COMMONWEALTH of VIRGINIA

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October 17, 2007

TO: The Honorable Timothy M. Kaine
Governor of Virginia

The Honorable John H. Chichester, Chairman
Senate Finance Committee

The Honorable Vincent F. Callahan, Chairman
House Appropriations Committee

FROM: James S. Reinhard, M.D. James Reinhard

SUBJECT: Report of the Study of the Mental Retardation System in Virginia

Pursuant to Item 302 TT, *2006 Appropriations Act* and continued by Item 311 AA, *2007 Appropriations Act*, I am very pleased to transmit to you the final report of the study of the mental retardation system in Virginia.

As required by the study, DMHMRSAS in conjunction with DMAS, The Arc of Virginia (Arc), consumers, Parents and Associates of the Institutionalized Retarded (PAIR), the Virginia Association of Community Services Boards (VACSB), and private providers (VNPP) collaborated together to determine how the Medicaid Mental Retardation Home and Community Based Waiver can be improved to provide a person-centered, individualized support focus.

The study also required an examination of all aspects of funding the service continuum, including Medicaid and Medicaid Waivers, and to make recommendations for the development and funding of a full continuum of care for consumers with mental retardation.

I wish to express my sincere appreciation for all of the individuals who shared their time, knowledge and resources in the development of this report and the recommendations.

If you have any questions or concerns, you may contact me directly or Lee Price, Director, Office of Mental Retardation Services, (804) 786-5850, or via email at lee.price@co.dmhmrsas.virginia.gov.

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A Study of the
Mental Retardation Service System in Virginia

PREFACE

The 2006 Appropriations Act (Item 302 TT) and the 2007 Appropriations Act (Item 311 AA) requires a report of the study of the mental retardation system in Virginia by the Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services in conjunction with DMAS, The Arc of Virginia (Arc), consumers, Parents and Associates of the Institutionalized Retarded (PAIR), the Virginia Association of Community Services Boards (VACSB), and private providers (VNPP). These entities collaborated together to determine how the Medicaid Mental Retardation Home and Community Based Waiver can be improved to provide a person-centered, individualized support focus.

The study also required an examination of all aspects of funding the service continuum, including Medicaid and Medicaid Waivers, and to make recommendations for the development and funding of a full continuum of care for consumers with mental retardation.

The report was required to be made to the Governor and the Chairmen of the House Appropriations and Senate Finance Committees no later than October 1, 2007.

MR System Study Report
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Executive Summary

The Department of Mental Health, Mental Retardation, and Substance Abuse Services developed a vision statement with its partners statewide. The collaborative vision that embraces self-determination, empowerment and recovery as the core of its foundation states, "*...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.*"

In House Bill 5002, enacted in 2006, the General Assembly directed stakeholders to review the Medicaid home and community-based waiver for persons with mental retardation to determine how the waiver program could be improved to provide a person-centered, individualized support focus. This was to include recommendations for changes as well as cost implications. In the 2007 Session of the General Assembly, the following language in the adopted budget (House Document 1650) stated:

Item 311. *AA. The Department of Mental Health, Mental Retardation and Substance Abuse Services, in conjunction with the Department of Medical Assistance Services and related state agencies, the ARC of Virginia, consumers, Parents and Associates of the Institutionalized Retarded, the Virginia Association of Community Services Boards, and private providers shall continue reviewing the Medicaid home- and community-based waiver for persons with mental retardation. . . In addition, the department shall make recommendations for the development and funding of a full continuum of care for consumers with mental retardation.*

In response to Item 311 AA of the 2007 Appropriations Act, numerous constituents from around the state met for many months beginning last fall to examine the Virginia system of services for individuals with intellectual disabilities. Those involved in assembling this report include self advocates and family members of individuals with intellectual disabilities, staff of DMHMRSAS central office and training centers, DMAS, DRS, local CSBs, private providers, advocacy organizations, and university staff (a full listing of all participants is available in Appendix B of the full report). This report synthesizes the work of six subgroups, which focused on the following key areas, as directed by the General Assembly:

- Person-centered, individualized supports;
- Behavioral consultation services;
- Skilled nursing services;
- Medical services;
- Employment, housing and other specialized supports; and
- An examination of other states' models of supports.

In addition to the vision of the Department mentioned above, the following principles were considered in developing the summary report for the study:

- The recognition that, while government cannot and should not be responsible for providing all of the resources that its citizenry needs or desires, it does have a responsibility to protect its citizens and provide equal access. Protection and equal access for persons with intellectual disabilities mean providing assistance as needed so that individuals may avail themselves of the supports routinely available to all citizens thereby creating meaningful and fulfilling lives.

- All persons who qualify for services have a right to understand the nature and level of available supports and expect delivery those supports in a reasonable and timely manner.

Experience and findings from this study indicate that the needs and desires of citizens with intellectual disabilities can be met adequately with a predictable amount of resources. It is estimated this will cost significantly more than is currently being made available in the system. This report analyzes the current system and offers a plan to raise the level of support in Virginia so that the needed resources can be well-predicted and managed.

It should be noted that the purview of this study required "examination of all aspects of funding the continuum" and, "to make recommendations for the development and funding of a full continuum of care for consumers." Subsequently, any recommendations for funding included in this document were made by the involved stakeholders within those parameters and without regard to budget constraints and competing priorities, or the Governor's budget development process, competing priorities for the Governor and General Assembly.

The study's findings and recommendations are extensive and many. For this reason, and in order to report back in a meaningful manner, the recommendations found in the main body of the report have been divided into three distinct sections:

Section I

This section (beginning on page 32) includes 21 recommendations designed to promote a comprehensive system of support and services that is responsive to individuals with intellectual disabilities and their families at all levels of their service needs. The first five are considered to be the core recommendations that, if approved in a package, would substantially move Virginia in the direction of a comprehensive support system. These five core recommendations are designed to reduce the waiting list for community-based services to a reasonable level for efficient and timely management within eight years. They are also intended to change the community infrastructure through substantial state investment while simultaneously supporting the needed rehabilitation of existing state training center facilities to maintain standards of health, safety, and code compliance. They are:

Recommendation #1

- **Fund MR Waiver slots for 800 individuals per year for the next four biennia for individuals who are waiting for services.**
- **Fund the capacity-building allotments of $4,000 for the start-up of each of the 800 slots.**
- **Fund by FY 2010 the purchase and implementation of a statewide assessment tool designed to transition and target supports to individuals in a more person-centered manner and enhance the state's ability to plan support systems and allocate resources.**

Recommendation #2

- **Invest in community infrastructure, including but not limited to new construction of four-bed community homes, available for both individuals choosing to exit facilities and those presently residing in the community.**
- **While building community capacity, simultaneously focus on renovations of those buildings at CVTC and SEVTC necessary to maintain health and safety standards for the projected populations.**

Recommendation #3

- **Reestablish the state's commitment to at least minimally support, through General Fund dollars, people with intellectual disabilities who have no other avenue for support.**

Recommendation #4

- **Provide for a 25 percent rate increase for all MR Waiver models of residential support of four beds or less (except "sponsored residential" homes) to make smaller settings financially feasible and promote the Money Follows the Person initiative.**

Recommendation #5

- **Fund 125 MR Waiver slots per year for the next two biennia for persons living in any one of the state-operated training centers, private or public ICFs/MR, nursing homes, and long-stay hospitals who wish to live in the community so that Virginia can take full advantage of the CMS Money Follows the Person initiative.**
- **Beginning with the third biennia (FY 2013) after successful implementation of the first bullet of this recommendation, fund 60 slots per year (one slot per month distributed to each of the five Health Planning Regions) to be held in reserve for crisis situations to mitigate family stresses that might otherwise result in an institutional placement or to enable an individual to leave an institutional setting when it is no longer needed or desired.**
- **Fund capacity building allotments of $4,000 for the start-up of each of the slots.**

The remaining recommendations (beginning on page 37) in Section I are critical to building a comprehensive support system. The MR Waiver is intended to be an alternative to institutional placement. These additional recommendations are designed to create the services and levels of support in the Waiver that are currently found in the state training centers and other ICFs/MR. By doing so, individuals and their families will be able to choose their supports from an array of available community options as opposed to being limited to only one option for comprehensive services. These include recommendations aimed at supporting individuals with major health and behavioral needs and also in a manner that allows more complete access to employment, choice of living arrangements, and personal control over their own services. Combined with the first five core recommendations, these additional proposals would address many of the systemic issues which prevent successful outcomes for individuals and their families and help Virginia to turn a new page in supporting individuals with intellectual disabilities.

A full estimated cost breakout of the top 21 recommendations can be found on page 42 of the full document as well.

Section II

The person-centered planning recommendations found in Section II (beginning on page 47) address person-centered practices that are critical in the systems shift from a program approach to an individual approach of support. The Person-Centered Planning Leadership Team has developed the following vision, values and principles to help guide the continued transformation of the system:

> *We see a Virginia where individuals of all ages and abilities have the supports we need to enjoy the rights of life, liberty and the pursuit of happiness and the opportunity to have a good life.*
>
> *Having a good life means different things to different people. It includes joy and happiness, health and safety, dreams, meaningful activities, intimate relationships with family and friends, having a home, transportation, work, money, bank accounts and the ability to contribute to family and community.*
>
> *We believe that our journey to a good life is best led by the voices of individuals and by following these person-centered principles.*
>
> *Principle 1:* *Listening. Individual choices and descriptions of a good life are respected and followed.*
>
> *Principle 2:* *Self-direction. Personal choice and control are supported.*
>
> *Principle 3:* *Community. Relationships with families, friends and people in the community are very important and at the center of planning.*
>
> *Principle 4:* *Abilities. The experience, talents and contributions of individuals, families and communities are strengthened and supported.*

Principle 5: *Accountability. There is shared responsibility for supports and choices.*

Beginning on page 48, there are 15 recommendations to support the above principles.

Section III

The recommendations in Section III (beginning on page 49) are supplemental to those in the first two sections in transforming the system's infrastructure. Each of these 24 items represents a system's change issue that, if implemented, would improve the quality of individuals' lives in the basic areas of employment, health and safety, and housing.

Summary

Virginia has established the infrastructure to support individuals with disabilities through the local CSBs, state training centers, the Mental Retardation and Day Support Waivers and the oversight of DMHMRSAS and DMAS. However, many gaps exist in the present system of supports. Facilities at aging training centers require upgrades and improvements in order to ensure the health and safety of their residents. Many individuals in the community are in urgent need of the kinds of supports offered by the MR Waiver but must await the availability of a slot. There is a need for non-Waiver funding for individuals unable to access Medicaid at the present time. Around the state there are inconsistencies in the availability of services often due to Medicaid reimbursement rates that fail to attract providers of services. Finally, there is a need for the expansion of existing and development of additional MR Waiver services to ensure individuals' health and safety.

It is the belief of those who developed this report that it offers Virginians with intellectual disabilities the best plan to fill individuals' most urgent needs, honor choices, assure health and safety and ensure that individuals and their families can enjoy a good life. The process used to develop this report also allowed stakeholders to work together in a positive and constructive way, and they are likely to continue to work together to improve the lives of many individuals with intellectual disabilities and their families with the implementation of the recommendations contained in this report.

Introduction

Virginia's system of services and supports for individuals with intellectual disabilities is a mix of state, local, and federal efforts. Supports and services are provided in a variety of settings with costs totaling more than $785 million dollars annually. State funds account for approximately 46 percent of the total cost. Slightly more than 26,000 individuals are identified through the Community Services Boards (CSBs) as living in the community and are either receiving or are in need of services. In addition, there are about 2,000 persons living in state-operated or community-based Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR). Of the 26,000 individuals living in the community, slightly more than 7,000 are receiving services through the Medicaid Mental Retardation (MR) Home and Community-Based Waiver and 300 are receiving services through the Medicaid MR Day Support Waiver.

The recent increases in reimbursement rates for MR Waiver services was the first significant rate adjustment in the 16-year history of the waiver. Additionally, a total of 1,354 new community waiver slots have been allocated since July 2004. These improvements have been significant. Even so, gaps exist in Virginia's system of services and supports. As of September 10, 2007, the statewide waiting list totals 3,749 individuals (1,849 with urgent needs and 1,900 with non-urgent needs). Some persons wishing to leave the institutional system of care have difficulty finding services to adequately meet their needs. Individuals living in community settings have limited options available to them if their support needs rise to more critical levels. Individuals are living in old buildings that have difficulty complying with regulations at the state-operated training centers. The most common models of service delivery in Virginia are those often criticized as contrary to the vision and principles of the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS), as outlined below.

Virginia has made significant improvements in recent years through the funding of waiver slots and rate increases for the Medicaid Waivers. However, it still ranks among the bottom ten states in per capita spending on services for persons with developmental disabilities while remaining in the top ten of the states in per capita income[1]. Other states have developed systems that much more effectively address the emerging needs of their citizens with intellectual disabilities through their state appropriations.

Experience and findings from this study indicate that the needs and desires of citizens with intellectual disabilities can be met adequately with a stable and predictable amount of resources. It must be recognized that this will cost substantially more than is currently being made available in the system. This study will analyze the current system and offer a plan to raise the level of support in Virginia so that the needed resources can be well-predicted and managed. The benefits of a fully-funded and functional system of support will be immediate and recognizable.

The following vision and principles have been considered in the development of the recommendations contained in this study.

- The Department of Mental Health, Mental Retardation, and Substance Abuse Services envisions:

> ". . . 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."

- The recognition that, while government cannot and should not be responsible for providing all of the resources that its citizenry needs or desires, it does have a responsibility to protect its citizens and provide equal access. Protection and equal access for persons with intellectual disabilities, in addition to ensuring adequate services to meet challenging medical and behavioral conditions, mean providing assistance as needed so that individuals may avail themselves of the supports routinely available to all citizens thereby creating meaningful and fulfilling lives.

- All persons who qualify for services have a right to understand the nature and level of available supports and expect delivery of those supports in a reasonable and timely manner.

Virginia is the recipient of two major grants from the Centers for Medicare and Medicaid Services that, when successfully completed, will help realize the above stated principles as well as the recommendations outlined in this report. The **Real Choice Systems Transformation Grant**, awarded late 2006, requires collaboration among the DMHMRSAS, the Department of Medical Assistance Services (DMAS) and other state agencies and partners on focused systems change initiatives. These initiatives will make improvements in the system's infrastructure to help provide better and more accessible information to citizens in need, promote choice and control in service delivery, and enhance the development of information technology. The second award is a **Money Follows the Person** demonstration initiative which significantly increases the amount of federal dollars available to help people move from institutional care into their home communities, as desired.

During this biennium, these initiatives, coupled with other planned departmental initiatives for individuals with disabilities, represent a unique opportunity for Virginia. Implementing key recommendations outlined in this study will greatly advance services and supports for individuals with intellectual disabilities in the Commonwealth. Capital improvements in community infrastructure at this time, combined with certain enhancements to the MR and DS Waivers, will enable Virginia to provide greater community options for people who are currently living in institutional environments. These changes will also be necessary to successfully access the time-limited funding opportunities presented by the Money Follows the Person award.

[Note on the use of terms: One national organization that has moved away from the use of the term "mental retardation." It is the American Association on Mental Retardation (AAMR), which just this year changed its name to the American Association on Intellectual and Developmental Disabilities (AAIDD). This change has been made at the request of advocates who felt stigmatized by the use of the term "mental retardation" to describe their disability. This report will use the term "intellectual disabilities" whenever possible.]

Highlights of the History of the Virginia Service System for Individuals with Intellectual Disabilities

An understanding of the evolution of Virginia's system of services for persons with intellectual disabilities is critical to understanding the state's present position as well as the desired direction for the future. Medicaid, created on July 30, 1965 through Title XIX of the Social Security Act, is the health care program for individuals and families with low incomes and resources, and those who meet certain eligibility categories such as aged, blind or disabled. Jointly funded by state and federal government and managed by the states, Medicaid is the largest source of funding for medical and health-related services for people with disabilities. Virginia began receiving Medicaid funding for its large state institutions over 30 years ago. By contrast, community services were funded through general fund dollars from the late 1960s until 1990.

The "Make Waves II" campaign in the late 1980s/early 1990s sought to expand the system of supports for individuals with intellectual disabilities through adding federal Medicaid dollars to existing state funding. When state revenue shortfalls limited the opportunity for expansion, the initiation of the MR Waiver in 1991 converted funding for community services from all state dollars to a mix of state and federal. Due to the budgetary constraints of the time, several important services (dental care and direct behavioral supports) were not originally included in the MR Waiver, others (such as Supported Employment) began to be replaced by more economically viable services and the unavailability of new funding prevented the desired level of services expansion.

Since 2000 several positive events have occurred. The Olmstead Supreme Court decision of 1999 has resulted in Virginia making steps toward promoting the expansion of community services through policy, executive branch support and the exploration of grant initiatives. Agreement was established on the identification of criteria for an *urgent needs* waiting list, with management of the waiting lists for the waiver now done through the CSBs and waiting list information and data reported to DMHMRSAS. One of the largest influx of state dollars into the intellectual disabilities system occurred in 2004, with the release of 700 community MR Waiver slots and 160 slots for persons living in training centers. The new Day Support Waiver was implemented in 2005, with a total of 300 slots. In the last year new rates approved by the Governor and the General Assembly were implemented for the MR Waiver. For a more comprehensive history of the service system, see Appendix A.

Current Status of Virginia's System of Services and Supports for People with Intellectual Disabilities

Administration of the Service System for People with Intellectual Disabilities

The primary responsibility for services to individuals with intellectual disabilities in Virginia rests with DMHMRSAS. The current mission statement of the DMHMRSAS, which echoes the desires of the self-advocates, is:

> "We provide leadership and service to improve Virginia's system of quality treatment, habilitation, and prevention services for individuals and their families whose lives are affected by mental illness, mental retardation, or substance use disorders. *We seek to promote dignity, choice, recovery, and the highest possible level of participation in work, relationships, and all aspects of community life for these individuals."*

DMHMRSAS operates five training centers, or publicly funded ICFs/MR, across the state. Together with DMAS, DMHMRSAS administers the MR and Day Support Waivers, the primary funding sources for community-based services. Case management services, delivered by local Community Services Boards/Behavioral Health Authorities (CSBs/BHAs), are also funded by Medicaid. Case management is required for individuals on the MR and Day Support (DS) Waivers, and also available to Medicaid recipients not receiving Waiver services and through local funding or private pay to individuals ineligible for Medicaid.

Statistical Overview

Funding for the Virginia MR Service System is currently three-pronged and directs:

1. The greatest per person financial resources toward those residing in the state's publicly funded facilities (state training centers) where most residents possess intensive medical or behavioral challenges;
2. Fewer per person resources toward those receiving funding through the MR Waiver; and
3. Little to no resources toward those community residents waiting or ineligible for Medicaid or the Waiver.

The following chart illustrates the services available per funding stream:

	Day Support	Prevocational	Supp. Emp.	Vocational/ Shelt. Wkshp.	AD& CD Respite	Residential	AD& CD Personal Assistance	Skilled Nursing	Asst. Tech & Env. Mods.	Ther. Consult	Crisis Stabilization	PERS	AD & CD Companion	Case Mgemt	Psychiatric	Pharmacy	Nutritional	Social Work	Medical	Psychology	Dental	Phys Therapy & Occ Therapy	Speech & Language	Acute Care & Transport.
State Training Centers	X	X	X	X	X AD only	X	X AD only	X CVTC only	X	X	X			See Soc. Work	X	X	X	X	X	X	X	X	X	X
Community ICFs/MR	X	X	X	X	X AD only	X	X AD only	X	X	X	X			See Soc. Work	X	X	X	X	X	X	X	X	X	X
MR Waiver	X	X	X		X	X	X	X	X	X	X	X	X											
MR Day Support Waiver	X	X	X																					
State Plan Option †														X	X	X			X	X	X *	X	X	X
Local & State Dollars and DRS Funding	X		X	X	X																			

** Available to children only.* ***"AD & CD" = Agency-Directed and Consumer-Directed* *†All State Plan services are available to MR & DS Waiver recipients.*

	State Training Centers	Community ICFs/MR	MR Waiver	MR Day Support Waiver	Local & State Dollars and DRS Funding
Total Annual Cost in FY 2006	$197,872,440	$40,532,655	$410.8 million	$4.3 million	Figures Not Available*
Total Number Served in FY 2006	1,560	337	6,599	227	Approximately 20,000
Average Cost/Person in FY 2006	$126,841	$120,275	$62,296	$18,791	Figures Not Available*

*Data on all local funding not collected by DMHMRSAS.

Design of the Study

Purpose

The basis for this study was Item 302 TT (House Bill 5002), enacted during the 2006 Session of the Virginia General Assembly, which stated:

> *The Department of Medical Assistance Services, in cooperation with the Department of Mental Health, Mental Retardation and Substance Abuse Services, the Virginia Association of Community Services Boards, the Arc of Virginia, and other stakeholders, shall jointly review the current Medicaid home and community-based waiver for persons with mental retardation to determine how the waiver program can be improved to provide a person-centered, individualized support focus. In conducting the review, the Department shall assess the need to upgrade availability of therapeutic behavioral consultation, skilled nursing, medical and other specialized supports for individuals who are served through the waiver. Also, the department shall review successful models of waiver funded community supports used by other states to serve individuals with mental retardation for potential application to Virginia. The Department shall report on its review of the waiver program including recommendations for changes and cost implications by December 1, 2006, to the Governor and Chairmen of the House Appropriations and Senate Finance Committees.*

During the initial phase of the study, the day-to-day management of the MR and Day Support (DS) Waivers was transferred from DMAS to DMHMRSAS. This led to an extension on the final report to September of 2007. During the 2007 session of the General Assembly, the scope of the study was expanded in the budget (HB 1650) to include the entire system of intellectual disabilities services delivery in the Commonwealth with the intended outcome being a series of recommendations to improve the overall system, as specified in Item 311 AA.

> *The Department of Mental Health, Mental Retardation and Substance Abuse Services, in conjunction with the Department of Medical Assistance Services and related state agencies, the Arc of Virginia, consumers, Parents and Associates of the Institutionalized Retarded, the Virginia Association of Community Services Boards, and private providers shall continue reviewing the Medicaid home and community-based waiver for persons with mental retardation, pursuant to Item 302 TT. of this act, to determine how the waiver program can be improved to provide a person-centered, individualized support focus. This review shall include an examination of all aspects of funding the continuum, including Medicaid and Medicaid waivers. In addition, the department shall make recommendations for the development and funding of a full continuum of care for consumers with mental retardation. Recommendations shall be made to the Governor and the Chairmen of the House Appropriations and Senate Finance Committees no later than October 1, 2007.*

This study has coincided with existing studies being conducted related to person-centered planning, recommended by the Office of the Inspector General, initiatives of transformation outlined in House Document 76 of the 2005 General Assembly, and other recommendations related to improving the delivery of services and supports to persons with intellectual disabilities.

The original (MR Waiver-related) questions to be investigated via the study were:

1. How can the current MR Waiver program be improved to provide a person-centered, individualized support focus?
2. Do therapeutic behavioral consultation services need to be more available to MR Waiver recipients?
3. Do skilled nursing services need to be more available to MR Waiver recipients?
4. Do medical services need to be more available to MR Waiver recipients?
5. What specialized supports do MR Waiver recipients need other than those that are currently available?
6. What are other successful models of Waiver funded community supports used by other states to serve individuals with mental retardation?

Methodology Overview

The study design included:

1. Six focus teams comprised of individuals with special interests/abilities in the following areas of focus. Each team discussed the issues related to their area and made recommendations:
    - Behavioral,
    - Medical,
    - Housing,
    - Employment,
    - Waiting List, and
    - Person-Centered Planning.

2. Multiple regional discussion groups held throughout the state involving 242 CSB case managers and providers of services to persons with intellectual disabilities.

3. A telephone survey of 236 recipients (or family members) of MR Waiver services and 95 individuals (or family members) on the Statewide Waiting List.

4. A review of other selected states' home and community-based services (HCBS) waivers for people with intellectual and developmental disabilities.

5. A Steering Committee to coordinate the various facets of the study and provide general direction and guidance.

6. Reporting and discussion of the study to The Advisory Consortium on Intellectual Disabilities (TACID) for periodic review and comment.

Further details of the study design and are included in Appendix B of this report. The Appendices also contain the individual reports from the focus teams, discussion groups and individual/family surveys.

Study Findings

The Positive Impact of the Current Service System for People with Intellectual Disabilities

Individuals Receiving Funding through the MR Waiver

1. The promotion of choice

- The MR Waiver provides an alternative choice to an ICF/MR.
- Those choosing MR Waiver have a choice of supports to meet their needs from a broad menu of Waiver services and a choice of service providers within each service. Participation in the MR Waiver enables some individuals not otherwise eligible for Medicaid to access State Plan services.
- When a slot is available, MR Waiver allows long-time community residents to remain in their community when elderly caregivers die or are no longer able to support them, or provides needed support for a family to permit one or both parents to continue to work and support their family.

