

**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.

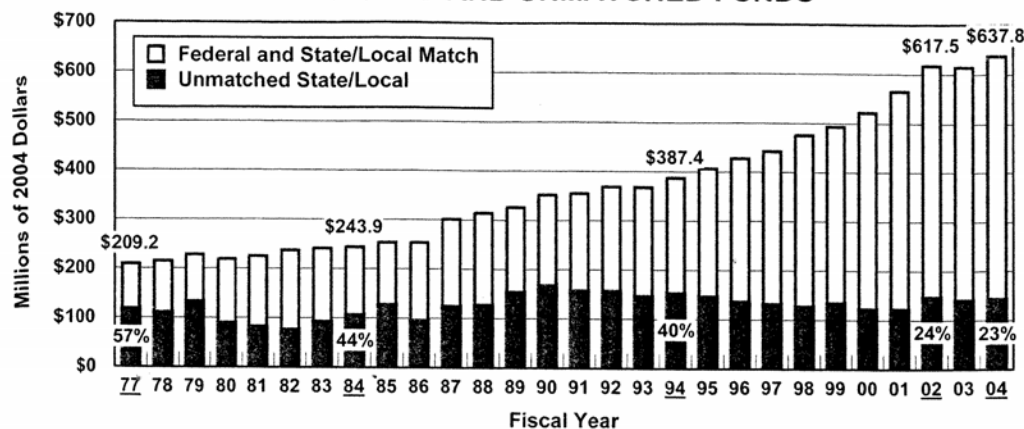
⁴ Larson, Doljanac, & Lakin, in press

Table 1 Residences of Virginians with MR		
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**

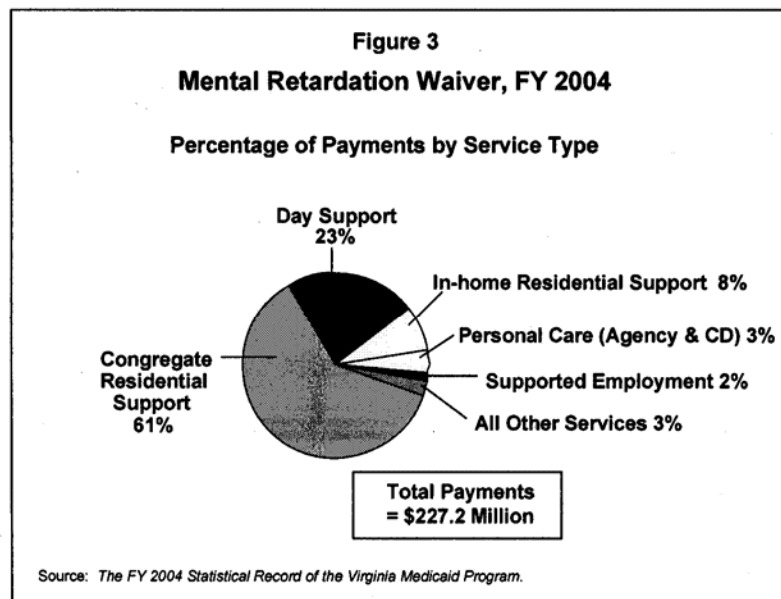


⁵ Braddock, 2005

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

Appendix B

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.