE QUALITY OF CARE: ICFs/MR v. THE COMMUNITY

To remain certified and funded, ICFs/MR must meet 378 specific standards within 8 conditions of participation in major quality of care categories which are evaluated on an annual basis by CMS regional teams. These stringent requirements ensure that high quality care is being consistently delivered to the most vulnerable citizens of our society. Part of the annual review requires documentation that each and every resident, in fact, currently needs the ICF/MR level of care.

In contrast, as the deinstitutionalization movement has grown, there has been a corresponding increase in state audits, investigative media series and peer-reviewed studies documenting systemic abuse, neglect and death associated with community-based services for people with mental retardation². The community infrastructure is also plagued by a well documented staffing crisis in each and every state. The staffing crisis is characterized by high turnover, low wages, inadequate training, and a ballooning waiting list for services. Against this backdrop removing people from their facility homes to the documented dangers and uncertainties and isolation of community "homes" is unconscionable.

Robbing Peter to pay Paul is not a solution. We have a better idea.

THIRD: THE SOLUTION

Community Resource Centers are a proven model of cost-effective, high quality community-based long-term care options, including health care. With this model, people residing in the community access ICF/MR-based health care expertise on an outpatient basis. States that provide this option are currently using the existing infrastructure to help families maintain their loved ones in the family home with supports from the expert practitioners based at ICFs/MR. Services offered through this model include respite, dental care, medical and nursing care, equipment modification, communication technological support, speech, recreation, day services, evaluations and assessments,

¹ Robert Prouty, Gary Smith, and K. Charlie Lakin (eds.) (2005). *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2004*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institution on Community Integration.

² See, http://www.vor.net/abuse_neglect.htm

and a whole host of therapies (OT, PT, pool, equestrian, sensory, etc.), and much more. By eliminating or delaying the need for full residential care, states save millions of dollars and families stay together.

CONCLUSION

VOR supports a full array of residential options. While we have very serious concerns about the community's ability to safely serve all the residents of ICFs/MR, we absolutely support any initiative to better fund and expand community service options, so long as the solution does not include eliminating access to existing facility services for those few people with mental retardation who truly need that level of care..

Providing consumers a choice between home and community-based supports and ICFs/MR is supported by federal statutory and case law, including Olmstead and Medicaid³. The "least restrictive environment" can be a facility setting, where opportunities for inclusion in community events are often abundant. It is not uncommon for residents of state operated facilities to enjoy in any given week trips to the mall, movies, restaurants, parks, fairs, concerts and beach.

This Commission has been praised by the Congressional Quarterly for displaying "the kind of concentration, curiosity, and passion that suggested their concern about the stakes involved."

For VOR members, the "stakes involved" are our very fragile family members. The deliberations by Commission members take on a life or death aspect for our loved ones.

We can't express strongly enough how much we appreciate your effort to carefully consider every aspect of this very serious debate.

Thank you very much this opportunity to present our perspective before the Medicaid Commission.

³ See e.g., Olmstead v. L.C., 119 S. Ct. 2176, 2185 (1999), in which the Supreme Court held that unjustified institutionalization is discrimination under the Americans with Disabilities Act, with choice of the individual being a required criteria in determining whether community placement was required. To emphasize the importance of choice, and the ongoing role for publicly and privately-operated institutions, the Supreme Court stated: "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." 119 S. Ct. at 2187.

**The Myth of an "Institutional Bias" in Medicaid
 for Persons with Mental Retardation and Developmental Disabilities**

Often it is alleged that 70% of all Medicaid long-term care dollars pay for institutional care. Globally, this is true. Specifically, related to the mental retardation and developmental disabilities (MR/DD) population, it is not true. The Medicaid program for long-term care spends more dollars and supports more people with MR/DD in the community, including in the Home and Community Based Services (HCBS) waiver program, than for those in Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR).

What then, is the basis for the 70% myth? The answer lies in the fact that the Medicaid program covers more than people with MR/DD; it also covers people who reside in nursing facilities (NF), most of whom are elderly. The so-called institutional bias in the numbers occurs because Medicaid defines "institutional care" to include all Medicaid-eligible populations, the vast majority of whom reside in NFs. The facts are far different when one separates the MR/DD and elderly populations.