A middle-aged Fairfax-Falls Church man had lived with his now octogenarian parents for most of his life. As they became more infirm, they moved him into an apartment and they moved into an Assisted Living Facility. The CSB provided some in home residential services. His parents and brother also provided support to him. Unfortunately, as their health deteriorated, his parents were unable to be of any assistance to him and his brother was not often available. The man began to suffer depression and his functional abilities decreased. It became clear that he needed much more support and additional training. A Medicaid Waiver slot was assigned. The man is now moving into a barrier-free group home with other men. He will have increased community integration, social interaction, is returning to a day program and has staff support that is desperately needed to maintain his health and safety.

Assignment of a MR Waiver slot to a 13-year-old Fairfax-Falls Church child has prevented Foster Care placement. The mother is a single, working parent with two other children. She was unable to meet the needs of all three children and had decided to seek relief of custody of the child with intellectual disabilities because she has been focused primarily on that child. The case manager has located a group home that will provide the needed supports to this child. Now the mother and siblings will be able to visit regularly as it is close to their home. The mother will retain parental rights, be directly involved in decisions about care and training and be able to support her other two children in an improved manner.

The whole family will benefit because of the MR Waiver.

- Slots are highly portable and move with individuals to locations within the state where they want to live, close to family and friends, or where services or providers of interest are available.

- MR Waiver supports individuals who have lived in a training center, private ICF/MR or skilled nursing facility to live successfully in the community with the proper supports, if they so desire.

A Carroll County woman with very significant intellectual as well as visual and hearing disabilities had been institutionalized since the age of 8, for a total of 53 years. Upon arrival to her new community home through the MR Waiver about ten years ago, she was very withdrawn and solitary, hiding and cowering in the corner when addressed. She required significant assistance with toileting and ate with her hands. She hoarded and hid food in her bra and bedroom and would often take food from the trashcan. She did not speak for many months. She had very few personal belongings and no family contact upon admittance.

This woman, who is currently 70 years of age, now expresses her needs and desires and is a very loving and warm individual. She talks very openly and hugs staff and her housemates frequently. She enjoys going out into the community, dining out and one of her favorite activities is shopping (particularly for shoes!). She now has family contact and is planning to take a trip this fall with staff to visit her family members over five hours away. She receives gifts and cards in the mail from her family members and is pleased to receive them. She has gone on several vacations since living in the group home, including trips to the beach and Pigeon Forge, Tennessee. She seems very comfortable that this is her home.

2. Services are highly individualized and tied to identified needs of the individual

- Funding for environmental modifications and assistive technology is available for individuals enrolled in the Waiver who need structural or technological modifications to be able to navigate their home or community.

The assignment of a Medicaid Waiver slot to a 49-year old Fairfax-Falls Church woman who uses a wheelchair and needs much physical assistance with bathing, dressing, and applications of topical medications has allowed her to return home to live with her mother. The mother has had a number of back surgeries and is no longer able to provide the physical support that her daughter needs. They have a wonderful and loving relationship. The woman was in a respite placement during her mother's recent surgery and recovery. Now she receives in-home residential supports, both in-home and out-of-home respite, attends day support through the Waiver, and has Medicaid transportation. The case manager is working closely with mother and daughter to identify Assistive Technology which might improve her quality of life. The apartment is barrier free but there may be some additional Environmental Modifications needed. Her mother is so happy to have her back in the home and the wonderful smile on daughter's face was a reward for all who know this family. The mother has the added relief of knowing that should she need to move to a group home someday, the resources will be available for her daughter.

- Some individuals with complex medical needs are being successfully supported in the community in areas where Skilled Nursing services or nurses willing to appropriately train and monitor non-medical personnel (through nurse delegation) are available.

A 46-year-old man residing in Petersburg has no family members and his health has been failing. His medical problems were too advanced for the staff at the Assisted Living Facility (ALF) where he lived to manage. This resulted in multiple hospitalizations. Further, he had no socialization outlets or community integration opportunities while at the ALF. He had no motivation to participate in activities and there were no activities to meet his needs. He spent 4 months in the hospital awaiting a more appropriate set of supports.

He was given a MR Waiver slot and now is receiving appropriate medical care as well as close monitoring of his condition from his group home staff. In addition, the staff at his new group home are providing him supports to enhance his socialization and community integration opportunities. He is scheduled to soon begin participating in Day Support services to further address his needs. Without the waiver slot, this gentleman's health would have continued to be in jeopardy, he would not have had a home and no one to provide the supports that he needs.

- Services grow and change with the individual in the MR Waiver (e.g., due to increased medical needs, graduation from high school, aging or personal preferences).

One rural county in the Middle Peninsula/Northern Neck area had two children in very expensive residential placements who were over 18 years of age. Both were recipients of Waiver slots in July and one has moved and the other will soon be moving back to their home communities to a group home. The two individuals can benefit from being back in their home community, closer to friends and family, and the county saves the CSA funds that were being spent on the residential placement. The group home is a much more adult environment for these two young adults.

3. Flexible management of resources tailored toward individual needs

- Community-based services, offered through the MR Waiver, afford the opportunity for relationship building between persons with intellectual disabilities and community members without disabilities, to the benefit of both groups. The accessibility of natural supports (those available to all community members) to individuals receiving MR Waiver services enhances the lives of the individuals and maximizes the publicly-funded supports offered through the Waiver.

- Respondents to the MR Waiver individual/family survey rated Personal Assistance, Respite and Residential Support as the most helpful services under the current Waiver for themselves or their family member, with these same three services being viewed as having the highest degree of individualization and flexibility.

- Providers must comply with a variety of regulations to ensure that individuals' health, safety and medical needs are being met, regardless of funding source.

4. Resources are managed by DMHMRSAS and DMAS in an ethical and efficient manner

- The division of the Statewide Waiting List into urgent and non-urgent, with the requirement that individuals with the most urgent needs are served first, ensures that Waiver slots, when they come available, are allocated at the local level to those with the greatest need. This is considered to be an ethical means of managing limited resources for community-based services, as well as being a person-centered triage method.

- Changes and improvements in the system of service are more fluid as new technology is developed nationally and there is more individual ownership of the services by the persons and families who are using the services.

Individuals Receiving Funding through State-Operated ICFs/MR (State Training Centers)

1. Family security

- Family members of individuals residing in the state's training centers have expressed that the most important aspects of their choice of a training center service delivery setting are the availability of medical and therapeutic professionals, recreation activities, individualized activities, peer socialization, community involvement on and off the training center campus, and intensive oversight and monitoring of the wellbeing of their family member by multiple oversight organizations. In addition, direct operation of the facilities by the Commonwealth is viewed as resulting in more secure and consistent service delivery.

- Training centers are designed by regulation to ensure that all the health and safety needs, as well as identified service goals are addressed.

2. Limited economy of scale

- For some of the individuals who have extensive support needs that can only be addressed by highly trained medical and professional staff, there is an economy of scale built into an institutional environment that is difficult to duplicate in the larger community.

3. Provision of services not yet fully implemented in the community

- The training centers continue to receive requests for admission from individuals who have found that the supports they have received in the community have not met their needs due to their level of medical and/or behavioral issues, or due to the unavailability of a Medicaid Waiver slot when they reach a crisis point. Many of these individuals are admitted on a short-term basis for temporary support until they can return to a community setting. Others, for whom the training center is the least restrictive choice for maintaining a stable medical or behavioral condition, request a longer-term admission.

A 63-year-old woman living in Lynchburg had moved to the community 15 years ago, after residing at Central Virginia Training Center for 20 years. She had managed to live fairly independently in an apartment with a roommate for 14 years. She loved her independence and refused the help of others. During the past year, her health had deteriorated to the point where she was having seizures and would be found wandering the streets of Lynchburg in unsafe situations. Despite recently receiving a waiver slot to help support her community placement, she was refusing services. She was now living alone in her apartment in unsafe and unsanitary conditions and was unable to care for herself. She agreed to move to CVTC temporarily to keep her in a safe and supervised environment while waiting for guardianship services to become available to her to help in making better arrangements for her in a waiver funded community setting.

- Respite services are also provided through the training centers for individuals whose families need temporary specialized services and supports.

- Recent funding by the General Assembly for four Regional Community Support Centers (RCSCs) represents a positive step that will take the system closer to one of the goals of House Document 76: utilizing the training centers to support individuals residing in Virginia's communities. The training centers, through the RCSCs, will serve as a valuable resource for dental, therapeutic behavioral and other specialized services for those community residents. In addition they offer educational and training opportunities for the next generation of clinicians in specialized internships, externships and practicum experience.

Individuals Receiving Funding through Non-State Operated ICF/MR

Potential for growth of homes to meet emerging need

- Under current regulation, any potential provider with sufficient capital to invest up front for construction can initiate an ICF/MR of up to 12-beds without receiving prior funding allocation approval (as opposed to the MR Waiver that requires the allocation of a funded slot). If the provider can find enough people who qualify for Medicaid services, meet the ICF/MR admission requirements and want to opt for ICF/MR services rather than a Medicaid Waiver slot, they can establish the service upon licensing by DMHMRSAS and certification by the Department of Health.

- This service has the potential for bringing a level of service similar to that currently found in the training centers to more communities.

Individuals Who Are on the Waiting List or Who Do Not Qualify for the MR Waiver

1. CSB services

- State Plan Option Targeted Case Management Services are available to all who qualify for Medicaid and have a diagnosis of mental retardation.

- Case Management services are provided on a sliding fee scale for all persons who qualify and have no other third party source of payment.

- Some CSBs have local tax dollars and some state general fund dollars that allow them to provide limited services such as: family support, respite care, day support, and employment services.

2. Other Medicaid Waivers

- Some individuals on the MR Waiver Waiting List may also qualify for other Medicaid Waivers, primarily the Elderly & Disabled with Consumer Direction (ED/CD) Waiver and receive services through that Waiver while waiting for the MR Waiver. The ED/CD Waiver is much more limited in scope of services than the MR Waiver and thus rarely meets the full needs of those who are waiting for the MR Waiver.

A 44-year-old man residing in the Emporia area has profound intellectual disabilities. He lives with his elderly mother who has health concerns of her own. His mother did not realize the full advantage of a MR Waiver slot, but advocated for her son to receive services through the ED/CD Waiver. Unfortunately, the family experienced problems with keeping workers due to staff, who were not trained to work with individuals with intellectual disabilities, being afraid of this man. This resulted in his staying at home with his mother during the day and having no opportunities for socialization or recreational activities with others. His mother reports that he was very sad and agitated during this time. Obviously, this became a very stressful situation for both family members.

As a result of obtaining a MR Waiver slot, this gentleman is now receiving Day Support and may soon also be receiving in-home residential supports. His mother is very grateful for the Waiver slot and now realizes how important it is to her son and the positive impact it has on their lives. He now appears to be very happy attending his Day Support program and misses it on days when he does not go.

3. DRS funded services

- DRS funds Extended Employment Services, Long Term Employment Support Services, and Supported Employment for individuals who qualify for these supports.

4. Services through local philanthropy and other sources

- Some individuals receive needed assistive technology (e.g., eyeglasses, hearing aids, etc.) through local charitable organizations.

- A few individuals are fully supported privately or through non-Medicaid state or local funding.

An example of the success as well as the limitations of philanthropic funding is a 25 year-old man from Spotsylvania County who graduated from high school four years ago and has been on the statewide waiting list since July of 2003. He is fortunate to be able to attend the Rappahannock Adult Activity Center four days/week due to funding from the Rappahannock United Way. This permits his mother, who is the sole supporter of the family, to work those four days.

This man would very much like to participate in Day Support five days/week and with the MR Waiver he would be able to do that. In addition, the waiver would allow him to utilize Medicaid funded transportation to and from day support instead of having to be dropped off and picked up by his mother, further reducing her work hours. His receipt of full-time Day Support services would also enable his mother to work full-time, further improving their family's financial situation.

Gaps in Services and Barriers to a Desirable Service System as Identified by Providers, Individuals and Family Members

MR Waiver

1. Insufficient Funding for MR Waiver Slots and Reimbursement for Services

- The extended period of time in the 1990s with minimal or no increases in reimbursement rates for many of the waiver services caused providers to be unable to keep up with cost of living increases. This has led to larger groupings of individuals in some residential and day support environments decreasing the staff-to-recipient ratio. It is particularly difficult, given present reimbursement rates, to support individuals in smaller, more individualized settings where the development of community connections can occur and individuals with challenging behavioral and medical needs can receive more intense supports.

- Though recent rate increases have allowed some wage and benefit increases, the comparatively low reimbursement rates for many of the services make it difficult to attract and retain qualified staff and highly trained professionals.

- Because of limitations in the number of slots and large waiting lists, slots are allocated almost immediately upon receipt and critical needs that arise later during the year are difficult and sometimes impossible to successfully meet.

One CSB director of mental retardation services shared the experience of having one waiver slot to assign to an individual on their Urgent Needs Waiting List that consisted of 37 individuals. The director reviewed the profiles of the 37 individuals and divided them into three groups based on perceived urgency of need. One ranked "low urgency," 12 ranked "medium urgency" and 24 ranked "highly urgent." Of the 24 individuals that ranked highly urgent, the director further attempted to divide the individuals based on level of urgency of need. This highly difficult exercise resulted in five lower urgency, twelve medium level urgency and seven most highly urgent. The seven who ranked most highly urgent ranged in age from 8 to 82. All seven of them met more than one of the urgent needs criteria. Two of them met all seven criteria on the Level of Functioning Survey (an eligibility determining tool). Several had long lists of medical issues, and each individual's list of overall needs was impressive.

The CSB slot selection committee reviewed all seven highly urgent needs individuals and chose one individual to receive the slot.

One family in Petersburg includes three boys, six-year-old twins who have been diagnosed with severe intellectual disabilities and their 13-year-old brother. In order to meet the needs of the twins, the mother stays home as their full time caregiver. Because the mother is thus unable to work outside of the home, the father must work 50-60 hours a week to meet the economic needs of his family. The older brother, who obviously also needs attention from his parents, is often left to fend for himself as the demands of the six-year-olds leave little time for his parents to spend with him. The family has been in dire need of in-home supports and respite for the twins so their family can stay functional.

After five years on the waiting list, **one** MR Waiver slot recently became available to this family. Imagine the parents' dilemma in trying to provide input to the slot assignment team to help determine which of the twins should receive the slot.

The one slot made a difference for this family; however, they continue to struggle because in order to meet the needs of both boys an additional slot is required.

- The practice of allocating slots to individuals still in the community system and to specific training centers can cause some individuals in a mental health hospital, a nursing home, or the other training centers to remain in those settings longer than the individual needs or desires to live in that environment.

- The lack of funding for "general supervision" (time when staff are with individuals to ensure their health and safety, but not actively engaged with them in Residential Support services) prevents Waiver recipients from normal-paced lives, including unstructured time. Also, it further diminishes the already limited reimbursement rate by requiring providers to pay for staff without any source of funding.

- Medicaid does not fund the psychological evaluations required by regulation for determining Waiver eligibility.

2. Limited provider capacity for certain services and in particular geographic areas

- There is a lack of providers, particularly in certain geographic areas. This may be due to low reimbursement rates for certain services or the lack of certain qualified professionals (i.e., psychologists, endorsed PBS facilitators, nurses, etc.) choosing to reside in certain regions. Although an individual's slot may go with him as he moves around the state, there is no guarantee that comparable services will be available in his new location.

- There is an overall shortage of qualified Behavioral Consultation providers and a lack of knowledge of good behavioral practices among the direct support staff pool. The few behavioral experts within our state are prevented from serving the entire state because neither travel time nor telephone consultation is reimbursable. A number of providers with highly qualified staff provide the necessary support without reimbursement to avoid the burdensome requirements and paperwork.

The need for increased availability of Behavioral Consultation and crisis services is illustrated by the situation of the 12-year-old boy with intellectual disabilities in Henrico County who engages in impulsive and risky behavior including inserting knives and other metal objects into outlets, cutting telephone wires into the house, breaking and cutting objects in the home and knocking down beehives. The primary caregivers have inquired about relinquishing custody of this boy because of the unremitting stress of the situation and the recognition that the behavior is uncontrolled and dangerous.

- There is a lack of capacity within our state to deal with critical behavioral situations, causing an over-reliance on expensive out-of-state placements or potentially unnecessary institutional placements. The average annual cost to the Commonwealth of an out-of-state placement is $122,856.

3. Lack of affordable housing statewide

- There is a very limited number of affordable, accessible, community housing units for persons with intellectual disabilities and a lack of transitional funding to pay rent/mortgage prior to individuals qualifying for existing state and federal funding. There exist even fewer housing resources to support children and youth, as well as individuals with behavioral challenges.

- The recently released national study, "Priced Out in 2006,"[2] found that, "In 2006 national average rents for modest studio and one-bedroom units are now, for the first time, higher than SSI monthly income." In fact, the Washington, D.C. metro area (which includes Northern Virginia) was found to be the second highest-cost local housing market area in the country at 188.1 percent of SSI needed to rent a one-bedroom apartment. Virginia averaged 128.4 percent of SSI required to rent a one-bedroom apartment, higher than the national average of 113.1 percent.

4. Insufficient and unaffordable medical services for community residents

- There is a need for better coordination between an individual's health care provider and non-medically trained MR Waiver direct support staff in relation to medical issues.

- Many community health care providers do not accept Medicaid due to the low reimbursement rates and high paperwork requirements. Those who do usually have a quota of the number they will accept and little expertise in working with persons with intellectual disabilities.

- There are too few Skilled Nursing providers under the MR Waiver, due to low reimbursement rates, a lack of knowledge about/experience with individuals with intellectual disabilities among nurses and the statewide shortage of nurses. Currently in Virginia there is about an 8,000-person gap between the demand for full-time RNs and the supply of full-time RNs needed. The National Center for Health Workforce Analysis projects that over the next decade that gap will only continue to widen, so that by 2020 the shortage of full-time RNs will approximate 26,200 persons, leading to 37 percent of the demand going unmet. Particularly critical areas of demand in the state are will be in the Northern and Tidewater regions.[3]

> One medically fragile child in rural Middle Peninsula had a Waiver provider of Skilled Nursing for only three weeks during the summer even though she was authorized for the entire summer. The provider agency could not keep nurses employed because of the comparatively low rate of reimbursement.

- Dental services for adults are unavailable through Medicaid, leading to a higher prevalence of expensive procedures necessitated by years with lack of dental care and/or added costs for the CSB or the residential provider who takes the responsibility for obtaining the needed care at their expense.

- The lack of clarity regarding medical guardianship can be a barrier to receiving needed health care.

5. Insufficient services for persons with both a mental health and intellectual disability, particularly if the individual also has legal involvement

A 24-year-old Stafford County woman with intellectual disabilities and serious mental illness lives at home with her mother and step-father and works at Rappahannock Goodwill Industries two days a week. She has a great deal of difficulty staying awake due to her psychotropic medication and is thus in danger of losing her job, which means that she will be at home with her mother all day. The family engages an In-Home supports provider, who spends up to 25 hrs./week helping her learn daily living skills, but does not leave the house with this young woman. The staff change frequently and must be monitored by the family.

When at home, she disassembles furniture, computers and appliances and rips electric cables out of he walls. She steals food and overfills her mouth as she eats, aggravating a weight problem already exacerbated by her medications. She frequently soils herself, although she knows how to use the bathroom. She has eloped from the home, sometimes without clothes. In mid-winter, she packed up her possessions and went outside to the woods behind the house to live. She has violent, psychotic episodes. On an almost daily basis, she packs up her room into boxes and says she's "going to a group home."

6. Lack of support for paid employment opportunities in the community

- Under the current MR Waiver reimbursement rate structure, providers are paid more for Day Support than for developing employment opportunities that would lead to individuals with intellectual disabilities becoming tax-paying citizens. Thus, most individuals in the MR Waiver do not have access to Supported Employment services. As opposed to the original MR Waiver reimbursement rate of $65 for any full day an individual was successfully employed (regardless of what support was provided that day), the current rate of $17.64 per hour of job coach intervention ($20.29/hour for Northern Virginia) pales in comparison.

- The decrease in the number of Virginians with MR utilizing the Individual model of Supported Employment was an unintended consequence of the implementation of the MR Waiver. In addition to the implementation of a significantly lower rate for Individual SE at the onset, the MR Waiver requires individual SE providers to be DRS SE vendors in order to ensure minimum quality standards. However, state procurement law precludes providers from charging different rates to two agencies of the Commonwealth. DRS individually negotiated rates are significantly higher than MR Waiver Supported Employment rates (from $30.82/hour to $69.16/hour, with an average cost of $50.34/hour). As a result, a vendor of individual Supported Employment must choose between providing services to individuals through DRS and the MR Waiver.

7. Person-centered practices are found only in pockets across the Commonwealth

- Virginia currently lacks a majority of providers demonstrating person-centered thinking and knowledge, skills and abilities in person-centered planning, and using available tools to help individuals and their teams.

- There is a lack of balance between the need to address issues of liability and the protection of health and safety with the need for individuals to experience *the dignity of risk* associated with real life at home and in the community.

- There is a lack of circles of supportive individuals (not paid professionals) in the lives of people with intellectual disabilities across the state.

- Individuals with intellectual disabilities rarely have the opportunity to choose where and how they live, with whom, who supports them and how they are supported. In short, they experience very little control over their own lives.

- There exists a pervasive assumption of inability vs. ability when considering individuals with intellectual disabilities. This leads to approaching service delivery from a deficit-fixing/training/clinical mindset, rather than identifying strengths and offering supports to assist individuals achieve a good, comfortable life. Traditionally, Medicaid has been a medically-based program designed to "treat" individuals with health problems. Requirements for assessment, service planning, documentation and review have all been predicated on "fixing a problem."

- In place of educational resources for providers and state regulators about the importance of intimacy and healthy relationships in the lives of those with intellectual disabilities, there is more routinely the imposition of providers' and decision-makers' personal beliefs or interpretation of the law about these topics on the individuals whom they support.

8. Limitations in necessary supportive services

- The transportation system, currently a brokerage system funded by Medicaid, has the following commonly occurring problems: individuals are often left waiting, sometimes alone; they may ride vans for inordinately long periods of time; and they are not able to use this system for non-Medicaid-funded destinations such as community employment, necessary shopping or leisure activities.

- Preauthorization of MR and DS Waiver services is a lengthy, labor intensive, paper-driven process with no room for errors in submission dates, allowances for extenuating circumstances or support for person-centeredness and self-direction.

Day Support Waiver

- Services have been added to this Waiver which was designed by the General Assembly to be limited in scope; however, due to its structural limitations in scope and nature of services, the DS Waiver does not grow with the individual as his/her circumstances change.

One 20-year-old Chesterfield County resident recently received a Day Support Waiver slot. The family accepted this waiver and is able to utilize it for after-school supports. Unfortunately, when he graduates, Rodney's waiver will not "grow" with him. He is on the waiting list for the full MR Waiver and is in need of in-home supports. His family would like to have him live at home as long as his severe behaviors can be managed. The day that he may need to move out of his family home is sadly and quickly approaching. Rodney's family feels that his Waiver funding should "grow as his needs grow" and become a full waiver.

- These slots are not presently helpful for people who need other supports during the day, such as Companion, Respite, or Personal Assistance services.

State Training Centers

- The training centers currently average 50 years old, and are beginning to show signs of their age. Some need significant physical plant improvements to ensure the continued health and safety of their residents. For example, at Southeastern Virginia Training Center (SEVTC), roofs, heating systems, plumbing and HVAC ductwork need replacement. Central Virginia Training Center (CVTC) has many residential buildings lacking sprinkler systems or emergency generators and the underground telecommunications line, which are part of the fire alarm system, are not only inadequate to meet today's needs but commonly fail. Furthermore, the needs of training center residents have changed over time, as more individuals are served in the community. For example, when SEVTC was originally constructed, the living units were designed to house individuals with only minimal physical disabilities. They are now housing people with significant physical disabilities, resulting in insufficient storage space for needed adaptive equipment and lack of fully accessible bathroom facilities and kitchens.

- The full efficiencies to be gained from creating smaller training centers geared to individuals with the most critical needs (both training center and community residents in need of specialized services) have yet to be realized for a variety of reasons, including family/guardian choice for ICF/MR services and a lack of MR Waiver services for individuals with the most intense needs.

Services to Persons on the Waiting List or Who Do Not Qualify for the Waiver

- During the past 15 years, the system has come to rely so heavily on Medicaid Waivers for individuals with intellectual disabilities wishing to remain in the community that those ineligible or waiting for the Waiver have few to no supports at all.

A man with intellectual disabilities recently moved from Northern Virginia to Roanoke. He was not placed on the waiting list in Northern Virginia due to the availability of non-waiver services to meet his needs. He is now in need of a Waiver slot because in Roanoke there are few options for persons without Waiver. The family is concerned because he currently does not have opportunities for meaningful relationships and seems to be regressing in his ability to communicate and socialize. This individual's move to a rural area has made Waiver services more necessary and vital to his well-being.

- As of September 10, 2007, there were 3,749 individuals diagnostically and functionally eligible for the MR Waiver who are unable to access needed services because of a lack of available slots. These individuals are on the Statewide Waiting List. Of that number, 1,849 individuals are on the Urgent Needs portion of the list, meaning that they would not only accept services in 30 days, but that they have an aging or disabled caregiver, are at risk of homelessness, abuse, neglect or exploitation, or present extraordinary challenges to their caregiver due to the extent of their physical or behavioral needs.

- The respondents to the individual/family member survey who are on the Statewide Waiting List overwhelmingly indicated a need for otherwise unavailable residentially-based supports (Residential services = 86 percent, Respite = 72.6 percent and Personal Assistance = 71.6 percent).

- Three fourths of the individual/family member survey respondents indicated interest in the Waiver because they or their family member required medical supports.

- The average length of time on the Waiting List (per the individual/family survey) is 28 months; although, for many individuals (particularly those on the non-urgent needs portion of the list) the wait is significantly longer.

43	individuals have been waiting 7 years
189	individuals have been waiting 6 years
160	individuals have been waiting 5 years
317	individuals have been waiting 4 years
480	individuals have been waiting 3 years

- The long wait for needed supports may result in the erosion of previously learned skills, physically unhealthy inactivity, boredom that may in turn lead to challenging or even illegal behavior and prolonged financial and emotional burdens on the family. The number of individuals on the waiting list, combined with the length of time spent waiting, illustrates the depth of the need for expansion of service capacities throughout the state.

An illustration of the above system problem is the situation of a 23-year-old Spotsylvania man who graduated from high school one year ago. This man has intellectual disabilities, significant physical disabilities that necessitate a wheelchair for mobility and only communication through gestures. Because there was no funding for Day Support activities that would have allowed him to continue to participate in the community on a daily basis, his ability to enhance or even maintain his abilities is stymied. He is totally reliant on his mother for transportation, and she is unable to work because she now has full-time responsibility for him. This results in a depleted financial situation for the family. He has been on the urgent needs waiting list for 18 months.

Current Demographics that May Predict Future Funding/Services Needs

- Studies estimate that between 1 percent and 3 percent of Americans have mental retardation.[4] Given that the 2006 population estimate for Virginia is 7,642,884, we can extrapolate that between 76,429 and 229,287 of state residents have intellectual disabilities.

- As of December 1, 2006, there are 10,988 individuals diagnosed with intellectual disabilities between 3 and 22 years old being served by educational programs in Virginia[5]; 1,702 of these are between the ages of 18 and 22 ("transition-aged") and likely to need adult services very soon. An additional 8,533 children under six years of age are diagnosed with a developmental disability, some of whom will doubtlessly later qualify for services for persons with intellectual disabilities.

- National statistics estimate that 1.9 million people with developmental disabilities live at home with a family member and over 25 percent of these households include a parent or caregiver over the age of 60. A significant portion of these caregivers will be aging beyond their ability to continue in this role in the next 10 to 20 years.[6] The aging of family caregivers, combined with the aging of people with intellectual disabilities (including longer life spans as a result of medical technology) are factors in the increasing size of the MR Waiver waiting list, predictors of an ongoing need for more MR Waiver slots and a guarantee that higher levels of support will be needed as individuals age.

A Rockbridge County man of about 70 years of age lived with his 91-year-old mother. He had some home health care services and was on the MR Waiver waiting list for about 4 years before his mother had a stroke one weekend. He was fortunate that a MR Waiver slot was available soon after. He is now residing in a group home and receives Skilled Nursing services for his medical needs. Without the Waiver, he would likely be in a nursing home.

Another Rockbridge resident, who is also 70, lives with her 95-year-old father. She is anxious that she'll have to move when her father is no longer able to care for her. Because she has some mental health issues in addition to her intellectual disabilities, finding an appropriate community residence will be doubly difficult.

- In addition to the individuals who are currently being served or are on the Statewide Waiting List, 13,500 more community residents have been identified by CSBs but presently do not qualify for Medicaid or have not yet indicated that they would accept services in 30 days if offered to them (a Statewide Waiting List criterion). Their status could change at any point due to a breakdown in present supports that initiates a crisis and leads them to request services only to have their names placed on the Statewide Waiting List.
- Presently, some of the 13,500 individuals who do not qualify for the MR Waiver could benefit from some supports to enable them to work, volunteer or socialize during the day. The family members of some of these individuals are in need of respite or other ongoing assistance in order to maintain the individual in their home.

CMS Funding Initiatives

In addition to the basic components of our service delivery system, there are several CMS-funded initiatives underway currently in Virginia that involve the collaboration of a wide variety of stakeholders, and should result in facilitating some of the desired outcomes expressed in this report. These include the Systems Transformation Grant (STG) and the Money Follows the Person Demonstration project (MFP).

The five-year STG involves DMAS, DMHMRSAS, the Office of Community Integration, the Virginia Department for the Aging and other long-term supports stakeholders. Its overarching goal is to make significant improvements to Virginia's long-term support system so that citizens have a more simple, meaningful and integrated access to needed services. This will hopefully move the system closer to the vision of "One Community" (developed by the Olmstead Task Force) that welcomes individuals who are elderly or disabled and supports them as active and productive citizens. The grant has as its working goals:

(1) The expansion of a web-based, one-stop-system called "No Wrong Door" from supporting only seniors to also becoming a statewide program that serves Virginians with a variety of disabilities. This system will determine eligibility for various types of assistance, provide information about services and availability, track individuals' progress, measure the effectiveness of services and identify gaps;

(2) Making person-centered planning and self-direction simply the "way we do business" in Virginia though regulations/policies revisions, training/technical assistance efforts, and implementation incentives; and

(3) Transforming our information technology system so that the day-to-day processes of enrollment, preauthorization and waiting list submissions for the MR and Developmental Disabilities Waivers become accomplished electronically through the Internet, versus the current cumbersome, paper-driven processes.

The four-year MFP Demonstration project is another collaborative effort involving many of the same agencies as the STG. Through this project, CMS offers enhanced waiver match funds (75 percent vs. 50 percent) for supports delivered during the first year a former resident of a nursing facility, ICF/MR or long-stay hospital (LSH) resides in a small (four or fewer unrelated persons) community home. One goal is to enable 440 individuals with intellectual disabilities over a four-year period to exit institutions in favor of receiving supports in the community as well as enabling more than 500 individuals with physical disabilities, seniors or others to leave nursing facilities to live in the community. The work of this project is supported by the creation of a housing task force with broad-based membership, which will be established to focus on expanding affordable and accessible housing opportunities for people with disabilities and seniors. This effort is consistent with the goals of the project and in recognition of the significant barriers the current lack of appropriate, accessible and affordable housing pose for these individuals. The project also dovetails with the STG and some of the recommendations of this report in terms of listing priorities of utilizing the "No Wrong Door" system to enhance informed decision-making, incorporating person-centered processes into the transition plans and supports, and increasing consumer-directed options and individualized budgeting for those exiting the institutions.

RECOMMENDATIONS FOR SYSTEM CHANGE

The recommendations are divided into three sections and are advanced to ensure that Virginia continues to develop and fund an individual, person-centered system of supports. The recommendations reflect the need for important changes to Virginia's system of supports for persons with intellectual disabilities that have been recommended by self-advocates, family members, advocacy organizations, and other stakeholder groups who participated in the study.

The provider discussion groups held in eight locations in Virginia, the telephone surveys of families and individuals receiving services and on the waiting list for services, and the six work groups identified an extensive list of comments and recommendations. The resulting recommendations are a direct outcome of the study findings. Each section is introduced by related narrative discussion.

It should be noted that the purview of this study required "examination of all aspects of funding the continuum" and, "to make recommendations for the development and funding of a full continuum of care for consumers." Subsequently, any recommendations for funding included in this document were made by the involved stakeholders within those parameters and without regard to current budget constraints and competing priorities for the Governor and General Assembly.

Section I includes recommendations designed to promote a comprehensive system of support and services that is responsive to individuals with intellectual disabilities and their families.

Section II recommendations address person-centered practices that are critical in the systems shift from a program approach to an individual approach of support.

Section III recommendations improve infrastructure and quality.

Section I

Twenty-one Priority Recommendations Necessary to Achieve and Maintain a Responsive, Fiscally Efficient, and Comprehensive Support Delivery System

This study identified a large array of needs that are still prevalent in Virginia's system. There were many recommendations made by the stakeholder groups. This document will outline these recommendations beginning with the top 21 priority recommendations that, if implemented as a whole, would clearly address the needs of

Virginia citizens with intellectual disabilities in a systematic, understandable, and defendable manner. These 21 recommendations are not in order of priority, but rather are all critical to move Virginia from its present position of unmet need to one in which the most critical needs are met and individuals and family members have the support when and where they need it. Each recommendation represents a number one priority to some individual and his/her family. A subset of these 21 priorities are **five core recommendations** that have the potential to most dramatically shift our system from one that maintains a growing waiting list for services and fails to address the needs of others who do not qualify for waiver or ICF/MR services to one in which the most critical needs in our state are more effectively managed.

Five Core Recommendations that Represent Investing in Community Infrastructure, Supporting Those Currently Without Services and Moving People Out of Waiting List Status

Individuals Who Are "Urgent," Eligible and Waiting for Services and Supports

Individuals who meet the criteria for the urgent needs waiting list must be assigned Waiver slots before individuals on the non-urgent waiting list. The urgent waiting list has been growing by 580 individuals per year for the past three years. If this list is ever to become manageable, Virginia needs to mount an aggressive program for an extended period of time that provides funding for community-based services that exceeds the growth rate of the need for these services. The minimum level of full Waiver slots that is necessary to be funded on an annual basis to achieve manageable status of the urgent needs list is 800 community slots per year.

At the rate of 800 community slots per year, it is estimated that it will take approximately four biennia to meet the needs of all individuals who are on the urgent needs waiting list and begin to address the needs of the individuals on the non-urgent needs list. The following factors need to be considered when projecting future needs:

- The average cost of an MR Waiver slot is currently $62,296 (including case management, acute services, and transportation). In FY 2006, 56 percent of the MR Waiver service plans included congregate residential services while 62 percent of the total MR Waiver funding was spent on congregate residential services.
- A more aggressive funding of community Waiver slots will give greater access to more individuals whose needs have not reached critical levels necessitating out-of-home placements or other forms of congregate residential services. Supports provided to families while their family member lives at home relieves the overwhelming burdens that are currently often placed on families that lead them to seek earlier out-of-home placements.
- The more that services that can be provided to families at an earlier time, the more likely that they will opt for services to support their loved one in their own home, resulting in a leveling off and even a possible drop in the average cost of the

community Waiver slot (the family survey indicated that 71.6 percent of respondents to the waiting list survey indicated they wanted their family member to continue to live at home).

- The DMHMRSAS is currently piloting an assessment instrument developed by the AAIDD, called the **Supports Intensity Scale**, which is being used by other states to project resource needs of individuals who are receiving services. This instrument, if adopted by Virginia, could also be used in a similar fashion so that the Commonwealth's funding resources could be allocated to each individual based on identified needs, thereby making the cost of MR Waiver slots more accurate and predictable. This instrument should be ready for use in Virginia by FY 2010.

Individuals Who Are Waiting for Training Center Renovations and Community Capacity

In Fiscal Year 2006, the Governor and the General Assembly passed legislation that substantially increased in the capacity of the community to deliver services. They also requested a study to determine the costs of re-building CVTC and SEVTC at a size that would serve approximately half their census at that time. The cost estimates for the re-building of the training centers have proven to be substantially higher than the original estimates. At the same time, the Commonwealth has experienced difficulty moving individuals from the training centers into community homes at the rate that had originally been anticipated. Reasons that are most often cited for the slow transition of persons from training centers are:

- Lack of parental consent because of the belief that the state-operated facility offers a higher probability of permanence than the Medicaid Waiver system, offered through the CSB and private provider network, does not.
- The inability or unwillingness of many of the community providers to adequately serve individuals with high intensity medical and behavioral challenges.
- The fact that ICFs/MR cover dental services for adults and general Medicaid coverage does not include dental services for adults in the community.
- The belief that there is less oversight in the community system than in the state-operated system.

House Document 76, written in December of 2005, called for the reinforcement of the community infrastructure to enable persons with all levels of intellectual disability to have better choices should they wish to remain in their home communities while re-focusing the direction and the emphasis of the supports and services of the training centers. The vision for the training centers as established in HD 76 as smaller, more efficient operations that serve individuals with the highest level of need, while also maintaining a mission to reinforce the supports available to persons living in the community continues to be the direction that the DMHMRSAS is taking into the future. It should be noted that the Commonwealth has not heretofore made significant capital investments in building *community* infrastructure for persons with intellectual disabilities.

State capital expenditures for the construction of small community homes that would serve both former facility residents and community residents obtaining one of the new slots could be used to leverage funds and resources through CSBs. One recommendation is that up to half of the homes constructed in this manner would be owned and directly operated by the Commonwealth of Virginia under the administration of the training center serving that region. The remaining homes will be owned by the Commonwealth, but leased and operated by the CSB or a private providers, or could be built by CSBs and/or private providers with state dollars that are awarded through grants to localities by the Department. Operational funding will be provided by the MR Waiver; room and board paid from individual fees. While building community capacity is critical to meeting the waiting list needs as well as the needs of individuals wishing to leave institutional settings, the needs of the aging facilities must also be met with capital improvements to maintain health and safety. Financing the capital needs of the facility improvements and the community development could be accomplished through a bond package. The estimated annual service on $160,000,000 bond, split halfway between the facility needs for renovation and the community development needs would be approximately $13,000,000 annually for twenty years. An $80 million capital investment in the community would create more than 400 beds to be used by former residents of the training centers and by individuals in the community in need of an out-of-home placement. The other $80 million would be used for the rehabilitation of existing buildings at our training centers.

At a time when the aging training centers are in significant need of repair, it is even more critical that the goals established in 2005 for the reduction in the service capacity of CVTC and SEVTC be met on a schedule consistent with DMHMRSAS' ability to maintain the health and safety of all individuals being served. The "Money Follows the Person" initiative offers a unique and time-limited opportunity for the Commonwealth. One restriction on accessing the additional federal dollars of this initiative is that individuals leaving an institutional setting **cannot move into a congregate living setting of more than four persons**. Another restriction is that the residential setting into which they move **cannot be an ICF/MR**. Currently, the MR Waiver congregate residential reimbursement rate is not high enough for most providers to serve individuals with the most significant level of needs.

Individuals Who Are Waiting for Family Supports

By causing people to remain on waiting lists for an extended period of time for even a minimum level of services, individuals' needs escalate to a more critical level resulting in their requiring the most extensive and expensive services by the time they receive a MR Waiver funded slot. Furthermore, the earlier that at least minimal supports can be put into place for families of individuals with intellectual disabilities, the longer these families can negotiate their needs without resorting to more extreme and costly out-of-home placements. It has been the experience of Virginia, substantiated through our research of other states' circumstances, that when people have control over their resources, they tend to make wise decisions about the allocation of those resources. These resources would be distributed to the CSBs according to the density of identified populations with qualified needs and used for Family Support and other initiatives deemed valuable by the locality to serve this population with services of their choice at locations of their choice.

To enhance the ability of the Commonwealth to adequately support individuals in their home communities, it is recommended that Virginia:

Recommendation #1

- **Fund MR Waiver slots for 800 individuals per year for the next four biennia for individuals who are waiting for services.**
- **Fund the capacity-building allotments of $4,000 for the start-up of each of the 800 slots.**
- **Fund by FY 2010 the purchase and implementation of a statewide assessment tool designed to transition and target supports to individuals in a more person-centered manner and enhance the state's ability to plan support systems and allocate resources.**

Recommendation #2

- **Invest in community infrastructure, including but not limited to new construction of four-bed community homes, available for both individuals choosing to exit facilities and those presently residing in the community.**
- **While building community capacity, simultaneously focus on renovations of those buildings at CVTC and SEVTC necessary to maintain health and safety standards for the projected populations.**

Recommendation #3

- **Reestablish the state's commitment to support through General Fund dollars, people with intellectual disabilities who have no other avenue for support.**

Recommendation #4

- **Provide for a 25 percent rate increase for all MR Waiver models of residential support of four beds or less (except "sponsored residential" homes) to make smaller settings financially feasible and promote the Money Follows the Person initiative.**

Recommendation #5

- **Fund 125 MR Waiver slots per year for the next two biennia for persons living in any one of the state-operated training centers, private or public ICFs/MR, nursing homes, and long-stay hospitals who wish to live in the community so that Virginia can take full advantage of the CMS Money Follows the Person initiative.**
- **Beginning with the third biennia (FY 2013) after successful implementation of the first bullet of this recommendation, fund 60 slots per year (one slot per month distributed to each of the five Health Planning Regions) to be held in reserve for crisis situations to mitigate family stresses that might otherwise**

result in an institutional placement or to enable an individual to leave an institutional setting when it is no longer needed or desired.

- **Fund capacity building allotments of $4,000 for the start-up of each of the slots.**

Other Measures to Effect MR Waiver Reform and Increase MR Waiver Efficiencies

Assurance of Adequate Reimbursement of Services

In order to adequately support individuals with intellectual disabilities in the community through the MR Waiver in a stable and person-centered manner, providers require assurance that reimbursement levels will keep pace with the ever-increasing cost of living and enable providers to attract qualified, dedicated staff. Despite recent improvements in Medicaid Waiver reimbursement rates, many direct support staff still earn incomes that qualify them for public assistance in their local communities.

Supporting Those with the Most Challenging Needs

In order to support individuals with the most challenging needs in the community, reimbursement rates should reflect the added costs to providers of accommodating their medical and behavioral challenges. Currently, the reimbursement rates for more specialized care, such as behavioral, psychological, and nursing support, fall well below the average hourly pay rates for those professions. In addition, nursing and behavioral consultation providers are unable to bill for the significant time spent developing plans of care, providing telephone consultation, and traveling long distances to provide services. It is important for the future success of these services that their authorized billable activities are increased to include these tasks and that the billable units for nursing and behavioral consultation are changed to 15-minute intervals. Gaps in service limits negatively affect individuals' access to needed services and create disruptive patterns of high staff turnover. These disruptions are often seen to have a de-stabilizing effect to the individual receiving supports, thereby creating greater need for more intense levels of support than would be ordinarily required.

Ensuring Health and Safety

The complement of Medicaid-funded services available in the community should be expanded to include more medically-oriented supports such as dental and expanded nursing services to achieve parity with state training centers. Further, providers should receive reimbursement for all supports (including monitoring by staff overnight and during individuals' engagement in independent activities) that enable individuals living in the community to remain safe and possess a good quality of life.

Consumer Direction

The Commonwealth, as well as much of the country, is moving toward a system of support that calls for more consumer-directed models of service with greater control of services given to the individuals receiving services and their families. There is a need to expand the number of services which may be accessed through the consumer-directed model as well as to make Services Facilitation, the administrative service that is required by regulation to accompany any consumer-directed service, a more economically viable service for agencies and individuals to provide. Presently there is an insufficient number of Services Facilitators statewide due to the current reimbursement rates.

Recommendation #6
- **Establish an annual cost of living rate adjustment across the board to all Waiver services to keep the rates current with the increases in costs.**

Recommendation #7
- **Increase the Medicaid Waiver reimbursement rates for all Skilled Nursing to equal or more nearly approximate the private insurance rate for this service.**

Recommendation #8
- **Apply a tiered reimbursement system for Residential services similar to that which exists in Day Support. This would permit a High Intensity rate classification to be paid for persons who require a more direct and intense level of staff support.**

Recommendation #9
- **Over the next year, develop and subsequently fund a "Nurse Monitoring" service to provide a liaison between physicians and direct support staff.**

Recommendation #10
- **Make regulatory changes to add flexibility in the current system allowing for direct intervention services of behavioral consultants to become MR Waiver billable units.**

Recommendation # 11
- **Add dental as a covered MR Waiver service for adults with rates that reflect the specialized services required for those served by the Waiver.**

Recommendation # 12
- **Modify the MR Waiver regulations to permit Residential services to bill for monitoring the health and safety of individuals overnight and while engaging in other less structured activities.**

Recommendation #13

- **Adjust the MR Waiver rate for Individual Supported Employment (SE) to parallel and keep pace with the SE rates assigned to each employment services organization by the Department of Rehabilitative Services.**
- **Reimburse Group SE equal to or greater than high intensity Day Support or Prevocational services to demonstrate that employment is a highly valued service.**

Recommendation #14

- **Expand the number of MR Waiver services offered with a consumer-directed option in order to increase the flexibility and promote a broader array of choices.**
- **Increase the reimbursement rate for Services Facilitator services by 15% in order to attract more individuals and agencies to the provision of this service and improve the retention rate for those currently offering it.**

Improving the Quality and Flexibility of the Services to Better Meet the Needs and Desires of Individuals Being Served

The availability of a stable and qualified work force sufficient to meet the needs of the individuals with intellectual disabilities in the community is critical if Virginia is ever to achieve the status of equal protection for all persons. Sufficient and consistent training of direct support staff across the broad spectrum of services is seen as a critical tool in stabilizing this work force. One potentially valuable training tool, the College of Direct Supports, offered in conjunction with the University of Minnesota, is a Web-based training designed to improve the skills of direct support staff that has been in use in Virginia by the state-operated facilities and is being piloted in the community during FY 2008. Making available to staff ongoing training in best practices as well as the intermittent involvement of professionals skilled in psychiatry and behavioral intervention will have the desired effect of increasing the skills of this work force. Part of the responsibility for training lies with provider agencies and part with state employees charged with the up front quality assurance activities of training and technical assistance. In view of the fact that Virginia has experience a 50 percent growth in community programs for persons with intellectual disabilities since 2000 it is also important that DMHMRSAS and DMAS have sufficient staff to perform reviews of the ever burgeoning number of providers (there has been a 45 percent growth in the number of new group homes that have come on line in the past three years) for compliance with regulations and the implementation of health, safety and quality measures.

Housing

In order to live in the community, individuals with intellectual disabilities require housing that is accessible and affordable considering their limited incomes. The development of a consistent, housing policy that considers the needs of individuals with intellectual disabilities (who may also have physical disabilities as well) and involves multiple state agencies will increase the scope of affordable and accessible housing choices through better utilizing a combination of state and federal funding with a priority for persons with low incomes with intellectual disabilities.

Transportation

In order for individuals with intellectual disabilities to obtain access to employment opportunities, which may help them afford better quality housing, as well as necessary community resources, they require a transportation system that is dependable, safe and flexible enough to meet their needs. The current study being conducted by the State Interagency Transportation Coordinating Council is critical to the development of an adequate transportation system for individuals with disabilities. The participants in the MR System Study support a continuing collaborative effort to resolve the critical issues of transportation for persons with intellectual disabilities.

Recommendation #15

- **Establish the College of Direct Support as a line-item budget expense to be made available annually to all providers of services to persons with developmental disabilities.**

Recommendation # 16

- **Establish ongoing funds to support the training and endorsement of providers in Positive Behavioral Supports.**

Recommendation # 17

- **Increase the DMHMRSAS Office of Licensing staff by two FTEs to reflect the continued development of community supports and the need for authoritative review of regulatory compliance.**
- **Increase the DMHMRSAS Office of Human Rights staff by three FTEs to reflect the continued development of services and need for oversight, monitoring, and protection of human rights of individuals being served in the community.**
- **Increase the DMHMRSAS Office of Mental Retardation staff by three full FTEs to reflect the dramatic change that has occurred in the volume of community services in the past seven year period requiring additional up front quality assurance resources for preauthorization of services and training/technical assistance for providers.**
- **Increase the DMAS Quality Management Review staff by three FTEs to reflect the work load changes in the growth of the community support system.**

Recommendation #18

- **Fund a position for a psychiatrist with a specialty in developmental disabilities in the DMHMRSAS Division of Community Services to develop and provide coordination for a statewide network of mobile behavioral teams**

for persons with intellectual and developmental disabilities who also have mental health issues or other intensive behavioral needs.