The "institutional bias" of Medicaid myth as applied to services for persons with MR/DD can have dangerous consequences for our most fragile citizens. For example, proposals such as Money Follows the Person (MFP) and the Medicaid Attendant Services and Supports Act (MiCASSA) are motivated by a desire to "rebalance" the system by increasing community supports at the expense of "institutional" (including ICF/MR) options. In this process, ICF/MR care may become uneconomical and extinct, risking the health, safety and very lives of people with severe and profound mental retardation if these facilities close. While there is a great need to expand community-based options, it should not be done at the expense of another Medicaid population. Focus on expansion must address the areas of greatest need for people with MR/DD – the provision of quality community options, including ready access to health care services, and helping those on waiting lists for services.

Here are the facts about the Medicaid program:

- Nearly 70% of the Medicaid funds for long-term care (for both people with MR/DD and the elderly) are spent for services provided in "institutional" settings. However, only 20% of this funding is for people with MR/DD who reside in ICFs/MR (Table 1).
- When one looks at only Medicaid expenditures for persons with MR/DD who reside in ICFs/MR and in HCBS, it turns out that Medicaid spends more for community services (55%) than for institutional care (45%). (Table 2). Note: NF expenditures for MR/DD residents, who are only 2.4% of the NF population, are excluded from Table 2 because reliable data could not be located.

Table 1²

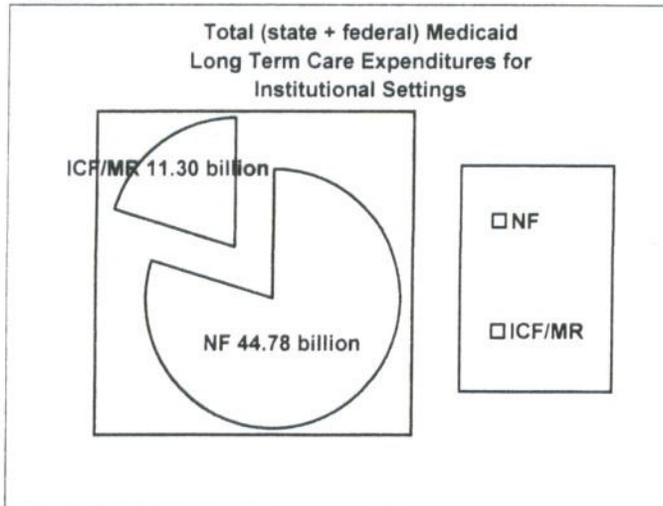
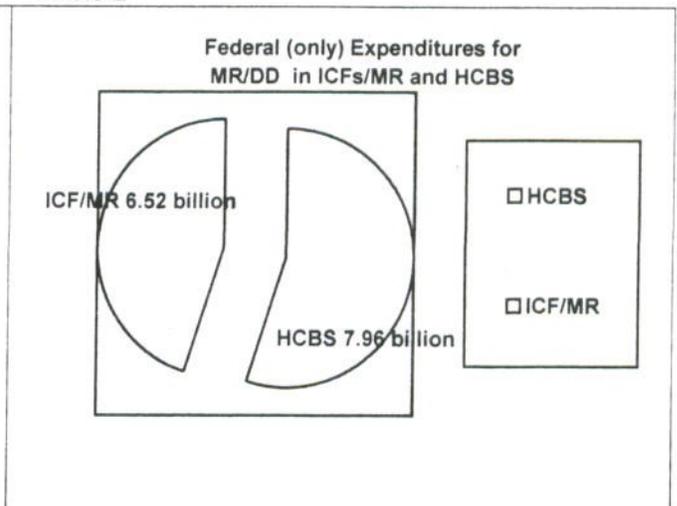


Table 2³



- HCBS recipients comprise 74% of MR/DD residents in Medicaid-funded long-term care settings. ICFs/MR recipients make up just 20% and the remaining 6% reside in nursing facilities (Table 3).
- Medicaid-funded HCBS and other community residences, as compared to ICFs/MR, comprise 95% of the residential placement options for persons with MR/DD (Table 4). These figures exclude individuals with MR/DD receiving services in the family home or their own home, which represents an additional 500,004⁴ people receiving non-residential community-based services, although it is unclear what percentage of this amount is Medicaid-supported.

Table 3⁵

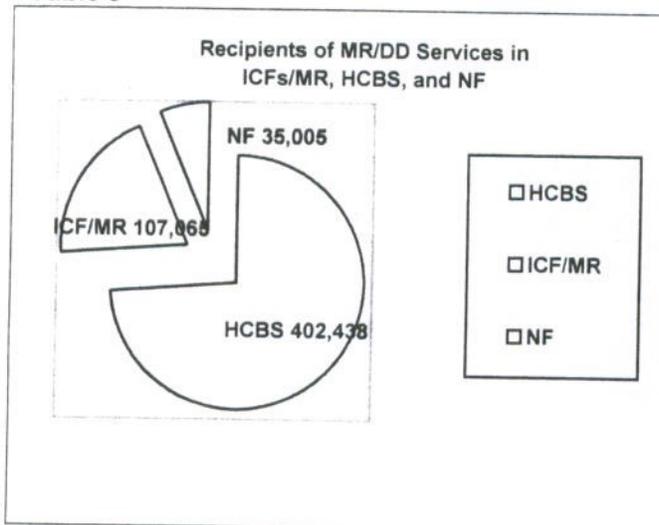
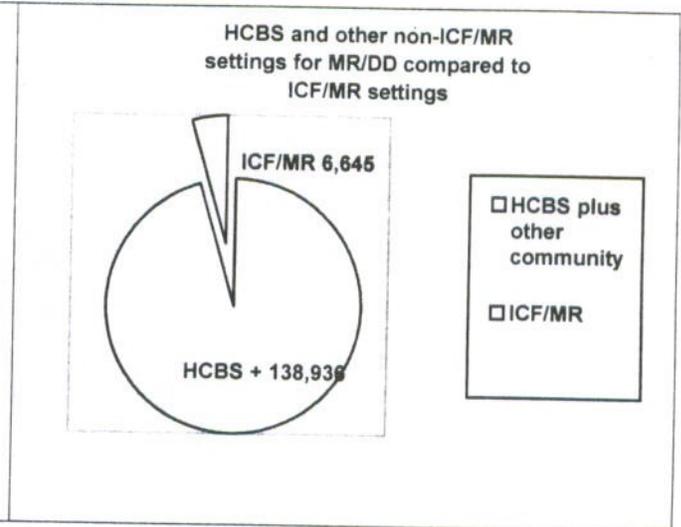


Table 4⁶



- 79.7% of individuals who reside in ICFs/MR have severe and profound mental retardation and require 24-hour around-the-clock care for their safety. Nearly half (47%) of these same residents have two or more additional conditions, and nearly all need help walking, toileting, eating, dressing and/or communicating verbally. By sharp contrast, the vast majority of people with MR/DD who reside in the community are far higher functioning individuals with little or no need for intensive care services.
- A 2003 peer-reviewed study by Kevin Walsh, Ph.D., concluded that "From the studies reviewed here, it is clear that large savings are not possible within the field of developmental disabilities by shifting from institutional to community placements." Thus, if more funds were spent to move people from ICFs/MR, little or no money would be saved, unless the quality of the lives of the clients were reduced through lesser quality care and services.

¹ Trend in the cost of Operating a Nursing Home: Analysis of Medicare Cost Reports for Skilled Nursing Facilities, Health Services Research and Evaluation, American Health Care Association (January 26, 2004)(Total number of residents in nursing facilities (2003) was 1,450,319, including 35,005 residents with MR/DD (see Table 3)).

² Steve Gold, "Medicaid 2003 Expenditures," Information Bulletin #68 (May 26, 2004).

³ Residential Settings for Persons with ID/DD served by State and Nonstate agencies on June 30, 2003. In R. W. Prouty, Gary Smith & K.C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 2003*, University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, <http://rtc.umn.edu/risp03/risp03.pdf>, Tables 3.4 (p. 66) and 3.7 (p. 73). *The federal government "match" is 56.85% (average) of state Medicaid spending.*

⁴ *Id.*, Table 2.9 (p. 45).

⁵ *Id.*, Tables 3.12 (p. 83), 3.13 (p. 84), and 3.2 (p. 60).

⁶ *Id.*, Tables 2.1 (p.34) and 3.1 (p. 58) (figure for HCBS plus other community settings derived by taking the total state and nonstate residential settings for persons with MR/DD, from Table 2.1, and subtracting total ICF/MR settings from Table 3.1).