Recommendation # 19

- **Develop a tiered system of reimbursement that allows procurement of the services of a psychiatrist or licensed doctoral-level psychologist as part of a mobile special behavioral team when those services are needed.**

Recommendation #20

- **Develop a comprehensive transportation system for citizens with disabilities that maximizes the use of the existing system infrastructure and capitalizes on federal funding and support initiatives in a planned coordinated effort.**

Recommendation #21

- **Develop and implement a consistent, coordinated housing policy among state agencies (involving Virginia Housing Development Authority, U.S. Department of Housing and Community Development, DMHMRSAS, DMAS, DSS, CSBs, and private providers of community-based residential services).**

Requested Financial Commitment in Support of Services for Persons with Intellectual Disabilities

Recommendation	FY09 SGF Cost	FY09 Federal Cost	FY10 SGF Cost	FY10 Federal Cost
1a. Fund MR Waiver slots for 800 individuals per year for community residents.	$ 27,680,000	$ 27,680,000	$ 55,360,000	$ 55,360,000
1b. Capacity funds	$ 3,200,000		$ 3,200,000	
1c. Fund the purchase and implementation of a statewide assessment tool. (the total 3-year purchase price of the Supports Intensity Scale is based on the number of assessments and is estimated at $273,004 to be split between SGF and federal match)			$ 48,000	$ 48,000
2. New construction in the community of four or fewer person residential models and needed renovations to training centers (estimated total cost of $160,000,000 obtained by bond)	Estimated annual service for 20 years $13,000,000		Estimated annual service for 20 years $13,000,000	
3. General Fund dollars to support those persons with intellectual disabilities who have no other avenue for support	$ 40,000,000		$ 40,000,000	

4. A 25% reimbursement rate increase for MR Waiver residential support models of four beds or less	$ 12,707,447	$ 12,707,447		$ 12,785,139	$ 12,785,139
Impact on other Waivers	$ 358,114	$ 358,114		$ 360,304	$ 360,304
5a. Fund 125 MR Waiver slots per year for persons living in institutional settings.	$ 4,325,000	$ 4,325,000		$ 8,650,000	$ 8,650,000
5b. Capacity funds	$ 500,000			$ 500,000	
6. Establish an annual cost of living rate adjustment for all Waiver services.				$ 6,417,767	$ 6,417,767
Impact on other Waivers				$ 3,483,763	$ 3,483,763
7. Increase the Medicaid Waiver reimbursement rates for Skilled Nursing to equal or more nearly approximate the private insurance rate.	$	$		$ 6,818,602	$ 6,818,602
Impact on other Waivers				$ 43,561,637	$ 43,561,637
8. Apply a tiered reimbursement system for residential services to permit a High Intensity rate classification.	$	$		$ 47,367,180	$ 47,367,180
Impact on other Waivers				$ 1,994,407	$ 1,994,407
9. Develop a "Nurse Monitoring" service to provide a liaison between physicians and direct support staff.	$	$		$ 617,400	$ 617,400

10a. Reimburse behavioral consultants for direct intervention services.	$	$		$ 150,000	$ 150,000
10b. Reimburse behavioral consultants and skilled nurses for plan development, telephone consultation, and some travel.				$ 150,000	$ 150,000
10c. Change the billable units for nursing and behavioral consultation to 15-minute intervals.				No fiscal impact	No fiscal impact
11. Add dental as a covered Medicaid Waiver service for adults.	$ 726,339	$ 726,339		$ 755,942	$ 755,942
12. Modify the Medicaid Waiver regulations to permit billing for monitoring the health and safety of individuals overnight and while engaging in other less structured activities.				$18,021,072	$ 18,021,072
13a. Adjust the Waiver rate for Individual Supported Employment (SE) to parallel and keep pace with the Department of Rehabilitative Services rates.	$	$		$ 221,952	
13b. Reimburse Group SE equal to or greater than high intensity Day Support or Prevocational services.					
Impact on other Waivers				$ 2,441	

14a. Expand the number of MR Waiver services offered with a consumer-directed option.					
14b. Increase the reimbursement for Services Facilitator services by 15%.	Cost neutral (costs of 14 b offset by savings in 14a)	Cost neutral (costs of 14 b offset by savings in 14a)		Cost neutral (costs of 14 b offset by savings in 14a)	Cost neutral (costs of 14 b offset by savings in 14a)
15. Establish the College of Direct Support as an annual budget expense.	$ 125,000	$ 125,000		$ 125,000	
16. Continue to fund the training and endorsement of providers in Positive Behavioral Supports.	$ 100,000			$ 100,000	
17a. Increase the Office of Licensing staff by 2 FTEs.				$ 150,000	
17b. Increase the DMHMRSAS Office of Human Rights staff by 3 FTEs.				$ 225,000	
17c. Increase the staff support at the Office of Mental Retardation by 3 full FTEs.				$ 112,500	$ 112,500
17d. Increase the DMAS Quality Management Review staff by 3 FTEs.				$ 112,500	$ 112,500

18. Add a position in the DMHMRSAS Division of Community Services that is qualified at the level of a psychiatrist.	$ 60,000	$ 60,000		$ 60,000	$ 60,000
19. Fund a mobile special behavioral unit, including the services of a psychiatrist or licensed doctoral level psychologist.	$	$		$ 575,000	$ 575,000
TOTAL COSTS	**$ 102,781,900**	**$ 45,981,900**		**$ 264,925,606**	**$ 164,723,213**

Section II

The Development and Provision of Person-Centered, Individualized Supports

Twenty years of knowledge, experience and talk about person-centered practices have brought little change in Virginia's system of services for people with intellectual disabilities. The Person-Centered Practices PCP report reflects the voices of individuals, their families and the people who support them and describes changes they believe will help to transform the current service system to a community of person-centered supports. It explores new ways of supporting individuals in making their own decisions about where and how to live, managing their own services and who to hire, and becoming increasingly more involved in their communities and increasingly less reliant on the traditional service system.

DMHMRSAS established the Person-Centered Practices (PCP) Leadership Team in October 2006 in response to "a vision for a new system of services." The Inspector General called for collaboration in the development and implementation of person-centered planning following reviews of the training centers and community residential providers. The PCP Leadership Team, charged with guiding the implementation of person-centered practices across Virginia, quickly drew the interest, participation and leadership of more than 80 experienced stakeholders across the state *(See Attachment A of the PCP Report in Appendix E).*

The PCP Leadership Team has articulated the following vision, values, principles and recommendations to guide the transformation of the service system for individuals with intellectual disabilities in Virginia and the implementation of the CMS-funded Systems Transformation Grant and Money Follows the Person Demonstration projects:

We see a Virginia where individuals of all ages and abilities have the supports we need to enjoy the rights of life, liberty and the pursuit of happiness and the opportunity to have a good life.

Having a good life means different things to different people. It includes joy and happiness, health and safety, dreams, meaningful activities, intimate relationships with family and friends, having a home, transportation, work, money, bank accounts and the ability to contribute to family and community.

We believe our journey to a good life is best led by the voices of individuals and by following these person-centered principles.

Principle 1: Listening. Individual choices and descriptions of a good life are respected and followed.

Principle 2: *Self-direction. Personal choice and control are supported.*

Principle 3: *Community. Relationships with families, friends and people in the community are very important and at the center of planning.*

Principle 4: *Abilities. The experience, talents and contributions of individuals, families and communities are strengthened and supported.*

Principle 5: *Accountability. There is shared responsibility for supports and choices.*

Recommendations:

1. Provide **vision and leadership** at the state and local level that embraces person-centered principles and practices.
2. **Revise regulations** for MR & DS Waivers, Targeted Case Management, Licensing and Human Rights to ensure these values are implemented in people's everyday lives.
3. Establish **a reimbursement rate structure that supports the vision, principles and values**.
4. **Value work** first, before considering alternatives to employment.
5. Offer meaningful activities, retirement options, and natural **ways to contribute** to community as alternatives or in addition to employment.
6. Promote **friendships** between people with intellectual disabilities and other community members.
7. Facilitate balance between **dignity of risk and health and safety**.
8. Promote **healthy relationships** in the lives of persons with intellectual disabilities and support the human need for **intimacy and special relationships**.
9. Support individuals in making **their own choices** about how to live their lives.
10. Promote **varied and fun, social and community activities** in individuals' lives.
11. Support individuals in living **where and with whom they want**.
12. Support **active and healthy lifestyles, and access to good medical, dental, psychiatric and other professional care of one's own choosing**.

13. Assure individuals have **money, transportation and other resources** and supports, not only for meeting daily needs, but also to pursue personal goals and dreams.

14. Assure **personal choice** in how to live one's life, spend one's time and practice one's spirituality.

15. Provide real opportunities for **lifelong learning**.

Section III

Additional Recommendations that Will Add to System Infrastructure and Quality Improvements

Employment Related Areas

Individuals with disabilities expressed employment and having access to their own money as an important in their lives. Several issues related to employment prevent individuals from engaging in meaningful work. These include:

- There is limited flexibility in helping an individual receiving Day Support (DS) or Prevocational (Prevoc) services to transition to work in the commercial sector. While Prevoc services are "aimed toward paid employment," they are restrictive, unclear and limited in scope.

- The current Waiver preauthorization process limits an individual's opportunity for accepting a time-sensitive employment opportunity or an individual's need to move to a more intensive level of support since a new authorization is needed and a work opportunity (or other immediate need) might be missed.

- Transition services ensuring the move from school to work or post-secondary training does not begin early enough to ensure a student's access to needed transition supports, work opportunities, and available work incentives options that exist for students only. The earlier services begin, the better the employment outcome.

- There is a lack of service coordination between institutional and community providers to ensure that individuals with intellectual disabilities leaving institutions can access employment services and supports both prior to and following discharge into the community of their choice.

- Many individuals in the MR Waiver and other publicly funded services are required to give up much of their newly earned income in order to retain Medicaid benefits. As an individual's expenses related to work significantly increases when employed (i.e. work clothes, uniforms, transportation, etc.), the earned income allowance and patient pay requirements need to be adjusted to encourage individuals to work.

- Additional funding for Long Term Employment Support Services is needed on an annual basis to help individuals with intellectual disabilities retain their current employment.

- The Virginia Department of Rehabilitative Services (DRS) is currently under an "Order of Selection" that defines what level or combination of disabilities an individual needs to have in order to be eligible for vocational rehabilitation and employment services by DRS and/or its vendors. An Order of Selection is essentially a waiting list initiated within a state when the vocational rehabilitation department does not have sufficient resources to serve all who are eligible under the regular requirements for service.

- Virginia's current Medicaid Buy-in, although a step in the right direction, prevents individuals who have earned and unearned income above 80 percent of the Federal Poverty Level from participating. Under the current initial legislation, only individuals eligible for Virginia Medicaid can become eligible. The federal goal is to allow individuals who are otherwise ineligible for Medicaid because of earned and unearned income to be able to "buy-in" and pay a premium to get Medicaid coverage. Once qualified, an individual can earn additional income and retain financial resources in amounts substantially above current Medicaid rules.

Recommendations to improve *access to employment*

- **Clarify Prevocational activities in MR Waiver policy.**

- **Change MR Waiver policy to allow presumptive authorization (through case manager verbal authorization followed by paperwork) when an individual needs to move between Group Supported Employment (SE) and Individual SE and DS services.**

- **DMHMRSAS and DRS will work with the Department of Education to support gainful employment in the community for students with intellectual disabilities as a desired and necessary outcome of secondary education.**

- **Add employment as a valued service to be included in discharge planning protocols for individuals transitioning into the community.**

- **Increase the current disregard from 200 percent to 300 percent (for 8-20 hours worked per week) and from 300 percent to 400 percent (20+ hours worked per week) of countable income (earned and unearned using Supplemental Security Income (SSI) rules). Alternately, only count earned income within the current thresholds. However, SSI and Social Security Disability Insurance work incentives should also be used to calculate the countable income standard.**

- **As there is no financial incentive to earn income if nearly all of it goes to patient pay or residential fees, modify the current DMHMRSAS licensing regulations for Residential services to require standardized procedures regarding assigning and collecting fees.**

- **Appropriate additional funding annually to keep pace with the number of individuals placed in SE and needing long-term employment support services to maintain employment.**

- **Appropriate sufficient funding to eliminate the "Order of Selection" for vocational services under DRS.**

- **Amend the current Medicaid Buy-In to accommodate its original federal intent.**

Health and Safety

In order to better ensure the health and safety of individuals on the MR Waiver with complex medical needs and to facilitate greater coordination between physicians and direct support staff in relation to medical issues, there exists a more active role for nursing personnel. This nursing involvement will become more critical as more individuals leave nursing facilities and ICFs/MR through the MFP Demonstration project.

Dietary consultation is becoming more of an issue with an aging population and increasing levels of obesity and there is a need to promote wellness and guide direct support staff to help individuals make healthy choices. In addition family members and direct support staff require information about medication interactions. Direct support staff requires medication administration training as part of DMHMRSAS Licensing regulations.

Providers are often conflicted regarding the balance of priorities between the health and safety of the individuals they support and the individuals' own desires for and rights to increased community integration.

Individuals exiting a training center or otherwise new to the MR Waiver may require certain environmental modifications and/or assistive technology prior to moving to their new home in order to meet their needs and to ensure safety. Under the MR

Waiver these services can only be provided once the individual has begun to receive other Waiver services.

In order to maintain compliance with CMS and ensure quality service provision there is a need for continued and consistent training for case managers and the direct support work force.

Recommendations to improve *health and safety*

- **Over the next year, develop a tiered system for Skilled Nursing (i.e., acute, sub-acute, chronic) with graduated reimbursement rates based on the complexity of the individual's medical needs and related services rendered. Take action to make the necessary regulatory and reimbursement structure changes.**

- **Add Nutrition Consultation services to the Medicaid Waivers. Take action to make the necessary regulatory and reimbursement structure changes.**

- **Add Pharmacy Consultation services to the MR Waiver. Take action to make the necessary regulatory and reimbursement structure changes.**

- **Change regulations/policy to allow these services to be accessed prior to and in the absence of other Waiver services, if this will facilitate a move to or remaining in the community. Alternately, ensure that capacity-building funding is available to each individual prior to the onset of MR Waiver services for needed modifications and equipment.**

- **Develop training modules for case managers and direct support staff related to health issues of persons with intellectual disabilities and medical management issues.**

Housing-Related Issues

Take measures to address the lack of affordable, accessible housing for people with disabilities in Virginia, initially targeting individuals transitioning from nursing facilities and ICFs/MR (the Money Follows the Person Demonstration Project may assist with this).

In-home Residential Support (supports provided to an individual in his family home, own home or apartment) is an under-utilized service in the MR Waiver, but offers excellent opportunities for forging relationships with non-disabled neighbors and community members. In order to further promote individuals' use of in-home (vs. congregate) residential support, explore the addition of the following supportive Waiver services.

Individuals with intellectual disabilities with or without MR Waiver funding are generally in the lower end of the income spectrum. Because of this fact, access to affordable housing is limited. If a person with intellectual disabilities also has concurrent physical disabilities and requires accessible housing, the available options are even more limited. Take steps to fill the void created by the lengthy waiting periods for Section 8 funding through transitional funding to pay rents/mortgages.

Recommendations to improve *housing options*

- **Add Chore services, Caregiver Living Expenses (i.e., Medicaid funded room and board for a person living with the individual with disabilities in exchange for providing wage-free supports), and Housing Access Coordination.**

- **In concert with the Money Follows the Person Demonstration project, develop a Bridge Subsidy supplement program, by which a state government agency covers rent/mortgage costs until a qualifying low-income individual receives Section 8 funding. Take action to effect the necessary regulatory and reimbursement changes.**

Summary

Individuals with intellectual disabilities in Virginia are fortunate in many ways. The state has an infrastructure established to support them through the local CSBs, state training centers, the Mental Retardation and Day Support Waivers and the oversight of DMHMRSAS and DMAS. However, many gaps exist in the present system of supports. Facilities at aging training centers require upgrades and improvements in order to ensure the health and safety of their residents; many individuals in the community are in urgent need of the kinds of supports offered by the MR Waiver but must await the availability of a slot; there is a need for non-Waiver funding for individuals unable to access Medicaid at the present time; around the state there are inconsistencies in the availability of services often due to Medicaid reimbursement rates that fail to attract providers of services; and there is a need for the expansion of existing and development of additional MR Waiver services to ensure individuals' health and safety.

It is the belief of those involved in developing this report that it offers Virginians with intellectual disabilities the best plan to reach the desired end of a system in which individuals' most urgent needs are filled, choices are honored, health and safety is assured and a good life can be enjoyed by the individuals themselves as well as their family members.

Endnotes

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[3] Maddox, P.J., MD. "Today Is the 'Good Old Days': Virginia's RN Workforce Trends or Healthcare Workforce Issues ARE Complex: Get Over It." Presentation to the Governor's Task Force on Health System Reform, 2007

[4] The Arc of the United States, October 2004

[5] Virginia Department of Education. "Totals for Students with Disabilities by Disability and Age, Ages 0 – 22+," 2006.

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Appendices

Appendix A
Historical Overview of the Virginia Service System for Individuals with Intellectual Disabilities

An understanding of the evolution of Virginia's system of services for persons with intellectual disabilities is critical to understanding the state's present position as well as the desired direction for the future. Medicaid, created on July 30, 1965 through Title XIX of the Social Security Act, is the health care program for individuals and families with low incomes and resources, and those who meet certain eligibility categories such as aged, blind or disabled. Jointly funded by state and federal government and managed by the states, Medicaid is the largest source of funding for medical and health-related services for people with disabilities.

During the 1950's:

- State involvement in funding services for persons with intellectual disabilities was limited to two state run institutions (Southside Virginia Training Center in Petersburg and Central Virginia Training Center in Lynchburg) which had been developed during the early part of the 20th century. Community services were few. Those community services that did exist were usually developed by community parents associations and Associations for Retarded Children (now called the Arc) and were typically vocationally oriented day programs and sheltered workshops.

In the late 1960s and early 1970s:

- The Virginia Department of Vocational Rehabilitation, which is now the Department of Rehabilitation Services helped to establish community sheltered workshops and provide assistance to those programs already being operated by non-profit associations through federal and state matching equipment grants and some funds for training. Many people with intellectual disabilities were able to participate in these programs.

- All states obtained federal dollars for the costs of operating their large state institutions. Through the Medicaid ICF/MR category states were eligible for federal dollars to offset the costs of their training centers.

- In 1968, The Community Services Board (CSB) system was established under Chapter 10 of the Virginia Code as a means by which localities could develop community funds to match state funds for the purpose of providing basic community services for persons with mental illness and intellectual disabilities. CSBs (some are also organized as Behavioral Health Authorities or BHAs) are mandated to provide case management and emergency services under the code. This public system of case management through the CSBs serves as the single point of entry into the publicly funded system for persons with intellectual disabilities and provides local oversight of services.

- Three more training centers were developed in the early 1970's in Northern Virginia, Southeastern Virginia and Southwestern Virginia to provide state operated ICF/MR services to persons with mental retardation to help train individuals for independence in the community.

- Virginia joined the Medicaid program in 1970. Virginia's initial Medicaid efforts for persons with intellectual disabilities focused on obtaining federal financial participation for the state's five training centers for persons with mental retardation under the ICF/MR program. The federal Medicaid dollars came with accompanying requirements to ensure the health and safety of the facility residents and to provide "active" treatment. The combination of federal oversight and funding greatly enhanced care and treatment provided at ICF/MR facilities.

In the mid-1970s to the 1980s:

- There was a major shift in federal Medicaid policy for persons with intellectual disabilities due to pressure from family and advocacy groups. The resulting changes in federal law allowed Medicaid to also pay for community-based care through what became known as *Home and Community-Based Waivers* in lieu of institutional care.

- Virginia's efforts to increase funding for community-based care for persons with intellectual disabilities were historically financed by state general funds, typically as a result of state legislative studies (Hirst-1967, Bagley-1980, Emick-1985). During the 1988 – 1990 biennium there was an increase of over 50 percent in previous funding. Governor Baliles and the General Assembly made this increase in response to awareness, the efforts of advocates and a statewide "Make Waves" campaign.

In the 1990s:

- In May of 1990, Northern Virginia Training Center (NVTC) received its first letter from the Department of Justice initiating the Civil Rights of Institutionalized Persons Act investigation. As a result, NVTC's census was reduced form 283 to 200 and it increased its staff to resident ratios. To help provide services to those individuals leaving NVTC, the training center began the state's first RCSC (Regional Community Supports Center). On June 3, 1998, the judge signed the order to dismiss the civil rights action without prejudice.

- By this time, most states were receiving federal dollars to expand community-based services and/or offset community service costs through the MR Waiver program. The "Making Waves II" campaign sought to move Virginia toward the use of more federal funding and expand the service system through the initiation of the MR Waiver during the 1990 - 1992 biennium. While state revenue shortfalls limited program expansion, Virginia did initiate an MR Waiver during this time and converted funding of many existing community programs from state general funds-only support to Medicaid funded State Plan Option and Waiver services. Despite this change:

1. Some important services such as dental care and direct behavioral supports were not originally included in Virginia's MR Waiver.

2. As MR Waiver funding expanded Day Support services, the newly emerging emphasis on employment for people with intellectual disabilities through Supported Employment began to wane in Virginia.

3. There was no new funding for this program or an expansion of services. Funds allocated to CSBs were transferred to DMAS to match federal funds for the MR Waiver.

- House Document 61 was delivered to the General Assembly in 1999. This report made a series of recommendations to strengthen the service delivery system for individuals with intellectual disabilities through the waiver, improve the development of person-centered plans, increase flexibility of services, and advised that DMHMRSAS work with DMAS to determine a methodology for establishing a rate structure appropriate to the services. In addition, the state match funding for the waiver should be appropriated to DMAS as opposed to taking it from the CSBs' allocations of state general fund dollars.

- In 1999, the United States Supreme Court said in a decision called Olmstead vs. L.C that persons with disabilities who live in, are "at risk" of living in, or are eligible for placement in facilities or institutions, have a right to live in the community if:
  1. They and their treatment teams agree that they can live successfully in the community;
  2. They choose to live in the community; and
  3. There are resources available to help them live in the community.

2000 and beyond:

- In the last decade several improvements have been made in the MR Waiver.
  1. Acting on HJR 240 (1996) and HJR 225 (1998) *Joint Subcommittee to Evaluate the Future Delivery of Publicly Funded Mental Health, Mental Retardation and Substance Abuse* Services recommendations, the 2000 General Assembly moved the MR Waiver state match funding to the DMAS budget.

  2. Management of the waiting lists for the waiver is now done through the CSBs and the reporting of waiting list information and data is made to DMHMRSAS. Agreement was established on the identification of criteria

for an *urgent needs* waiting list. All persons on this list must receive slots before services could be provided to persons on the *non-urgent needs* list. In 2001 consumer-directed services were added to the MR Waiver.

3. In July of 2004, one of the largest influx of state dollars into the intellectual disabilities system occurred with the release of 700 community MR Waiver slots and 160 slots for persons living in training centers.

4. In July of 2005, the new Day Support Waiver was implemented in Virginia with a total of 300 slots

5. In July of 2006, new rates approved by the Governor and the General Assembly were implemented for the MR Waiver. This increase was a ten percent increase for congregate residential services and a five percent increase for most other MR Waiver services.

6. In September of 2006, in an agreement between DMAS and DMHMRSAS, authority for the management of the MR and Day Support Waivers was transferred to DMHMRSAS. Under this agreement, DMAS retained the responsibility for administration of the waiver as the state's designated Medicaid agency while DMHMRSAS was responsible for management responsibility for the operation of the MR and Day Support Waivers. As a result, DMAS and DMHMRSAS have developed a strong cooperative relationship in bringing the MR and Day Support Waiver services to the community.

Appendix B
Study Design Details

Focus Teams
The six Focus Teams were facilitated by the Office of Mental Retardation (OMR) staff and membership included self-advocates, family members, public and private service providers, and state agency representatives with experience in the focus area. Each team developed a report that includes:

- The positive impact of the MR service system (particularly the MR Waiver) in the focus area;
- Areas where the MR service system can be improved to provide person-centered, individualized supports in the focus area;
- Identification of existing gaps in services and supports and areas where new specialized services need to be developed;
- Existing barriers identified to achieving desired success in the focus area;
- Investigation of other states' promising solutions to address the focus area;
- Recommended changes to the MR service system to improve Virginia's ability to address the focus area; and
- Estimated costs of the changes.

Discussion Groups
Community Discussion Groups – OMR, with the assistance of the CSBs, organized regional Discussion Groups with public and private providers statewide. OMR staff facilitated the Discussion Groups, at which participants responded to the following questions:

1. How does the MR Waiver* have a positive impact on the lives of people with mental retardation?
2. What are the best things about the MR Waiver that you would not want to see changed?
3. Are MR Waiver supports and services person centered? If not, what changes should be made to the MR Waiver to assist in developing person-centered plans and supports.
4. Is the MR Waiver easy to use? What changes should be made to make it easier to use?
5. Are there barriers to providing MR Waiver services? What are the barriers?
6. Are there adequate behavior consultation services available through the MR? How can this service be more available?
7. Are there adequate skilled nursing services available through the MR Waiver? How can this service be more available?
8. Are there adequate skilled medical services available? How can this service be more available?
9. What additional services and supports should be added to the MR Waiver?

*As these Discussion Groups were conducted in the spring, before the study was expanded to include the entire service system for individuals with intellectual disabilities, the questions and responses focused on the MR Waiver. However, some system-wide information can be gleaned from the participants' responses.

Findings from the Community Discussion Groups were summarized by location and statewide. These are attached.

Telephone Surveys
A sample of individuals receiving MR Waiver services* or their family members was surveyed telephonically by Richmond Consulting Group, LLC. The survey questions included:

1. What services and supports have helped you and your family member the most? How?
2. Do you think that the services and supports you receive are personalized to your needs?
3. Are there other services and supports that you need that you're not getting?
4. Is the MR Waiver easy to use? If not, what changes should be made to make the MR Waiver easier to use?
5. Do you get services that aren't helpful? Why?
6. Are you in need of help with behavioral, nursing or medical needs, but not getting the help you need? Are these services available to you? How can these services be easier to use or get?

*As these surveys were conducted in the spring, before the study was expanded to include the entire service system for individuals with intellectual disabilities, both the questions and the sample group focused on the MR Waiver. However, some system-wide information can be gleaned from the survey responses.

Individuals on the Statewide Waiting List and their families were similarly surveyed with the following questions:

1. What do you think the Waiver will do for you?
2. What Waiver services are you waiting to receive?
3. What supports or services do you need that are not offered by the Waiver at this time?
4. What services will you need in the next 5-10 years?

Findings from the two telephone surveys were summarized and attached.

Persons and Organizations Involved
The following individuals supported the work of this study through serving on the ***Steering Committee***.

- Leslie Anderson, Office of Licensing, DMHMRSAS
- Steve Ankiel, DMAS
- Mary Cole, Cumberland Mountain CSB

- Howard Cullum, The Arc of Virginia member *and* a family member of a person with intellectual disabilities
- Jennifer Fidura, Fidura and Associates
- Ed Gonzalez, OMR, DMHMRSAS
- Yvonne Goodman, DMAS
- Lee Price, OMR, DMHMRSAS
- Chris Reilly, The Arc of Virginia
- Jamie Trosclair, The Arc of Virginia
- Gail Rheinheimer, OMR, DMHMRSAS
- Cynthia Smith, OMR, DMHMRSAS
- Cheri Stierer, OMR, DMHMRSAS
- Teja Stokes, DMAS
- Karen Tefelski, vaACCSES
- Dawn Traver, OMR, DMHMRSAS
- Margaret Walsh, Office of Human Rights, DMHMRSAS
- Carol Webster, District 19 Community Services Board
- Tera Yoder, The Partnership for People with Disabilities
- Susan Bergquist, VACSB

The following individuals served on Focus Teams for this study.

Behavioral Issues

- Facilitator: Lee Price, OMR, DMHMRSAS
- Ruth Ann Bates, MSW, Central State Hospital
- John Bruner, PhD., Region IV Behavior Team
- Alan El Tagi, M.Ed, B.C.B.A., Professional Behavioral Specialist
- Sue Gross, M.A., B.C.B.A., Professional Behavioral Specialist
- Vickie Hardy-Murrell, Virginia Federation of Families *and* family member of an individual with intellectual disabilities
- Emily Helmboldt, LPC, LLC, Professional Behavioral Specialist
- Bethany Marcus, PhD., SEVTC
- Lynnie McCrobie, LCSW, Middle Peninsula-Northern Neck CSB
- George Pratsinak, Ph.D., SVTC
- Rafael Semidei, MD, SWVTC
- Ram Shenoy, MD, Private Psychiatrist
- Kimberly Shepherd, Blue Ridge Residential Services
- Teja Stokes, DMAS
- Betty Thompson, PBS Advocate *and* family member of an individual with intellectual disabilities
- Paula Traverse-Charlton, Hope House Foundation
- Mark Witherspoon, Psy. D., SWVTC

Medical Oversight

- Facilitator: Ed Gonzalez, OMR, DMHMRSAS

- Jennifer Boykin, Community Based Services, Inc.
- Mary Cole, Cumberland Mountain Community Services Board
- Cheryl Collier, Chesapeake Community Services Board
- Yvonne Goodman, Department of Medical Assistance Services
- Tracy Harris, DMAS
- Sandy Hermann, Advocate *and* family member of an individual with intellectual disabilities
- Cathy Key, Innovative Community Solutions, Inc.
- Christine Kocher, RNC, City of Virginia Beach Department of Human Services
- Yvonne Luster, Office of Licensing, DMHMRSAS
- Crystal McGlothlin, RN, Cumberland Mountain Community Services Board
- Susan Rudolph, RN, The ARC/Insight, Inc. of Greater Prince William County
- Dr. Malcom MacPherson-Smith, Southeastern Virginia Training Center
- Cheri Stierer, Ph.D., DMHMRSAS OMR
- Sue Vail, Community Volunteer, Advocate *and* family member of an individual with intellectual disabilities
- Joan Woody, Central Virginia Training Center

Person-Centered Planning

- Facilitator: Gail Rheinheimer, OMR, DMHMRSAS
- Teri Barker-Morgan, Virginia Board for People with Disabilities
- Ann Bevan, NHS Mid-Atlantic
- Chanda Braggs, DMHRMSAS Office of Licensing
- Nickie Brandenburger, Chesterfield CSB
- Kamala Bauers, Wall Residences
- Eileen Hammar, Partnership for People with Disabilities *and* family member of an individual with intellectual disabilities
- Jennifer Kurtz, Arlington CSB
- Mac McArthur-Fox, Community Opportunities *and* family member of a person with an intellectual disability
- Sherry Miles, DMHMRSAS Office of Human Rights
- Jennifer McElwee, Portsmouth BHS
- Ed Nicely, Chesterfield CSB
- Mark Russell, Community Leader, L'Arche Blue Ridge Mountains *and* member of the Virginia Board for People with Disabilities *and* family member of an individual with intellectual disabilities
- Brenda Sasser, Valley CSB
- Kimberly Shepherd, Blue Ridge Residential Services
- Teja Stokes, DMAS
- Dawn Traver, OMR, DMHMRSAS
- Paula Traverse-Charlton, Hope House Foundation
- Eric Williams, Blue Ridge BHA

Waiting List

- Facilitator: Dawn Traver, OMR, DMHMRSAS
- Joanna Barnes, MR Director, Arlington Community Services Board (CSB)
- Norma Draper, MR Waiver Services Facilitator *and* family member of an individual receiving MR Waiver services
- Dawn Machonis, Program Specialist – Community Support, Partnership for People with Disabilities *and* family member of an individual with intellectual disabilities
- David Meadows, Intake Supervisor, Henrico Mental Health & Mental Retardation Services
- Tom Meadows, Case Manager, New River Valley CSB
- Nancy Mercer, Executive Director, The Arc of Northern Virginia
- Kimberly Shepherd, Director of Operations, Blue Ridge Residential Services

Employment

- Facilitators: Susan Neal, OMR, DMHMRSAS & Gail Rheinheimer, OMR, DMHMRSAS
- Joanne L. Ellis, Career Support Systems, Inc.
- Robyn Fitzgerald, ICON Community Services
- Eileen Hammar, The Partnership for People with Disabilities *and* family member of an individual with intellectual disabilities
- John E. Hayek, Office of Employment Services & Special Programs, Department of Rehabilitative Services
- Christine Heiby, ICON Community Services
- Katherine Inge, T-TAP, Virginia Commonwealth University
- Evan Jones, Fairfax-Falls Church CSB
- Shirley Lyons, Henrico Area Mental Health/Retardation Services
- Donna Martinez, The Arc of Virginia member *and* The HEATH Resource Center of George Washington University *and* family member of an individual with intellectual disabilities
- Carmen Mendez, Virginia Beach Department of Mental Health
- Diana Messer, Crossroads CSB
- Peggy Moye, Valley CSB
- Bruce Patterson, Service Source
- Demis Stewart, Greater Richmond ARC
- Teja Stokes, DMAS
- Karen Tefelski, vaACCSES
- Ed Turner, Office of the Governor of Virginia *and* self advocate
- David Wilber, Eggleston Services

Housing

- Facilitator: Cynthia Smith, OMR, DMHMRSAS
- Terri Barker-Morgan, Virginia Board for People with Disabilities
- Bonita Bell, Richmond Behavioral Health Authority
- Dennis Brown, Fairfax –Falls Church Community Services Board

- Chip Dodd, Support Services of Virginia
- Bill Fuller, VHDA
- Darlene Lindsey, OMR, DMHMRSAS
- Martha Maltais, Region Ten Community Services Board
- Ann Manckia, Richmond Behavioral Health Authority
- Brian Miller, Prince William Community Services Board
- Lisa Poe, Richmond Residential
- Karen Smith, Greater Prince William Arc
- Jack Wall, Wall Residences
- Nate Worley, Community Personal Care

The number of individuals (242) and organizations (119) involved in the Provider Discussion groups was so large as to prevent listing all the names here. The telephone surveys involved conversations with 236 individuals on the MR Waiver (or their family members) and 95 individuals on the Statewide Waiting List (or their family members). Names of those surveyed are withheld to protect confidentiality.

Appendix C
Behavioral Focus Team Report

One of the most significant challenges in Virginia's system of support for individuals with intellectual disabilities is the challenge of designing, developing and managing a fiscally responsible, coordinated, support network of professional and para-professional staff sufficient to meet the needs of all Virginians with intellectual disabilities who are at risk of engaging in behaviors that are harmful to themselves or others. The primary financial support system in the community since 1992 has been the Mental Retardation Home and Community-Based Waiver. Services through the Waiver are available to less than one third of Virginia's population of persons identified with intellectual disabilities. Even within the Waiver, there has been a significant history of poor development of community capacity for qualified professionals able to meet the demand for services. A year ago, the number of persons qualified to serve and be reimbursed under Virginia's Waiver as behavioral consultants had fallen to only twelve in the entire Commonwealth.

Only in the past two years has there been any significant progress in growing the number of qualified community professionals. One major change has occurred through a collaboration of efforts involving the Virginia Board for People With Disabilities, which offered grant dollars for development of a Positive Behavioral Support (PBS) Training and Endorsement Program in Virginia, The Partnership for People With Disabilities who developed the curriculum, The Department of Medical Assistance Services who changed regulations to approve endorsed PBS professionals for Medicaid Waiver reimbursement as well as persons certified in Applied Behavioral Analysis, and the Department of Mental Health, Mental Retardation , and Substance Abuse Services which has been funding the training and endorsement of PBS providers since July of 2006. Other significant developments have occurred through regional partnerships involving Community Services Boards, Training Centers, and Mental Health Hospitals. These efforts are specific to each region and vary in their complexity and ability to meet the demand. Finally, the funding of the Regional Community Support Centers (RCSCs) at each of the five existing Training Centers in Virginia has opened up that avenue for the provision of behavioral support services to the community.

Still, in Virginia, there remains a need for statewide coordination of effort through a system of supports that is well articulated and understood throughout all communities in Virginia when the need arises. Virginia is still under pressure to place high profile individuals who are challenging the system of support into expensive out-of-state intensive support environments. Persons who are exhibiting challenging behavior continue to present the greatest pressure on the system for entrance into one of the training centers at a time when the state is trying to do a better job of meeting the needs of individuals in their home communities.

Another area of concern expressed by the committee is the need to continue to train direct service providers in the most effective techniques of working with individuals who have potentially challenging behaviors. Often, episodes of aggression occur through ineffective interactions with direct support staff. These episodes can escalate out of control and leave the provider with few choices other than to resort to calling for crisis interventions or alternative outside residential placements. Many of the situations can be avoided completely through better training of all of the direct support professionals.

In developing the recommended changes to our system to provide a better support structure, the sub-committee reviewed the systems that other states have developed. One state, Vermont, totally eliminated their state institution system several years ago. When they eliminated the institutions, they set up a community network of professionals that are equipped to provide crisis stabilization in the community. At the core of this system is a team that meets weekly to review where everyone is in the system throughout the state and the progress being made. Other states, such as New Mexico, have developed mobile teams of professionals that can be dispatched to any part of the state when needed to help stabilize individuals in the community. While their focus is to stabilize the individual in their present home environment, there are back-up systems in place to remove them to another residence if needed.

While the committee recognizes that there is no one single approach that will answer all of the issues that are presented in Virginia, there are several things that can be done to provide greater support for people who are at risk of losing their community placement due to behavior that is risky for themselves or others. The approach that the sub-committee is recommending involves:

- Regulatory changes to the current Waiver that increase the flexibility of professionals to engage directly with individuals receiving supports
- Regulatory changes that increase the reimbursable activities to reflect actual practice and time spent delivering services
- A tiered system of reimbursement to reflect a higher reimbursement rate for psychiatrist and psychologist level of service to function in a direct intervention proceeding as a part of a specialized team
- A tiered reimbursement system for residential support similar to the difference already existing in day support as high intensity and regular intensity to add stability at the direct support level.
- A statewide coordinated effort headed by a position located in Central Office that is qualified in the Medical/Psychological and the Developmental Disabilities specialties to facilitate and organize the mobile units around the Commonwealth, coordinate training and development of best practice in the state, and to facilitate the development of community capacity for serving individuals with intellectual disabilities with special behavioral needs.
- Continued training of direct support staff in dealing effectively with individuals in the community and for continued development of the capacity for community behavioral consultations services.

The specific recommendations are as follows:

Issue:
The current regulations for behavioral consultation services focus on the services of a qualified provider in designing behavioral interventions and training direct support staff in implementing plans. This focus makes it difficult for the provider to be reimbursed for providing direct intervention services when direct intervention may be the most effective and most needed service.

Recommendation:
Change the regulation stated in 12 VAC 30-120-249 B 2 to eliminate the phrase "may not include direct therapy."

Issue:
Reimbursable activities for behavioral consultation services are too restrictive and do not allow for reimbursement of time that is normally associated with the provision of the service.

Recommendation:
12 VAC 30-120-249 C to be re-written as follows:

C. Service units, descriptions, and limitations. The unit of service shall be one-quarter hour (15 minutes). Travel time within 30 miles of the consultant's address and telephone conversation time to arrange logistical concerns are not billable.

Behavioral Consultants provide the following services:

a. Assessment, including observation of the individual and the environment; interviews with family, caregivers, and providers; review of records and documentation; administration and scoring of scales; analog and situational assessment and analysis.

b. Written behavior support plan which includes a description of the behaviors to be addressed, a description of environmental factors that influence the behaviors, a description of the procedures and interactions with the individual that are designed to assist the individual to function in the environment, and any data collection procedures that will be used to monitor the effectiveness of the plan.

c. Training and management, including written and/or face-to-face presentation of the support plan and the principles that underlie them; demonstrations; role plays; modeling; observation and feedback, review and analysis of data; and adjustments, modifications, and revisions to the plan and environment to maximize its effectiveness.

d. Specialized and intensive services may be used for individuals with intense needs after additional review and approval prior to providing the services. These services include:

  1. *Crisis intervention*
  2. *Participation in crisis stabilization services described at 12 VAC 30-120-227*
  3. *Specialized implementation of behavior support plans*

4. *Use and management of restrictive procedures*
5. *Monitoring of implementation*

12 VAC 30-120-249 D (Provider Requirements)
Replace the Behavioral Consultation requirements up through D. 3 with:

Behavior Consultation may be performed by professionals licensed by the Department of Health Professions with the training and experience needed to provide this service, and by persons meeting requirements described by the Department of Mental Health, Mental Retardation, and Substance Abuse Services.
Documentation Requirements:

1. *An ISP with required elements*
2. *A written support plan, support strategies, or interaction guidelines.*
3. *Maintain a record of all service contents, including date, description of service provided, and duration of service provided.*

Issue:
There is a need to develop mobile crisis teams that would be able to respond to critical behavioral situations in any part of the Commonwealth. These teams should have the capability for the direct response of or consultation by a psychiatrist when needed.

Recommendation:
Development of a tiered system of reimbursement that is capable of securing the services of a psychiatrist or psychologist as part of a special behavioral unit when those services are needed.

Issue:
There is a need to stabilize the direct support work force through better reimbursement and training in special needs of individuals who engage in problem behavior.

Recommendation:
Apply a tiered reimbursement system for residential reimbursement similar to the one existing in Day Support. This would allow for a High Intensity rate classification to be paid for persons who require a more direct and intense level of staff support. This rate would apply only in congregate settings of less than five individuals.

Issue:
There is a need for statewide coordination of crisis stabilization and intensive therapeutic behavioral services in Virginia.

Recommendation:
Add a position in the Division of Community Services that is qualified at the level of a psychiatrist with a specialty in developmental disabilities to provide coordination to the mobile teams and all intensive therapeutic behavioral services for persons with developmental disabilities.

Issue:
Need for continued and consistent training for the direct support work force.

Recommendation:
Establish continued funding for the web-based College of Direct Support as a primary vehicle for community direct support workers.

Issue:
Need for the continued expansion of the community capacity for Behavior Consultation services.

Recommendation:
Continue to fund the training and endorsement of providers Positive Behavioral Support.

Appendix D
Medical Oversight Focus Team Report

The Medical Oversight Focus Team was charged with identifying and recommending needed improvements regarding health related issues that can affect the outcomes of individuals receiving services. The specific study questions addressed by this group were:

a) Do skilled nursing services need to be more available to MR Waiver recipients?
b) Do medical services need to be more available to individuals with intellectual disabilities?
c) What other specialized supports do individuals with intellectual disabilities require?

Positive Impact

Discussion of the positive impact of the MR Waiver concluded that

- It allows choice of providers;
- Skilled nursing services are available in certain areas of the state;
- Nurse delegation (a Registered Nurse training and following up with ongoing monitoring a non-licensed staff person in performing a medical procedure she deems that this individual is capable of performing on a specific individual) is working where nurses are available;
- Individuals can access Environmental Modifications and Assistive Technology as means of obtaining needed medically oriented construction or devices.

Some children who have not been able to obtain an MR Waiver slot have had their medical needs met through Early and Periodic Screening Diagnosis and Treatment (EPSDT).

Enhancing the Person-centeredness of Medical Services

A person-centered delivery system is in planning through the Systems Transformation Grant. How an individual's general health will be monitored can be part of the process and will be developed by obtaining the input of the individual and his/her family.

Existing Gaps and Services to Fill those Gaps

Medical needs in the community should be met to the same extent as in an institutional setting; however, individuals with intellectual disabilities residing in the community often do not have the same access to the following services:

- Medical consultation with individual, family members and staff delivered by a nurse;
- Dental Services for adults;

- Nutritional Services delivered by a dietician to those with difficulties maintaining, losing or gaining weight, as well as those with medical conditions related to food consumption.

Community providers of supports may have difficulty obtaining pertinent information regarding the individual's care, as the hospital is not responsible for sharing this information.

Direct support staff require more training on healthcare and aging issues pertinent to individuals with intellectual disabilities.

EPSDT is often under utilized by children with intellectual disabilities.

There is occasionally difficulty in obtaining customized equipment *prior to* an individual's move to the community from a state training center where such equipment abounds. Currently individuals may not access MR Waiver services for home modifications or equipment until after the move has taken place. This is not helpful if it is needed in order for the individual to enter the community home (e.g., a ramp, bathroom modifications, special lift, etc.).

It is difficult to find providers of Skilled Nursing services under the MR Waiver, particularly in certain areas of the state.

Barriers

Direct support staff and even managerial staff in community programs for persons with intellectual disabilities are not medically trained, nor do they generally need to be. However, greater access to a nurse to review medical information and how it is being interpreted is needed. This would be particularly helpful in hospital-to-community transitions in which the individual may need nursing services but residential provider may be unable to serve because they have no licensed medical personnel.

Staff turnover is an issue that can affect continuity of care across all services. In the MR Waiver, there is often difficulty obtaining and retaining nurses in large part because the reimbursement rate is not comparable to home health services or private insurance funded nursing services.

Medical guardianship needs to be clarified, as the lack thereof can be a barrier to receiving needed health care.

The committee identified a need for educating present and future medical professionals in order to build capacity to properly care individuals with disabilities.

Recommendations

- Add dental services to the MR Waiver.

- Roll out person-centered planning statewide, with an emphasis on medical care. As a part of this, include a "Health Needs Assessment" as part of each individual's plan that would follow the person from service provider to service provider.
- Review MR Waiver skilled nursing services with the goal being to increase flexibility in their delivery. Move the billing unit structure to a 15-minute unit of service.
- Consistently fund Assistive Technology & Environmental.Modifications required *to enable* an individual to move to their new community residence from a training center or family home.
- Add a nurse management/monitoring service to the MR Waiver available to providers prior to and after accepting new individuals into their programs to ensure continued health and safety of medically fragile individuals and provide a liaison between non-medically trained support staff and the individual's physician(s) to partner for better health care of the person receiving services.
- Expand provider capacity of skilled nursing services, physical therapy and occupational therapy through increasing the reimbursement rates for these services to rates comparable to third party insurance payers & home health providers.
- Add nutritional consultation and pharmacy consultation for individuals requiring special diets and the review of medication interactions, side effects, as well as direct support staff medication training
- Develop a tiered system of skilled nursing services provision (acute, sub-acute, chronic needs) that would identify the level of care the person requires and pay for intense medical supports for short periods of time.
- Increase training for direct support professionals and case managers on medical management topics and crisis stabilization. Mandate requirement for providers to attend trainings and/or take specific coursework on-line (e.g., College of Direct Support).
- Increase the OMR capacity for training (i.e., increase the number of Community Resource Consultants).
- Shore up the Regional Community Support Centers where needed to provide a full range of specialty care unavailable to individuals with intellectual disabilities in the community.
- Develop the capacity for substitute decision makers and expand capacity for medical guardianships.
- Encourage universities to incorporate curricula on developmental disabilities for new and future medical professionals. In addition there should be training on providing medical services to individuals with intellectual and developmental disabilities to assist in educating our future medical professionals.
- Develop a more thorough and secure communication process for sharing and using information regarding individuals and their health and safety support needs.
- Reimburse nurses for their transportation time.

Increase the reimbursement rate for providers serving individuals with significant medical needs to encourage providers to accept these "high risk" individuals and provide them with the appropriate level of supports.

Appendix E
Person-Centered Practices Focus Team Report

Background

Twenty years of knowledge, experience and talk about person-centered practices have brought little change in Virginia's system of services for people with intellectual disabilities. This report reflects the voices of individuals, their families and the people who support them and describes changes they believe will help to transform the current service system to a community of person-centered supports. It explores new ways of supporting individuals in making their own decisions about where and how to live, managing their own services and who to hire, and becoming increasingly more involved in their communities and increasingly less reliant on the traditional service system.

DMHMRSAS established the Person-Centered Practices (PCP) Leadership Team in October 2006 in response to "a vision for a new system of services." The Inspector General called for collaboration in the development and implementation of person-centered planning following reviews of the training centers and community residential providers. The PCP Leadership Team, charged with guiding the implementation of person-centered practices across Virginia, quickly drew the interest, participation and leadership of more than 80 experienced stakeholders across the state (Attachment A).

Members include self-advocates, parents and other family members, case managers, direct support professionals, program managers, CEOs, MR directors, licensing specialists, human rights advocates, policy analysts, resource consultants, trainers and other advocates. There are representatives from Community Services Boards, the five state training centers, private providers, the Virginia Board for People with Disabilities, the Partnership for People with Disabilities, New Voices, Virginia Network of Provider Providers, vaACCSES, the Arc, Community Opportunities, the Office of the Inspector General, DMAS, the Department's Offices of Licensing, Human Rights, Community and Facility Services, Mental Retardation and Division of Health and Quality Care.

The PCP Leadership Team is organized into six smaller teams, each working on different tasks in the development of an implementation plan. The names and a summary of their charges are: (Attachment B)

Team 1: Evaluation and Quality Improvement: Determine and implement measures of success and roadmaps to quality.

Team 2: Commitment and Support: Gather commitment and support from all stakeholders needed to carry out the implementation plan.

Team 3: Training and Informational Resources: Develop a training plan and resource library that will guide all stakeholders in making the changes needed for person-centered practices in Virginia.

Team 4: System Change and Service Development: Identify the changes in services, policies and regulations to reflect our values and vision.

Team 5: Framework and Tools: Develop the process and documenting tools to be used across Virginia.

Team 6: Vision and Direction: Articulate a vision for Virginia and lead the work of the other 5 teams.

The PCP Leadership Team has convened 5 times since October 2006. Meetings are opportunities for individuals and families to present their stories, for the department and service providers to share their commitment to change and for all members to participate collaboratively in planning Virginia's transformation to person-centered services and supports. The 6 smaller PCP teams meet more frequently and present the progress of their work to the PCP Leadership team for review. Changes and next steps are recommended by a small workgroup representing all teams.

The PCP Leadership Team's *System Change and Service Development Team (*Team 4) served as the PCP Focus Group for the MR Waiver study (2006 General Assembly's House Bill 5002) and provided the information and recommendations for this study. This final report includes the input, recommendations and support of the PCP Leadership Team.

Several terms that will appear throughout this report have been defined by the PCP Leadership Team and are available in the Glossary (Attachment C).

Positive Impact of the MR Waiver

Before the MR Waiver, living in an institution was the only option for many individuals with intellectual disabilities. The Waiver makes it possible for individuals to lead satisfying and happy lives in homes and apartments in their communities. The MR Waiver offers an array of services that can expand or change as the needs and choices of an individual grow and change. When available and provided by creative and supportive staff, MR Waiver services can be effective in supporting the involvement of individuals in regular community life.

Real stories illustrating the positive impact of the MR Waiver are found in Attachment D and summarized below.

- The MR Waiver allows individuals who have lived their whole lives in their homes and communities, to remain when elderly caregivers die or are no longer able to support them.

- Individuals using Waiver slots can move throughout the state, to be close to family and friends or where services or providers of interest are available.

- MR Waiver supports individuals who have lived their whole lives in institutions to live successfully in the community with the proper supports.

- Community-based services offered through the Waiver are building relationships in the community between persons with disabilities and those without.

- Start-up funding is available for environmental modifications to homes in the community before individuals begin MR Waiver services.

- MR Waiver services can change when needs and choices change (such as transition from high school, moving to a new home, aging).

Gaps and Needs

During the past 15 years, the MR Waiver has become the primary funding source to support community living for individuals with intellectual disabilities living in Virginia. While the MR Waiver's array of services has helped more than 7000 people to live more meaningful lives in the community, many thousands of people remain on waiting lists to receive any service or support. Many still live in training centers, nursing homes and with overburdened and aging families.

For many who are fortunate enough to receive an MR Waiver slot, the services available today in Virginia do not always offer an inclusive, community life experienced and enjoyed by individuals without disabilities. Individuals remain in segregated and congregated settings, with few opportunities or services that help them to become contributing members of their communities. Flexible, person-centered, general fund dollars, once available to help support family members at home and reduce the need for more expensive services later, have been minimally available in Virginia during the 2000s.

Gaps and challenges of the MR Waiver are illustrated in the real stories in Attachment D and summarized below.

- MR Waiver slots do not follow individuals out of or into the state, so when families move, the individual cannot follow.

- Center-based services are more available, easier to deliver and provide more income for the provider than community-based, but can isolate individuals, rather than promote community connections.

- The Day Support Waiver is limited in scope and choice of services, and does not change as the circumstances of the individual change.

- Day Support Waiver slots are not helpful for people who want to work, or who need other non-congregate services, such as Companion, Respite, Personal Assistance and Supported Employment.

- Start-up funds are not available directly to the individual to spend on personal moving needs, such as furniture and other household items, deposits and equipment needs.

- Medicaid doesn't fund psychological evaluations and physical exams required by Medicaid for establishing SPO and Waiver eligibility, and initiating services.

- Dental services for adults are not available through Medicaid, so the overall health of individuals suffer, and the result is higher incidences of expensive procedures made necessary through years of neglect.

- The transportation system is not only not working for individuals and families, it's an increasing risk to health and safety. There are complaints from across the state of people kept waiting or dropped off and left alone. While it will take people to day programs, it won't take the same person to the jobsite or non-Medicaid appointment or when using the resources in the community with unpaid supports.

- There is a dearth of clinical and medical resources and personnel in communities skilled in providing services to individuals with intellectual disabilities.

- Rural areas are often even more limited in both generic and specialized resources.

- The MR Waiver has a complex and inflexible authorization and documentation system that does not support person-centeredness and self-direction.

Barriers

The present reality in Virginia is that **barriers** to our vision of an inclusive community exist. Those identified by the PCP Leadership Team include the following:

- Inadequate reimbursement rates that prevent the one-to-one supports necessary for building connections in the community.

- Reimbursement rates that favor larger settings.

- Rules and regulations that limit creativity and vision.

- Provider participation requirements that limit the availability of providers and the ability of individuals to select who provides their supports and services.

- Policies that restrict provider flexibility in supporting people to have real lives.

- A need for balancing risk with safety in a way that enables equal access to privacy and community.

- The continued reliance on old "models of support" (such as medical, behavioral, developmental), sustained by regulations that are heavily weighted toward safety, and with limited opportunity for individuals to make personal choices and learn from experience.

- Limited understanding of person-centered thinking and practices, few providers with knowledge, skills and abilities, few tools and system supports to help individuals and their teams balance personal safety with living and dignity of risk.

- Lack of circles of supportive individuals (not paid professionals) in the lives of people with intellectual disabilities across the state.

- Assumption of inability vs. ability when considering individuals with intellectual disabilities.

- Lack of understanding about the importance of intimacy and healthy relationships in the lives of those with intellectual disabilities; lack of education and imposition of personal and cultural values; the lack of privacy, opportunities and support to have healthy intimate relationships.

- Failure of service planning teams to support the individual in directing the planning.

- Lack of employment opportunities and little emphasis on the value of work in the lives of people with intellectual disabilities; lack of supported employment providers.

- Lack of opportunities for volunteer activities and contributing to community in unpaid ways.

- Approaching service delivery from a deficit-fixing/training/clinical mindset, rather than finding strengths and offering supports to assist individuals with achieving a good, comfortable life.

- Lack of options to control one's own funding, services, providers.

Other States

The current medical, clinical, programming model in Virginia's system does not align with the more progressive person-centered models available in other states. Reform to HCBS Waiver programs in many states was due to individual and class action suits, grant opportunities, strong collaboration among stakeholders and continuity of state and local leadership.[1] Wyoming (long embracing person-centered planning) rapidly expanded

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community services as a result of a lawsuit, and "was blessed by strong legislative support…with solid leadership and stakeholder collaboration."[2]

Following the proceedings in Boulet et al. vs. Celluci et al. in 1999, the state of Maine settled a case by committing $355.8 million to expand services between 2002 and 2006. The case resulted in the court decision "that inadequate funding does not excuse failure to provide services with reasonable promptness."[3] Wisconsin, with a strong advocacy community, sought several grant opportunities and invested in family and community support, supported living arrangements and other individualized services and supports.[4] Kansas, with a mission shared across stakeholders and state leadership, developed a strategic plan to reform its system of services.[5] Connecticut, with law suit pending, also took advantage of federal grant opportunities, with its history of supported employment, was able to move quickly with "the ability of state officials to effect policy change across the system."[6]

States that have been most successful in implementing person-centered practices have several things in common:

- **Shared vision and values across stakeholders**
- **Continuity of leadership**
- **Vigorous and flexible family support programs**
- **Emphasis on quality improvement**
- **Statewide training of all stakeholders in person-centered planning**
- **Self-advocacy and other empowering practices.** [7]

Additional solutions in other states that also hold promise for Virginia:

- *Personal Planners*

Some states have introduced new roles and responsibilities beyond the case manager to enhance success with person-centered planning. In Maine, a **Planning Process Coordinator** is selected by the individual to promote self-advocacy and engage the individual in the planning process. This person helps the individual with choosing team members, developing an agenda, sending meeting invitations, screening out personal topics from the planning agenda. This role is designated by the individual, and can be a volunteer or an existing paid provider.[8] North Carolina has created the role of **Certified**

Peer Support Specialist (CPS). The CPS is an individual who uses services, and has received training to provide support and advocacy to other individuals.[9]

- *Expectations for Outcomes from Service Providers*

Massachusetts ensures a person-centered approach to service delivery through a two-part process that includes both a licensure and certification process. The licensure process, similar to Virginia, gives legal authorization to provide services and supports, and is based upon the presence of essential safeguards in areas relating to health, safety and rights. The certification process reviews the outcomes in individuals' lives, in addition to health and safety, such as relationships, community connections, individual control, growth and accomplishments. Individual outcomes are viewed as equally as important as health and safety, but are recognized to take enormous effort, creativity and time to ensure both. The provider's ability to achieve other quality of life outcomes for those being supported is considered part of a provider's quality improvement process and may occur over time in partnership with the state regulators.[10]

- *Individual Budgets*

The introduction of an individual budget (a.k.a. individualized resource allocation) helps individuals develop plans for services and supports that best meets their unique needs and preferences. Virginia's current system funds programs versus personalized services, so choice, flexibility, creativity and cost-effectiveness are compromised. Individual budgets design supports around an individual rather than a service setting, funds are portable across providers, and individuals gain authority and flexibility over a variety of the most useful services and supports tailored to their needs and preferences. Wyoming's DOORS[11] and Maryland's New Directions Waiver are good examples of true individual planning and self-direction of support.[12]

- *Case Management/Service Coordination*

As in Virginia, case management (increasingly and more aptly referred to as **service coordination**) plays a pivotal role in establishing eligibility, coordinating and monitoring Waiver and other services to individuals with intellectual disabilities. In a few states (Kansas, Wyoming, Wisconsin), individuals have a choice of traditional or independent case management services.[13]

Case management services vary some across the states in terms of how often and when they're provided. They may vary based on need as is seen in Maryland, or may be time limited as in New York's Waiver.[14] Several states limit caseload size to regulate the workload, improve quality of service, facilitate person-centered planning, ensure regular monitoring of individual needs and services provided, and finally, decrease the frequent case management turnover. Kansas, Wyoming, Wisconsin, and Connecticut have a case management ratio between 30 and 35 individuals. Maine has implemented a maximum caseload size of 35 individuals and the choice between self-directed or agency-directed case management.[15] Similarly, New York limits caseload of service coordinators to 30 individuals.[16]

- *Support Broker*

Some states use a support broker/services facilitator to help individuals with developing their plans and managing their services. The role and responsibilities of a support broker go beyond that which is expected of a case manager/service coordinator. The primary functions of a support broker/services facilitator include specialized help to the individual and family with developing a person-centered plan, developing an individual budget, managing that budget, developing emergency back-up plans, managing services, as well as recruiting, hiring, and terminating staff. In Maryland, Connecticut, and Vermont, this service is funded under the individual budget, is selected by the individual from among friends, certain family members, or other approved providers. The support broker (whether paid or unpaid) is required by CMS when implementing individual budgets. Orientation, training and background checks are expected to ensure the quality of support provided. In Maryland's and Connecticut's Waivers, the case manager may also serve in the role of support broker, albeit with a more limited case management caseload as they assume the support broker responsibilities.[17]

Recommendations

1. Provide vision and leadership at the state and local level that embraces person-centered principles and practices.

- Articulate a shared vision, values and person-centered principles (see Attachment F).
- Increase the availability of resources for training and technical assistance.
- Provide incentives, assistance and guidance to local communities and providers for converting congregate programs into community-based services, such as supported employment, supported living, companion services.

2. Revise regulations, policies and procedures in the MR Waiver, DS Waiver, Targeted Case Management, Licensing, Human Rights, to reflect the shared vision, values and principles.

- Remove and/or change non-person-centered language and jargon, such as "mental retardation" to "intellectual disabilities;" "case management" to "service coordination;" "consumer," "resident" or "client" to "individual" and "self-advocate."
- Eliminate requirements for "training in problem areas," "treatment approaches" and "behavior management."

- Eliminate the medical, clinical, deficit models of support and require person-centered planning and practices.

- Develop a person-centered planning process in which individuals living in the community and in training centers can direct their supports.

- Limit caseload sizes, standard staff to individual ratios and size of congregate settings; shared bedrooms only upon request.

- Mandate self-assessments and quality improvement plans of all providers.

- Require more skills and training of direct support professionals and provider agencies.

- Provide training and opportunities for individuals to self-direct their services, personalize their supports and staff qualifications, hire, train and manage their employees.

- Acknowledge and support the roles that person-centered entities, such as microboards and circles of support, can play in helping individuals and teams make informed decisions.

- Require that residential providers allow individuals to keep financial resources that are needed and a reasonable amount of money to spend as they wish.

- Eliminate requirements that restrict the development of friendships and intimacy.

- Reduce unnecessary reauthorization of services when minor changes are made.

3. Establish a rate structure that supports the vision, principles and values.

- Pay more for services that promote personal contributions, inclusion in the community, valued roles and relationships with individuals without disabilities.

- Utilize individualized rates and budgets to support providers in serving more challenging individuals.

- Change the rate structure and cover costs for Services Facilitation activities to assure providers are available across the state.

4. Value work first, before considering alternatives to employment.

- To enable Supported Employment to be available in the MR Waiver, reimburse at the individual SE vendor rates approved and reimbursed by DRS for the service.

- Educate providers, state leaders and others on the value and possibilities of supported employment for individuals with intellectual disabilities and the value and opportunities to the community.

- Conduct community education and media campaigns for members of Chambers of Commerce about people with disabilities, tax benefits and other reasons and incentives for employing persons with disabilities.

- Explore other types of Supported Employment services that are successful in other states, such as self-employment, a micro-business and customized employment.

- Add Supported Employment as a consumer-directed service, so individuals can hire a job coach of their choice.

- Explore the bundling of current residential, day support and supported employment services for potential cost-effectiveness, fluidity and reduced paperwork for providers and individuals.

- Change Waiver (and DRS) regulations to promote more flexibility with Supported Employment services (e.g., MRW provider requirement that SE providers be DRS vendor ties them to Commission on Accreditation of Rehabilitation Facilities (CARF) accreditation and limits opportunities for other creative SE options becoming popular across the country).

5. Offer meaningful activities, retirement options, and natural ways to contribute to community as alternatives or in addition to employment.

- Include services that support meaningful retirement options.

- Eliminate the "training" requirement in residential and day support services.

- Assure that residential supports are available when needed, so individuals may stay at home, work, leave and return on individual schedules.

- Educate case managers, providers & families about tax shelters, trust funds, the importance of transition and retirement planning, end of life plans, dying at home.

- Allow reimbursement for general supervision as an aid to aging in place and allowing individuals to live regular lives, instead of constantly "programmed" and "trained."

6. Promote friendships and connections between people with intellectual disabilities and other community members.

- Provide incentives in all services for building relationships and natural supports.

- Structure rates that support high staff to individual ratios.

- Permit billing for services to multiple (but no more than 3) individuals (as in Congregate Residential and DS Services) for In-Home Residential Support and Personal Assistance, to support existing relationships and facilitate the formation of new ones.

- Use peer mentors.

- Use community living coaches.

- Structure the billing unit for Residential Support services so that a certain number of days away from the residence are fully funded in order to enable individuals to be more supported in maintaining their connections with family and friends.

- Add a service for building recreation and leisure connections.

- Promote self-direction and individual budgets that support inclusion in the community (e.g., payment for memberships, traveling in the community, volunteering).

7. Facilitate balance between dignity of risk and health and safety.

- Assist providers in supporting individuals in spending time with friends and outside of the service system.

- Incorporate into Virginia's planning process, a tool for balancing dignity and risk, such as Michael Smull's "donut."

- Explore and support circles of support and microboards in helping individuals, families and providers make ethical and sound decisions.

- Explore the addition of an "ethicist consultation" to the MR Waiver.

- Develop guidance materials and other support materials for individuals and those who support them in making wise decisions about personal risk and safety.

8. Promote healthy relationships in the lives of persons with intellectual disabilities and support the human need for intimacy and special relationships.

- Assure training for staff.

- Update the Staff Orientation Workbook and other training materials to address intimacy and relationships and include related ethics information.

- Implement a per diem reimbursement for residential services, so providers can feel freer to support individuals in spending time with people besides staff.

9. Support individuals in making their own choices about how to live their lives.

- With the individual as "leader," use a single service plan that integrates the responsibilities of the whole team.

- Hold semi-annual meetings of the whole team, review the plan with the individual and make changes that are needed or desired.

- Promote direct support professional involvement at team meetings and in the development of the plan.

- Promote a "Personal Planning Partner," or someone chosen by the individual to help coordinate and facilitate the individual's planning meeting, as well as helping the individual with person-centered planning and self-advocacy.

- Recognize the individual's circle of support for assuring informed decisions; consider "assisted competence" as an alternative to authorized representatives and guardianship.

- Expand the types of MR Waiver services that can be self-directed to promote a broader array of choice and control.

10. Promote varied and fun, social and community activities in individuals' lives.

- Train staff in person-centered planning, finding opportunities to connect people, using available social/community options.

- Allow day and residential services to include varied and fun social and leisure activities.

- Increase the availability and use of Companion Services.

- Implement a daily rate and individual budgets.

11. Support individuals in living where and with whom they want.

- Study the impact of the current reimbursement structure in developing alternatives to group homes.

- Propose a state initiative to promote affordable housing to expand home ownership.

- Educate providers/families/self-advocates about fundraising as a means to buy homes, with individuals either renting or paying the mortgage.

- Lower the individual's room and board/increase spending money by facilitating linkages to not-for-profit agencies that buy houses and permit providers to lease them inexpensively.

12. Support active and healthy lifestyles, and access to good medical, dental, psychiatric and other professional care of one's own choosing.

- Educate providers in identifying activities of interest to the individual that promote active and healthy lifestyles.

- Educate providers about general wellness principles such as good nutrition, healthy cooking, exercise, relaxation and stress reduction.

- Provide training to community health care professionals in disability issues to avoid the decline in individuals' medical/dental care that can accompany a move to the community.

- Add dental services to the MR Waiver.

- Educate providers/families that patient-pay is reduced by the amount spent on dental and medical.

- Educate providers that "community integration activities" should be those with genuine value to the individuals, such as experiencing the community through walking vs. riding around in a van.

13. Assure individuals have money, transportation and other resources and supports, not only for meeting daily needs, but also to pursue personal goals and dreams.

- Educate case managers and family members to ask residential providers about their fees and factor that into choice-of-provider decisions.

- Obtain benchmarks of average rent/costs for various areas to guide providers in setting reasonable room/board/general supervision costs and families and individuals in making informed choices.

- Seek other means to pay for costs over and above the Waiver supports (rent, utilities, food, etc.).

- Add to the MR Waiver, payment for room and board of a person living with the individual in exchange for providing wage-free supports.

- Fix the broken transportation system.

- Invest in Family Support dollars and other flexible funding.

14. Assure personal choice in how to live one's life, spend one's time and practice one's spirituality.

- Educate providers of their responsibility to support individuals in their chosen expression of their spirituality. Taking everyone to the same house of worship for the sake of staff convenience is unacceptable.

- Promote increased use of Companion services.

- Include reimbursement for general supervision.

- Move to a daily rate.

15. Provide real opportunities for lifelong learning.

- Add a new service or modify Prevocational Services to include transportation and participation in classes in the community that assist with career advancement (e.g., cooking classes for person interested in food service).

- Remove the requirement in residential and day support that an individual receives "training," and reward creative ways of helping people learn new skills of their choosing.

Person-Centered Practices Report Attachments

Attachment A: PCP Leadership Team membership

Attachment B: PCP Leadership Team Workgroups and Charges

Attachment C: Glossary

Attachment D: Stories – Success and Challenges

Attachment E: Person-Centered Principles

Attachment F: References

Attachment A – PCP

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Hammar, Kit	Self-advocate
Harp, Lisa	Self-advocate, New Voices
Hutson, Paul	Support Provider, Community-Based Services
Martin, Rhonda	Parent, Support Person
Moore, Linda	Parent
Moore, Tim	Self-advocate
Neal, Susan	Office of MR, DMHMRSAS
Phillips, Courtney	Support Person, Group Home Supervisor
Russell, Mark	Parent, VA Board for People with Disabilities, Res. provider
Waldron, Steve	Provider Association, VaACCESS, Advocate
Yarbrough, Dana	Parent, Parent-to-Parent, Partners in Policymaking, Partnership

Attachment B – PCP

Person-Centered Planning Leadership Team

Guiding the Implementation of Person-Centered Services and Supports
Across Virginia for Individuals with Intellectual Disabilities

Workgroups and Charges
October 2006 – July 2007

Team 1: Evaluation and Quality Improvement

a. Identify or develop measures, tools and methodology to evaluate how well we're doing in person-centered planning and person-centered services and supports.
b. Identify what makes it successful, why it fails, the gaps in Virginia and the areas of focus needed.
c. Identify ways to guide providers in their growth and development towards greater person-centered services and supports.

Team 2: Commitment and Support

a. Identify ways to demonstrate Virginia's commitment towards person-centered services and supports that promote self-determination, community inclusion and meaningful learning.
b. Identify strategies, resources and supports at the state and systems level to promote person-centered planning and approaches in local communities and training centers.
c. Develop or identify guidance materials and supports to local communities and training centers for implementing person-centered planning and approaches.

Team 3: Training and Informational Resources

a. Determine what skills, information, training and expertise in person-centered practices, self-determination, community inclusion and state-of-the-art services are needed by whom.
b. Identify the training, resources, and expertise already available or can be developed and by whom.
c. Identify strategies to make training, information, resources and expertise more available to all stakeholders – a "depth and breadth" approach.

d. Determine ways to assure consistency in training, messages and materials for all stakeholders.
e. Determine how to evaluate the effectiveness of the training and how to maintain it across the system.

Team 4: System Change and Service Development

a. Identify the types of person-centered services and supports that are needed in Virginia to accomplish individualized planning, self-determination, community inclusion and meaningful learning for individuals receiving services in the community and in the training centers.
b. Identify specific changes that are needed in regulations, policies, procedures, and funding that will promote the development and implementation of person-centered supports, self-determination, community inclusion and meaningful learning.
c. Develop a report for the MR Waiver Study, specific to the changes needed for the development of "person-centered, individualized support" in the MR Waiver.

Team 5: Framework and Tools

a. Identify and review the person-centered tools and paperwork that are being used in Virginia now.
b. Research and evaluate what other states are using.
c. Determine the critical components of all person-centered plans and services.
d. Identify a suggested format and/or examples of meaningful plans and paperwork for services that are Licensed by DMHMRSAS and/or funded by Medicaid.

Team 6: Vision and Direction

a. Develop a shared vision of a good life in Virginia.
b. Develop a position paper on person-centered planning.
c. Provide guidance, examples and direction to this person-centered planning effort, by answering the following questions:

    i. What services and supports do we want, and how do we want them to be done?
    ii. What training and information about person-centered planning do we want?
    iii. What other training would be helpful for us as we start doing more things?
    iv. What training do we think people who support us should get?
    v. What language do we expect to be used?
    vi. How do we want our plans to look?"

d. Review materials and plans of the other teams, and make recommendations as needed.
e. Recommend ways to build community across the PCP Leadership Team and across Virginia.

Attachment C - PCP

Glossary

Circle of support:

A group of 3 or more who have been designated by the individual with a disability to assist him/her to accomplish personal life goals and to support the individual in making decisions and, if so designated, as a substitute decision-maker.

Microboard:

An organization, incorporated under the laws of the Commonwealth, whose mission and scope is to develop, provide and oversee the delivery of services and supports, within a formal organizational structure, to an individual who requires assistance in decision making. Microboard membership is comprised of the person with a disability and others in personal, unpaid relationships with the individual.

Person-Centered Planning:

A planning process that focuses on the needs and preferences of the individual (not the system or service availability) and empowers and supports the individual in defining the direction for his/her own life. Person-centered planning promotes self-determination, community inclusion and typical lives.

Person-Centered Practices (Person-Centeredness):

Practices that focus on the needs and preferences of the individual, empowers and supports the individual in defining the direction for his/her life and promotes self-determination, community involvement, contributing to society and emotional, physical and spiritual health.

Attachment D - PCP

Successes

Toby lived with his mother who was dying of cancer. After she passed, Toby was no longer able to live in the apartment and with no supports, became homeless. In addition to intellectual disabilities, he has diabetes and congestive heart failure. Toby received a waiver slot, and moved into his own apartment earlier this year. He is receiving residential supports and is working with an employment provider in the hopes of getting a job in the community in the near future. The day *he moved, Toby smiled all day and said, "This is the best thing that happened in a very long time."*

Ronald is 28 and lives with his family, who recently learned they must move to a neighboring county. They expressed a great deal of relief when they realized that their son's MR Waiver slot will travel in the state with him. They will be able to move this summer to care for their parents and Ronald will still be able to live with them. They are building their home and part of the home will be an apartment for Ronald. He plans to receive in-home supports there.

Through the MR Waiver, Brendan, who has lived 20 years in a state mental health facility, became a community resident. His behavior at the institution was risky to others, and he was denied him the opportunity to move. Brendan cannot tolerate loud noises and people who are disruptive, so it was clearly not a good place for him to be. Brendan moved, and while he still needs intensive support from staff and others, has lived in the community almost 10 years. He has unique support needs, lives in a home in the country with his support person. Brendan has a life of his own design that includes friends, meaningful daily activity, and church involvement. He goes for daily walks, swims weekly in a community pool, goes to the library, and shops.

Jeff has an avid interest in firefighters, fire stations and equipment, but was banned from all local fire stations for stealing equipment. He receives services through the MR Waiver, and with non-center based day support, he has been able to reestablish visits to fire stations. His goal is to be able to eventually volunteer there. During visits, he shares photos and discussion with the firefighters on equipment and safety. Jeff is developing new relationships, which he hopes will lead to a volunteer position there in the near future.

Joe is blind and must use a wheelchair to get around. He attended the Vision Program at CVTC and was well respected by staff. He had the opportunity to visit homes in the community with the help of the training center staff. The group home, with the back screened-in porch and yard for sitting in the sun (a favorite activity), was Joe's choice, but was on a hill, and the driveway was fairly steep. The doors were narrow and the only entrances to the home involved at least one step. With start-up funds available to individuals enrolling in the MR Waiver, modifications were made to Joe's new home. Doors were widened, a ramp was installed from the driveway to the back door and another up to the porch. A simple strip of Plexiglas was installed in the hallway for Joe to also be able to travel through his house.

Challenges

Rodney recently received a Day Support Waiver slot. The family accepted this waiver and is able to utilize it for after-school supports. Unfortunately, when he graduates, Rodney's waiver will not "grow" with him. He is on the waiting list for the full MR Waiver and is need of in-home supports. His family would like to have him live at home as long as his severe behaviors can be managed. The day that he may need to move out of his family home is sadly and quickly approaching. Rodney's family feels that his Waiver funding should "grow as his needs grow" and become a full waiver. His chances to receive the services he will need are limited. Rodney remains on the Urgent Waiver waiting list along with 93 other Chesterfield residents.

Jonathan was diagnosed with Alzheimer's in 2006. He is 48 years old and has lived in his current home for 16 years. He would like to remain there as long as possible, but for his group home to bill the Congregate Residential rate, they must provide "training" which isn't supporting Jonathan's needs. .

Ralph and Roger are brothers. Ralph has MR Waiver, but Roger does not. Ralph lives in a group home and receives day support services. Roger lives in an Assisted Living Facility, and does not have the services he needs under the MR Waiver. Roger was eventually offered a Day Support Waiver slot, but had to decline, after learning that he would have incurred a patient-pay and could no longer afford to remain in the ALF. With the change in patient pay rules, Roger is now interested, but has not yet been offered a slot.

Matthew was five when his family from Arizona, where they were recipients of the Waiver, to Virginia. He received several supports in the home, including personal care, occupational therapy and physical therapy. Prior to moving, they contacted a family friend, who was familiar with Virginia, and were told that Virginia was a wealthy state and would have "plenty to offer." He is now on the MR Waiver waiting list, and the family is considering moving back to Arizona.

Brianna has intellectual disabilities and total hearing loss. She is prone to challenging behavior when others around her do not understand what she is trying to say or when she is not understood. Brianna wants to work in a competitive job, but needs ongoing support to be successful, but cannot find a Supported Employment provider who'll provide services under the MR Waiver, since DRS will reduce their vendor rate significantly if they do, and they will no longer be able to provide job coaching services. Brianna is currently attending a day support program five days a week, but continues to hope for a job one day.

Attachment E – PCP

Person-Centered Principles and Practices

We see a Virginia where individuals of all ages and abilities have the supports we need to enjoy the rights of life, liberty and the pursuit of happiness and the opportunity to have a good life.

Having a good life means different things to different people. It includes joy and happiness, health and safety, dreams, meaningful activities, intimate relationships with family and friends, having a home, transportation, work, money, bank accounts and the ability to contribute to family and community.

We believe our journey to a good life is best led by the voices of individuals and by following these person-centered principles.

> *"I am listened to." "I have a voice." "I listen to others."**

Principle 1. Listening

Individual choices and descriptions of a good life are respected and followed.

- You can learn about the things that are important to me and my choices by getting to know me, by "listening" (even when I'm really speaking through my actions), and by asking different questions of me and of others who know and care about me.

- My story and experiences are seen as important and are used to help develop my plan. People who are involved in my support take time to share and learn about my history.

- I have what I need to fully take part in planning my own supports, including any assistive technology I need. I am able to share my needs and choices in the ways with which I am most comfortable and that are understood by others.

- People who know, care and support me are learning about the things that are important to me and about my dreams. I invite people I want to be part of my life and to help with my planning.

- Things that are important to me because of my family background and/or my nationality are respected and supported in helping me build a good life with others.
- My description of a good life is respected and shared by those who support me. Those who support me want my life and my plan to work for me.
- My plan for a good life for me is based on what's important to me, on my choices and on my dreams.

"I have choices." "I am responsible for my choices." "I am respected."

Principle 2. Self-Direction

Personal choice and control are supported.

- My rights, responsibilities and dignity are recognized and protected at all times.
- I am in charge of and responsible for my future, services, resources and the help I need.
- Even if I cannot speak for myself, I have the support I need to have the control I want over my life, services and resources.
- I have the right to change my plan at anytime. People who work with me on my plan regularly ask me what is important to me because things may change over time.
- I have choices about all of my supports both the ones paid for and those that come from friends, family and other people I know.
- I have the right to take risks even when others don't agree with my choices. I am supported to make my own choices and to learn from both the good ones and the bad ones. I deserve to be supported to have a good life today and not "some day when I'm ready."
- I choose how, when and with whom to spend time and share my interests, gifts and talents.
- I choose supports that fit with my description of a good life for me. My plan and the supports that I need are not based on the services

that people who work for government or who provide services think are best for me.

- I know what is important to me and I have a voice in Virginia.

"I have friends and family I see often." "I am a part of my community." "I have found groups, organizations and social activities that interest me."

Principle 3. Community

Relationships with families, friends and people in the community are very important and at the center of planning.

- I am supported in staying connected to my family, friends and community.
- I am supported in making new connections and friends.
- I receive supports to meet others with confidence and dignity.
- As I make new friends and connections, I have more people who care about me and who can support me in my life.

"I am able to contribute to family and community." "I learn new things."
"I am respected." "People are nice to me." "I respect others." "I am nice to others."

Principle 4. Abilities

The experience, talents and contributions of individuals, families and communities are strengthened and supported.

- Information that I need is easy to get and easy for me to understand.
- I have opportunities to learn new things in ways that work for me.
- The people who support me have the skills needed to do the job. They want the best for me, and they encourage me to be my best self.

- I am important as a person and I am able to contribute to my family and community.
- The things that I spend time doing and the changes in me for the better are based on my gifts, talents, and abilities.
- New and better ideas about how to support me and skills to do the job well are rewarded.

"I am responsible for my choices." "I receive quality support."

Principle 5. Accountability

There is shared responsibility for supports and choices.

- Things that are written in my plan happen in my life.
- Support is available when my family and I need it.
- I am supported in taking responsibility for my choices and the things that I do.
- The people who support me understand my right to take risks and to learn from my good and bad choices. I understand my responsibility to try to make choices that keep me healthy and safe. Together we try to balance my right to take risks with my health and safety.

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Appendix F
Waiting List Focus Team Report

The MR Waiver Statewide Waiting List, first created in 2001, was designed to be a mechanism for allocating scarce resources (in this case funding for MR Waiver and now Day Support Waiver slots). In regards to the MR Waiver, the division of the Statewide Waiting List into the urgent and non-urgent categories enables slots to be allocated first to those most in need. Individuals found eligible for the MR Waiver must be in need of services within 30 days in order to be placed on either list. Those meeting additional criteria, indicating greater urgency of need, are placed on the urgent need component of the list. Only individuals qualifying to be on this list are eligible for MR Waiver services (until there are no more individuals on the urgent needs list statewide). It is felt that this is a highly effective way of ensuring that citizens most at risk of institutional placement but desiring supports in the community actually receive those supports through a Medicaid Waiver. Individuals may access the Day Support Waiver from either section of the overall Statewide Waiting List, as slots are awarded according to date of need for that waiver.

The Waiting List focus group of the MR Waiver study was charged with considering the pros and cons of the waiting list, as well as recommending changes to mitigate any negative features and thus enhance the MR Waiver.

Positive Impact of the MR Waiver Waiting List

While most would be hard-pressed to identify many benefits to a mechanism that forces people to wait to receive badly needed services, the group did want to point out that the division of the list into urgent and non-urgent, with the individuals with the most urgent needs being required to be served first, has the advantage of ensuring that Waiver slots, when they come available, are allocated to those with the greatest need. This appears to be an ethical basis of managing limited resources for community-based services, as well as being a person-centered triage method. Some triage method of assigning Waiver slots is used in 47 out of 51 states/territories in the U.S. Most CSBs (charged with reviewing all the individuals on their urgent needs list whenever a slot comes available) have strict processes for determining who gets the available slot. These meetings typically involve "blind" reviews (in which the individuals' names are removed from the materials describing their circumstances) of those on the urgent needs list and some CSBs include outside community members in these meetings to ensure an unbiased process.

The CSBs' submission of the names and dates of need of individuals they place on the Statewide Waiting List provides concrete evidence of the need for additional funding, providers and potentially services. In this way, the waiting list is an invaluable planning tool and provides the state with the knowledge it requires to more fully fund the need, should that path be chosen. However, the committee suspects many more individuals need services than are on the Statewide Waiting List at this time, as not all require/desire Medicaid funded services, know to ask for these services if they qualify or want the type of services the current MR Waiver offers.

Enhancing the Person-Centeredness of the Service System for People with Intellectual Disabilities Concerning the Waiting List

The Statewide Waiting List is comprised of 3749 individuals – 1849 on the urgent portion and 1900 on the non-urgent (as of 9/10/07). The desired outcome where the Waiting List is concerned is to significantly decrease or even eliminate it. The most person-centered outcome for the individuals on the Waiting List would be to receive the supports for which they are awaiting. Receiving these supports in a flexible way that enables these individuals to have "an ordinary life" is the desired result.

Other specific strategies for enhancing person-centeredness in this area include more outreach to younger individuals' families (i.e., children in their early school years) to educate the parents on the service system beyond the school years, so that they may begin to be prepared. Many families of children who receive mandated special education services while in school are shocked when their children graduate that there is no mandated support system for the adult years and if the parents did not contact their CSB early to begin transition planning (including getting on whatever waiting list for which their son/daughter was eligible), there may be significant delays before supports for their grown child resume, leading to loss of skills on the part of the individual and disruption of the family routine if the caregiver(s) works outside of the home. It was suggested that DMHMRSAS develop a brochure to relay to the school systems (to in turn relay to parents of special education students) that details what parents should do to plan for the post-school years. This brochure could direct parents to the DMHMRSAS website for more information, as well as recommend that parents stay in touch with the CSB case management system so as to provide updates as family situation changes occur. This last recommendation about the website would require further enhancement of the DMHMRSAS website, such as the inclusion of more practical information for families on how to access the waiting list and navigate the MR Waiver system. The Florida state website is recommended as a model to use in further developing the Virginia site.

A final avenue to pursue is to require that every case manager and direct service provider obtain training in person-centered practices and that the MR Waiver regulations/policies be revised to better support the implementation of person-centered practices.

Existing Gaps and New Services to Fill Those Gaps

The gap that exists is the lack of availability of services for all those who have been determined eligible for the MR Waiver, as well as those in need of supports who do not qualify for a Medicaid Waiver. The lack of availability of services is directly related to the lack of funding to meet the existing level of need for services throughout the state.

Barriers to Success

Barriers to accessing needed services are two-fold: a lack of funding for sufficient slots to support all those currently on the waiting list and a lack of sufficient numbers of providers of some services, particularly in certain geographic areas. Regarding the former, nationally recognized expert, Gary Smith, states in the paper, The Question of System Size," that ". . . when system capacity reaches more than 200 persons [receiving intensive supports outside of the family home] per 100,000 population, a state's waiting list is likely to be relatively small." According to this and our existing Virginia data (state population of approximately 7 million with over 7,000 people on the MR & DS Waivers combined), we are currently serving approximately half of the individuals who will need waivers. Assuming a static state population, Virginia needs 7,000 more "comprehensive Waiver" slots to render our waiting list "relatively small." This will take 17 years at a rate of 400 slots per year or 10 years at 700 new slots per year.

Possible Solutions from Other States

Virginia is far from alone in its possession of an extensive waiting list for services for people with intellectual disabilities. The committee members examined information about a number of states that have also grappled with waiting list issues. Information was reviewed about 17 different states with more in-depth information gathered about 10 of these states. It was learned that while one of the examined states has no waiting list (South Dakota), others have significantly higher waiting lists than Virginia.

All of the states reviewed had determined that part of their approach to lowering waiting list numbers was to adopt a Supports Waiver (see below) for persons with intellectual disabilities, *in addition to* their comprehensive waiver (such as our MR Waiver). Nearly half of the states currently operating Supports Waivers (eight of the 17 reviewed) were further nudged toward this solution by litigation over their waiting lists, which were perceived by advocates as barriers to community access (some of these lawsuits referenced the Olmstead decision or the Americans with Disabilities Act).

Supports Waivers are geared toward preventing out-of-home placement through offering less than 24-hour supports. Thus, persons on the waiting list for services, who do not require out-of-home placement (as would be provided under the comprehensive waiver), are enabled to have some of their needs met and thereby continue to remain in the community via a Supports Waiver. Costs are capped for each individual at significantly less than the average ICF/MR rate. In fact, Supports Waivers represent roughly 20% – 50% of the per capita costs that states incur in "comprehensive" waivers, since they emphasize less costly *in-home* services vs. the more expensive 24-hour care *group homes.*[1] Furthermore, they are designed to encourage the use of non-traditional providers of care such as family and neighbors, often through the use of "consumer-directed" services.

Supports Waivers' average participant cost were 23.5% of states' comprehensive waiver costs over the past seven years. The outcome in states with Supports Waivers is to generally permit more individuals to be served while moderating the increases in the average participant annual expenditures.[1] In nearly all states, the actual costs of Supports

Waivers are lower than the capped amount (see Appendix A), suggesting that, for the most part, people tend to use only what they need.

Another factor related to decreasing the Statewide Waiting List that was examined in other states was their eligibility processes/tools. The committee theorized that one reason there are so many individuals in need of services in Virginia and unable to even get on the Statewide Waiting List is that the criteria for gaining access to the MR Waiver is stricter than other states. Eligibility criteria in Alabama, Tennessee, Florida, Oklahoma, Texas and Nebraska were investigated. While there was great variability in these states' criteria, none seemed to have as "institutionally focused" a functional eligibility tool as Virginia has in the Level of Functioning Survey.

Recommended Changes to the MR Waiver to Improve Virginia's Ability to Address the Waiting List

The focus group recommends that Virginia actively pursue applying for a Supports Waiver through the Centers for Medicare and Medicaid Services (CMS). After investigating the types of supports and overall structure of this type of Waiver in 17 other states, the committee recommends a Supports Waiver, which includes the option for all services to be Consumer-Directed.

While overall expenditures per person would be capped (see below), the committee advises against individual caps for given services, as this tends to unnecessarily restrict individuals' access to needed services. Instead the use of individualized budgets, based on assessed need would produce a more person-centered result.

Another means of providing some services to persons currently on the Statewide Waiting List or not eligible for Medicaid funded services that was discussed by the committee was the implementation of widespread distribution of Family Support Funds. These have been used in the past in Virginia and represent a capped allocation from the General Fund to individuals and their families to enable them to purchase needed technology items, and some limited services, such as respite, to enable the family to continue to support the individual in their home in the absence of more comprehensive services.

Issue:

Virginia maintains a waiting list of close to 4000 persons for MR Waiver services. There is a lack of funding for all of these individuals to receive services under the comprehensive Waiver.

In addition there are approximately 13,000 other identified individuals with intellectual disabilities in the state receiving few or no formal services due to their inability to qualify for the primary source of funding for services: Medicaid.

Recommendation:

1) Develop and implement a Supports Waivers, which would be geared toward preventing out-of-home placement through offering less than 24-hour supports in a capped-cost format. Thus, persons on the waiting list for services who do not require out-of-home placement (as would be provided under the comprehensive waiver) would be able to have some of their needs met and thereby continue to remain in the community.

The committee recommends a Supports Waiver include the following services/supports (all to have the option of being Consumer-Directed) to adequately manage the need:

- Supports Broker/Services Facilitator;
- "Community Support Services" – to include Personal Assistance, In-home Residential, Companion, Respite, Chore, and Homemaker services plus what the group termed "Community Access" (a generally 1:1 version of community-based Day Support);
- "Person Directed Goods and Services" to include a voucher for some or all of the following supports a person to (1) clean house for the Waiver recipient, (2) perform grocery shopping, (3) transport the individual to community locations for purposes of shopping, employment, etc. The voucher might also be utilized to pay for psychiatric, counseling, crisis response team or other MH supports for persons with dual diagnoses;
- Assistive Technology and Environmental Modifications (to include vehicle modifications) combined into one service (ideally with a monetary cap above the current $5000 in the MR Waiver), with the recognition that permitting increased van modifications may decrease transportation costs through Logisticare);
- Day Support;
- Therapeutic Consultation;
- Supported Employment;
- Crisis Stabilization.

To enable those on a Supports Waiver being able to access a comprehensive Waiver slot at the point that their needs change and out of home residential supports are required, several possibilities were suggested:

- Convert Supports Waiver slots to MR Waiver slots as individuals' needs change;
- Enable a Supports Waiver recipient to easily access the MR Waiver via a pool of emergency slots, with the MR Waiver to DD Waiver transition of children at age 6 as a model. A potential method for creating this slot pool initially would be to urge/require those currently on the MR Waiver, who only use a minor level of services, to move to the Supports Waiver, retaining those slots for emergencies.

2) In the absence of a Supports Waiver, the committee recommends providing those not receiving any Waiver funding due to ineligibility or their status on the waiting list with Family Support funds. This limited expense alternative would put some money for the purchase of needed services and supports in the hands of those who at present have little or no supports.

Issue:
Parents/family members do not understand how to navigate the MR Waiver system and obtain services for their loved ones.

Recommendation:
1) Develop a brochure to relay to the school systems (to in turn relay to parents of special education students) that details what parents should do to plan for the post-school years. This brochure could direct parents to the DMHMRSAS website for more information, as well as recommend that parents stay in touch with the CSB case management system so as to provide updates as family situation changes occur.

2) Further enhance the DMHMRSAS website to include more practical information for families on how to access the waiting list and navigate the MR Waiver system.

Issue:
Many individuals on the MR Waiver statewide waiting list and those who do not qualify for the MR Waiver face barriers in leading the type of lives that they desire.

Recommendation:
Require that every case manager and direct service provider obtain training in person-centered practices and that the state (MR Waiver, Office of Licensing, etc.) regulations/policies be revised to better support the implementation of person-centered practices.

Issue:
Many citizens may be artificially excluded from needed supports due to diagnostic and functional eligibility criteria.

Recommendation:
1) The current functional eligibility tool in Virginia (the Level of Functioning Survey) is outdated and unnecessarily institutional in its focus/language. This may unnecessarily exclude some individuals from MR Waiver eligibility and thus needed supports. The eligibility criteria of six other states were reviewed. Several had criteria that better reflected skills that are necessary in the communities of today. The committee recommends exploring the replacement of the present LOF with another functional eligibility determiner that will better discern individuals who require Waiver level supports.

2) DMHMRSAS should be named the lead agency for services for persons with developmental disabilities other than mental retardation. 32 of the 50 states operate under a "Developmental Disabilities" program designation. 9 are "Mental Retardation-only" organizations and the other 9 are either labeled "MR/DD" or house these state services in a larger multi-disability agency.

[1] Human Services Research Institute, "Gauging the Use of HCBS Supports Waivers for People with Intellectual and Developmental Disabilities (Draft)," April, 2007.

Appendix G
Employment Focus Team Report

Team Vision

The Commonwealth shall value work as a priority before considering alternatives to employment.

Work is a critical component of community, a social expectation and a cultural standard. It is a true measure of integration, helping us to define our role in society and affecting how we are perceived. The dignity, responsibility, self-competence, and economic independence of employment and/or a meaningful career reduces dependence on public benefits, enhances self-reliance, changes attitudes, and promotes full community inclusion.

Employment in Virginia

Virginia currently enjoys a statewide unemployment rate of approximately 3.2%, yet almost **70 percent** of Virginians with disabilities are unemployed or underemployed. Virginians with disabilities want to live and work in their communities. Like all Virginians, they want to earn wages, pay taxes, and purchase goods and services in their communities.

Studies and individual experiences show that individuals with disabilities want to work and can work. They represent a rich pool of talent with strong work ethics and stable long-term employment with little or no turnover. Moreover, people with disabilities deserve equal access to employment in a morally responsible and affluent society (Huang and Rubin, 1997).

However, the complexity and restrictions of federal, state and local programs and funding make it difficult to support individuals with intellectual disabilities in competitive employment in Virginia. There is limited knowledge in the use of work incentives and uncertainty about the loss of resources and medical coverage as individuals attempt self-sufficiency through work.

As of December 2004, there were 113,256 Virginians with disabilities receiving SSI benefits and 155,830 Virginians with disabilities receiving SSDI benefits. Almost 66 percent of all disabled recipients that receive SSI were diagnosed with a mental disorder. Unfortunately, only 6,451 or 5.6 percent of Virginians receiving SSI benefits work. Of the 6,451 Virginians receiving SSI that work, only 24 percent (1,554) earned above the Medicaid threshold for Virginia and were in SSI 1619b status; less than one-half of one percent (16) had Plans for Achieving Self Support Plans (PASS); and less than eight percent (522) took advantage of Impairment Related Work Expenses (IRWE). These figures present conclusive evidence that, for Virginians with mental disabilities who want to work and who receive government disability benefits, there has been no clear path to higher income through available work incentives.

An even smaller percentage of individuals with disabilities are employed through Virginia's MR waiver system. Thirty-eight, or less than one-half percent, of over 7,000 individuals currently receiving MR Waiver services are receiving Individual Supported Employment (SE). Competitive employment for waiver recipients is virtually nonexistent. The Medicaid rate for Individual SE contributes significantly to this problem and will be discussed throughout this report.

Brief History of Employment for Individuals with Intellectual Disabilities in Virginia

During the 1980s, Virginia prioritized the integrated employment of people with intellectual disabilities. The Rehabilitation, Research and Training Center (RRTC) at Virginia Commonwealth University demonstrated that individuals with significant disabilities could work in regular jobs in the community, given a good job match and individualized, flexible, ongoing supports. Supported employment programs were rapidly developing across the country, and Virginia was a state leader in supporting individuals with significant disabilities to leave developmental centers and sheltered workshops to earn minimum wage and above in part-time and full-time jobs in their communities.

In 1985, the federal Office of Special Education and Rehabilitation Services awarded the Virginia Department of Rehabilitative Services (DRS), in collaboration with the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS), a five-year systems change grant to develop a statewide system of supported employment services. An Office of Supported Employment existed in both departments and five supported employment consultants, employed by DMHMRSAS, were available to providers and local communities in the five Health Planning Regions. Technical assistance, training and start-up funding were available to new providers and Virginia grew from three providers in 1985 to more than 40 by the early 1990s. Local DRS offices and Community Services Boards (CSB) worked in partnership to pay for initial and long-term support services.

In Virginia, SE became a reality for people with intellectual disabilities through this grant. After the grant, no funds were available to continue the newly developed infrastructure and SE began to fade. From the onset of the MR Waiver, Day Support services were favored over the low rates and complex, restrictive policies of SE and only people who came from ICF/MR living arrangements were eligible. Additional reasons for the failure of MR Waiver funded SE include: a requirement that the service is not available from DRS or the school system, higher reimbursement in day programs and prevocational services, and because it is a non-traditional way of supporting individuals with disabilities with no incentives for providers.

The reimbursement rate for Individual SE is the principal reason individuals in the MR Waiver do not have access to these services and history is helpful in understanding the urgent need for change. Since this is the same service also purchased by DRS, it must be provided at the same rate to both state agencies. Since SE programs were first established in the mid-1980s, each SE provider submits a rate-setting package annually, based on the organization's costs, to DRS who then negotiates individual rates with vendors. Medicaid does not accept these varied rates, but instead pays a standard rate of $17.64, significantly below the DRS hourly rates. Even those SE providers willing to accept the Medicaid rate, are disallowed from accepting a lower payment, and have been forced to leave the Medicaid program in order to maintain their vendor agreement with DRS. They are the only vendors eligible to provide SE under the MR Waiver, yet they are excluded.

Knowing the history of the Medicaid reimbursement rate is also helpful. The original MR Waiver application included daily payments for providers each day that individuals were successfully employed. Provider rates were established at $65 (more than four hours) and $32.50 (two - four hours) regardless of the actual number of hours the job coach worked. This was an early attempt in Virginia to pay for outcomes, but SE was not utilized before reimbursement was reduced to $16 an hour of service.

Positive Impact of the MR Waiver on Employment

Although Individual SE for those participating in the MR Waiver has decreased dramatically over the last 15 years, the number of Virginians participating in Group SE has steadily climbed over the last seven from 230 individuals to 511. Most recognize however, that this number could be higher with reforms to the MR Waiver.

MR Waiver Employment Services

The MR Waiver includes three employment services, Prevocational (Prevoc) services, Individual Supported Employment and Group SE and are defined in the regulations as:

*"**Prevocational services*** means services aimed at preparing an individual for paid or unpaid employment. The services do not include activities that are specifically job-task oriented but focus on concepts such as accepting supervision, attendance, tasks completion, problem solving and safety. Compensation, if provided, is less than 50% of minimum wage.

*"**Supported Employment – Group and Individual Competitive Employment*** means 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."

Other Employment Services

Two agencies within the Health and Human Resources Secretariat have the lead responsibility for vocational rehabilitation services in Virginia under the federal Rehabilitation Act of 1973, as amended (PL 93-112). This act provides federal grants to states for employment related services to individuals with disabilities, giving priority to those who are considered to be "significantly disabled." DRS is responsible for providing vocational rehabilitation services to individuals with disabilities unless the individual has a primary disability of blindness or vision impairment. In that case, the Department for the Blind and Vision Impaired provides vocational rehabilitation services.

The DRS mission is to work in partnership with people with disabilities and their families as well as to collaborate with the public and private sectors to provide and advocate for the highest quality services that empower individuals with disabilities to maximize their employment, independence, and full inclusion into society.

The DRS is currently under an "Order of Selection." When, due to limited resources, all eligible Virginians with disabilities cannot be served, the law requires that DRS provide services to persons in priority categories. Individuals who are determined eligible for services are placed into priority categories. DRS can open and close categories based on its available resources.

Currently, all categories are closed under "Order of Selection" other than services for individuals with the most significant disabilities. Three hundred individuals are currently on a waiting list established by the implementation of "Order of Selection" for DRS time-limited vocational services. However, when funds are limited, it has an overall "trickle down" effect of limiting the number of hours authorized for individuals deemed eligible to be served. Thus, individuals do not necessarily receive the level of services they need or require even if they meet the "Order of Selection." These time-limited vocational services include but are not limited to work adjustment, situational assessments, job development, job placement, job coaching and training, and job stability services.

Long-term follow along services and periodic supports are provided for DRS supported individuals who have no other source of long term employment support services available. These services, funded entirely by state dollars, include Extended Employment Services (EES) and Long-Term Employment Support Services (LTESS) and are provided by CARF accredited Employment Services Organizations (ESOs). These ESOs are the same vendors qualified to provide SE services under the MR waiver.

OVERVIEW
Employment Services

Program or Service	Received Services	State Funds	Federal Funds	Total Funds	Average Per Capita Cost
MR Waiver (SE Ind) - FY06	45	$ 2,194.25	$ 2,194.25	$ 43,895	$ 975
MR Waiver (SE Grp) - FY06	511	$2,692,028	$2,692,028	$ 5,384,057	$ 10,536
Vocational Rehabilitation (VR) Program (FFY06)	9,782	$3,446,154	$12,732,975	$16,179,128	$1,653*
Supported Employment (SE) (FFY06)	3,892	$1,316,581	$5,514,552	$6,831,133	$1,755**
SE for Individuals with Physical Disabilities (SFY 06)	127	$287,472	0	$287,472	$2,264***
Extended Employment Services (EES) (SFY 07)	626	$3,045,227	0	$3,045,227	$4,968
Long Term Employment Support Services (LTESS) (SFY 07)	2,478	$5,117,917	0	$5,117,917	$1,208 (Ind) $4,656 (Grp)
CSBs & Local Sources					

* Agency served approximately 24,000 individuals in FFY 2006 with 9,782 receiving one or more purchased services. "Served" means DRS core services and/or purchased services. State/Federal Fund distribution based on 21.3% state and 78.7% federal funding.

** For FFY 2006 not life of consumer program (RSA 636), also these individuals and funds are included in the VR totals and also include Title VI funding.

*** Includes both provided and purchased services.

Successes in Other States

For purposes of this report, **Colorado, Tennessee, Minnesota and Maryland** supported employment waiver programs were reviewed and compared against Virginia's supported employment programs under the MR Waiver. The definition for waiver supported employment programs for all five states is very similar. Each state stresses various program objectives. For example, Colorado, Minnesota, Tennessee and Virginia stress that supported employment is paid and occurs in community settings where persons without disabilities work. The MR Waivers for Colorado, Minnesota and Virginia stress that supported employment services are for persons for whom competitive employment at or above the minimum wage is unlikely due to the nature and complexity of their disabilities.

Activities that are allowable under Virginia's Waiver are not easily tailored to the individual when compared to the other states. An individual may receive training in specific skills or specialized supervision or transportation to/from work sites, but the choices available remain generic. On the other hand, the Maryland, Tennessee and Colorado MR Waivers are focused on the individual's preferences and needs that form the basis for the service plan. Allowable activities in Colorado, Maryland and Minnesota stress the individual. Whether individualized assessment, individualized counseling, individualized job development or appropriate job matching for the individual, all three states seem to recognize the importance of the individual as a consumer of services. Colorado appears to allow the most flexibility and does not impose any service limits and only imposes a financial limit of $35,000 per year per recipient. The individual can receive as many services as can be negotiated with the provider. Services are oriented toward long-term support.

Tennessee has recently made employment a top priority for individuals with disabilities. In order to increase the number of individuals who are employed, the Tennessee Department of Mental Retardation Services initiated *Employment First* that establishes employment as the first day service that is considered in an individual's service plan. Supported employment is easily combined with other day services. *Employment First* also strives to increase the service capacity of day service providers and has three critical elements included in their plan:

1) Clear and effective communication between DMRS, Vocational Rehabilitation (VR), the Council on Developmental Disabilities and advocates;
2) Every individual served by DMRS in the community must have a least one job site assessment every three years; and
3) The development of tools and resources for in-depth discovery for making a good job match -- what that job seeker wants, needs and has in skill and interests.

Success is reliant on Home and Community-Based Services Waiver funded SE, favorable rates for SE, Money Follows the Person, blended VR and DMRS funds, Social Security work incentives, training, Community Work Incentive Coordinators and natural supports.

Units and Reimbursement Rates – State Comparison

A review of unit types and reimbursement rates include wide ranges for both categories. The smallest unit is 30 minutes in Minnesota. The largest reimbursement rate was a maximum spending limit of $35k per year for an individual in Colorado. States contacts showed the unit type most used is a "day." Whatever the reimbursement rate or unit type, paid claims were only made to licensed or certified providers and/or certified vendors as each state so identified them. All states were billed monthly. Only Virginia reported a specific fixed rate for enclaves or work crews.

State	Unit Type	Reimbursement Rate
Tennessee	Employment Based Services - Individual (1-3 at site, 3 contacts a week) - Group (4 or more at site) - Special Rate (1:1) - Follow-Along (2 contacts per month)	$77.25 - $128.20 “ “ “ “ “ “ “ “ “ “ “ “ $338.20/month
	Community Based Services	$38.65 average
	Facility Based Services	$59.40 average
Colorado	No preset limit on hours provided. No pre-set rate, rate locally and individual provider negotiated.	$35,000 spending limit per individual per year
Maryland	Day	$48.02 – 1st tier $48.98 – 2nd tier $49.96 – 3rd tier $50.96 – 4th tier $51.98 – 5th tier (+2% ea yr)
Minnesota	30 minutes Partial Day (4-6 hours) Day (6+ hours)	$17.30 for 30 minutes $79.48 for partial day $98.78 for a day
Virginia Waiver	Individual SE: hour Group SE: unit One unit (1-3.99 hours/day) Two units (4-6.99 hours/day) Three units (7+ hours/day)	$17.64 per hour $20.29 per hour – NoVa $35.84 per unit $41.22 per unit - NoVa
Virginia DRS	Hour	$50.34 per hour (state average) ($30.82 to $69.16)

Barriers and Proposed Solutions to Increase Employment of Virginians with Intellectual Disabilities

MR and Day Support Waivers:

Rates:

Issue: Even though Individual SE is a service in Virginia's MR Waiver (and was recently approved by CMS for our Day Support Waiver), it is virtually unavailable for individuals in a Medicaid Waiver because of the reimbursement rate. Current MR Waiver regulations require an SE provider under the MR Waiver to be a vendor of SE with DRS. Since the late 1980s, each DRS vendor has had an individually negotiated rate based upon a rate-setting methodology that reflects the actual costs of providing supported employment. These rate packages must be reviewed and approved by DRS annually.

Medicaid has a standard reimbursement rate that is significantly lower than the individual vendor rates approved by DRS. In addition, under state procurement law, providers may not charge one state agency a different rate than another. The Medicaid rate is insufficient to support the knowledge, skills and expertise needed by organizations that provide Individual SE services, and SE providers are forced to restrict their services to individuals receiving DRS funding only.

This conflict in rates has prevented waiver recipients from being competitively employed or to lose their employment supports. Less than one-half of one percent or 45 individuals received Individual SE during FY 2006, and only 38 are now actively receiving Individual SE in 2007.

Recommendation: **Adjust the Waiver rate for Individual SE to parallel and keep pace with the SE rates assigned to each vendor of SE by DRS and make the necessary regulatory and reimbursement structure changes.**

Issue: Even though work is an important and valuable outcome for individuals with disabilities, Group SE is reimbursed at a lower rate than High Intensity Day Support or Prevocational Services.

Recommendation: **Reimburse Group SE equal to or greater than Intensive DS or Prevocational services.**

Issue: There are no incentives for employment service providers to expand community-based employment in unserved or under-served areas of Virginia.

Recommendation: **State agencies should establish clear financial incentives for providers to achieve community-based employment (Group SE and Individual SE) as an outcome for all individuals who are interested.**

Flexibility and Individualized Support:

Issue: Individuals in MR Waiver have limited options for integrated employment.

Recommendation: **Allow self-direction of SE for individuals to select, pay and train their own job coaches.**

Issue: There is limited flexibility in Day Support and Prevocational services for individuals to transition to real jobs in the community. While Prevocational services are "aimed toward paid employment" they are restrictive, unclear and limited in scope.

Recommendation:	**Clarify and expand the types of activities allowable under Day Support and Prevocational services that develop employment skills, to include such services as situational assessments in different work environments, work trials, paid and unpaid work experiences.**
Recommendation:	**Clarify the rule that individuals eligible for Prevocational services *"are not expected to be able to join the general workforce or participate in a transitional sheltered workshop within one year of beginning waiver services (excluding supported employment programs)"* does not refer to individuals who are expected to enter *regular* center-based employment or *supported* employment.**

Issue: Individuals in Prevocational services are restricted to compensation of less than 50% of minimum wage.

Recommendation:	**Remove reference to 50% of minimum wage limitation.**

Issue: The waiver preauthorization process limits the individual's ability for accepting a time sensitive employment opportunity or an individual's need to move to a more or less intensive level of support. Under current Virginia policy, a new authorization is needed and a work opportunity (or other immediate need) might be missed in the meantime.

Recommendation:	**Revise MR Waiver preauthorization policies and procedures to support the flexibility needed for supporting individuals in employment.**

Issue: The small billing units of Day Support, Prevocational and Group SE and other cumbersome documentation requirements limit quality time that could be spent supporting the individual. These are long-term services and a longer unit provides better stability in services.

Recommendation:	**Habilitation Services under the waiver should be billed as a monthly unit of service.**

Issue: The limit of 3 units per day/780 units per year for a combination of DS, Prevocational and Group SE services does not allow variety or flexibility in activities during the week. For example, an individual may attend a Prevocational or DS program for several hours in the morning and SE for several hours in the afternoon or evening. Both providers may be providing 2 units per day, but only one provider can be compensated accordingly. The inability to bill limits providers' ability and interest in supporting individuals receiving services from another provider.

Recommendation: **Allow flexibility in billing (see previous recommendation) and change the current restrictions.**

Issue: Competitive employment requires flexibility in days, hours and schedules of work. The majority of individuals who live in group homes attend day programs with regular schedules Monday - Friday, and most group homes do not have staff available during these hours to accommodate individuals who have jobs requiring different hours of support at home. The billing structure for services in a group home does not reflect this need for flexibility, and individuals receiving these services are rarely able to work in regular jobs in the community.

Recommendation: **Revise the rate structure for group homes to a monthly unit that reflects actual cost of services, includes certain fixed costs and allows flexibility of hours away for individuals who live there.** (See CMS State Medicaid Manual for examples of how states can overcome this problem).

Employment and Transition:

School to Work:

Issue: Services to ensure a smooth transition from school to work or post-secondary training do not begin early enough for most students.

Recommendation: **DMHMRSAS and DRS should work with the Department of Education (DOE) to clearly establish gainful employment in the community for students with intellectual disabilities as a desired and necessary outcome of secondary education.**

Recommendation: **DMHMRSAS and DRS should work with the DOE to clearly define the transition services and the parties responsible for providing those services.**

Recommendation: **Through the General Assembly, assure sufficient funding is available to provide, as part of the Individual Education Plan (IEP) process, community case management and supported employment services for transition age students with intellectual disabilities who are not receiving MR Waiver Services.**

Recommendation: **DMHMRSAS should develop printed materials to be disseminated through the annual IEP process, case managers and disability organizations to students and families that describe employment in the community as a desired, expected and possible outcome for transition age students with intellectual disabilities.**

Recommendation: **Support informed choice by adding benefits planning and work incentives education to Individualized Education Plans before students transition.**

Recommendation: **Establish cooperative agreements with public school systems and state agencies to facilitate utilization of experienced job coaches as a means of gaining work experience before the student exits from high school. Increasing employment of students with disabilities will provide the opportunity to gain valuable work experience prior to graduation, thus, increasing the likelihood of success.**

Training Center to Community:

Issue: There is a lack of service coordination between institutional and community service providers to ensure that individuals with disabilities leaving training centers and ICFs/MR can access employment services and supports both prior to and following their move to the community.

Recommendation: **Add employment as a valued service to be included in discharge planning protocols for individuals transitioning into the community.**

Recommendation: **Include vocational and employment consultations from employment specialists on assessments, benefits planning & consultation, planning and supports individuals transitioning to the community.**

Disincentives to Work:

Issue: Employment improves the quality of life, but many individuals in the MR Waiver and other publicly funded services are required to give up much of their newly earned income. An individual's expenses related to work significantly increases when employed (i.e. work clothes, uniforms, transportation, etc).

Recommendation: **There is currently no financial incentive to earn income if almost all of an individual's income goes to patient pay or costs currently borne by local communities.**

Recommendation: **Increase the current disregard from 200% to 300% (for 8-20 hours worked per week) and from 300% to 400% (20+ hours worked per week) of countable income (earned and unearned using SSI rules) OR only count "earned" income within the current thresholds. However, SSI & SSDI work incentives should also be used to calculate the countable income standard.**

Recommendation: **Modify the current DMHMRSAS licensing regulations for residential services to require standardized procedures regarding assigning and collecting fees.**

Issue: Individuals and families are often reluctant for individuals to work because they believe they will lose financial and medical benefits. The complexity and nature of work incentives and the interrelationship of a myriad of federal, state and local programs with which beneficiaries rely create uncertainty and fear of losing vital income supports and medical coverage if they attempt self-sufficiency through employment. There is a lack of understanding of the rules. Employment is often a family issue and not just an individual issue.

Recommendation: **Continue to educate individuals and family members on Supplemental Security Income, Social Security Disability Insurance and Medicaid rules as well as available state and federal work incentives utilizing current curriculum developed through the Virginia Board for People with Disabilities Work Incentives Training Grant.**

Recommendation: **Expand and continue current training on the use of free, individualized services provided by Community Work Incentive Coordinators employed by the Social Security Administration's Work Incentive Planning & Assistance grantees.**

Issue: Virginia's current Medicaid Buy-in, although a step in the right direction, prevents individuals who have earned and unearned income above 80 percent of the Federal Poverty Level from participating. Under the current initial legislation, only individuals eligible for Virginia Medicaid can become eligible. Once qualified, an individual can earn additional income and retain financial resources in amounts substantially above current Medicaid rules. However, Virginia's "first step" is contradictive to the overall purpose for which the Medicaid Buy-In Program was authorized by Congress. The federal goal is to allow individuals who are otherwise ineligible for Medicaid because of earned & unearned income to be able to "buy-in" and pay a premium to get Medicaid coverage.

Recommendation: **Amend the current Medicaid Buy-In to accommodate its original federal intent. A viable Medicaid Buy-In program will permit higher income and resource levels while ensuring**

continuation of needed health care coverage, thus providing an opportunity and incentive to seek gainful employment.

Ancillary Services:

Issue: Transportation to employment sites is limited to only those sites at which an individual is receiving a Medicaid-funded service (i.e., a provider's staff is present). An individual in SE services often may not receive daily SE services once established in a job. The inability to get Medicaid-funded transportation limits individuals' options for competitive employment.

Recommendation: **Eliminate the rule that a staff member has to be present when an individual is transported to a work site.**

Recommendation: **Develop natural supports in the work place to accommodate this requirement or allow individual to sign on their own behalf if appropriate.**

Issue: Personal assistance in a work setting is the key for some individuals to become or remain employed.

Recommendation: **Increase rates for Personal Assistants so that additional individuals are interested in providing this service.**

Recommendation: **Develop an effective and cost efficient way to have personal assistance on the job.**

Non-waiver Employment Issues:

Long Term Employment Support Services (LTESS)

Issue: Additional funding for Long Term Employment Support Services (LTESS) is needed on an annual basis to help individuals with intellectual disabilities maintain their current employment. LTESS provides periodic drop-in supports for individuals currently employed. LTESS funds go hand-in-hand with DRS time-limited services since DRS counselors are hesitant to authorize time-limited services for job placement, job coaching and job stability services without some form of long term follow along support.

Recommendation: **Appropriate a minimum of an additional $750,000 per year to keep pace with the number of individuals placed in SE and needing long-term employment support services to maintain employment.**

DRS Order of Selection:

Issue: DRS is currently under an "Order of Selection." When, due to limited resources, all eligible Virginians with disabilities can not be served, the law requires that DRS provide services to persons in priority categories. Individuals who are determined eligible for services are placed into priority categories. DRS will open and close categories based on its available resources.

Currently, all categories are closed other than services for individuals with the most significant disabilities. However, when funds are restricted, it has an overall "trickle down" effect of limiting the numbers of hours authorized for everyone served. Thus, individuals do not necessarily receive the level of services they need or require even if they meet the Order of Selection eligibility.

Recommendation: Appropriate sufficient funding to eliminate the "Order of Selection" under DRS.

Huang, W. and Rubin, S. "Equal Access to Employment for People with Mental Retardation: an Obligation of Society," Journal of Rehabilitation, January - March, 1997. Retrieved online 9/12/07 from http://findarticles.com/p/articles/mi_m0825/is_n1_v63/ai_19178151/pg_9.

Appendix H
Housing Focus Team Report

Many people with disabilities have long-term conditions that affect their activities of daily living. These individuals as a group are disproportionately poor when compared with their counterparts without disabilities and typically, as a group, have a high need for housing assistance and supportive services. Some members of this group need personal care assistance, adaptive equipment or removal of architectural barriers. Some in this group might benefit from case management, adaptive skills training, assistance with locating appropriate housing and crisis support.

Medicaid, an important source of funding for community supports, does pays for the service component for supportive housing. However it does not allow its funds to be used for housing-related costs such as room and board. In Virginia, Medicaid-funded Residential Supports do not pay for general supervision. The Social Security Administration has waiver authority it can grant to states on a case-by-case basis to modify existing policies and procedures to encourage testing alternative policies and procedures that promote independence and self-sufficiency for individuals with disabilities and their families. An effort must be made to encourage these two programs to work together to accommodate housing-related expenses for more persons and allow more flexibility in choice of housing decisions. It is essential to find ways to assure that individuals with intellectual disabilities can access mainstream affordable housing programs.

All people with intellectual disabilities and related developmental disabilities have a right to live in a community of their choice with accessible transportation options to allow full inclusion into that community. Adults should control where and with whom they live, and have opportunities to rent or buy affordable and accessible homes.

It is recommended that Virginia work toward promoting communities whose core principles include:

- Affordability
- Accessibility
- Independence
- Integration
- Choice
- Health and safety

These principles will help support the health, well-being and independence of individuals with intellectual disabilities.

It is now clear that with carefully tailored individualized services, those with intellectual disabilities can live in housing that they both control and choose (be it a house, a condominium, or apartment), no matter how significant their disabilities. A complete range of housing options should be available from which to make a selection, with adequate supports available. Transportation, one of the most vexing barriers, should be accessible and affordable.

Positive Effects of the MR Waiver

- The growth and development of community providers and residential services and supports has provided an alternative to institutionalization while promoting the value of choice being included in the daily business practices of service providers.
- There is now a state and local partnership resulting in a lifetime commitment and lifelong support to the individuals living within the community.
- Community Services Boards (CSBs) benefit from the use of Medicaid funds by maximizing their funding capacity to allow individuals to remain in their chosen communities.
- By supporting individuals who choose to stay in the community or transition from state operated training centers to the community, the resulting benefits to the community-at-large have included not only learning about and from these individuals but also enabling individuals with intellectual disabilities to give back to their communities.

Ways in Which Residential Services and Access to Housing Can Be Improved to Provide a Person-Centered, Individualized Support Focus

- Create a Bridge Subsidy program that provides rental assistance for individuals with intellectual disabilities who receive Medicaid Waiver services who are on waiting lists for housing choice vouchers.
- Set a priority for housing vouchers for individuals with intellectual disabilities desiring to live in community.
- Support individuals in choosing their roommates, staff, type, and location of housing modality to enable them to define their home, rather than being "placed" in a residential situation of another's device.
- Offer direct support staff a range of benefits that would put providers of supports and services in a more competitive position in a limited workforce (i.e., paid leave, health insurance).
- Offer providers more targeted standardized MR Waiver training on-site and in small groups.
- Make direct support staff training available in afternoons, evenings, and weekends.
- Encourage more appropriate use of substitute decision maker alternatives in lieu of full guardianship
    - Use of micro boards
    - Train volunteers to serve as alternate decision makers.
- Make available flexible funding for the purchase of vans and other modes of transportation to enable individuals to have access to the community rather than always participating as a group
    - 53/10 program through the Virginia Department of Transportation

  - Train individuals with intellectual disabilities to use public transportation.
- Broaden Logisticare eligibility for recreational transportation.

Existing Gaps and New Specialized Services that Need to be Developed

- Residential services for persons with a dual diagnosis (mental illness and intellectual disabilities) are inadequate and fragmented.
- The hourly rate methodology system for Residential services is a barrier to individuals with intellectual disabilities leading normal lives.
- The lack of reimbursement for general supervision in the home encourages regimented daily schedules.
- Provider reimbursement rates are low.
- There is insufficient information on the DMHMRSAS website about residential providers (i.e., the level of care needs that the provider can best support; wheelchair accessibility of house, etc.).
- Direct support staff training needs to be enhanced, with an emphasis on person-centered services, ideally using electronic technology.
- The current preauthorization of MR Waiver services is cumbersome and relies solely on paper, vs. electronic technology
- Adults residing in the community have difficulty obtaining affordable dental care, as Medicaid does not cover this service.
- Expenditures of individual residents should be more closely monitored, perhaps by a case manager to ensure appropriateness of expense and, in concert with the individual, to ensure account funds are accurate.
- There are currently insufficient supports to make it feasible for many individuals with intellectual disabilities to live on their own.

Existing Barriers

- Ill defined regulations and ineffective communication and training on regulations (e.g., trainings conducted by two different agencies may yield differing information).
- There are a limited number of affordable, accessible housing units for persons with intellectual disabilities. Few housing resources exist to support children and youth with intellectual disabilities, as well as individuals with behavioral challenges.
- Difficulties exits in obtaining practical assistance from Regional Community Support Centers (RCSCs).
- There is presently an inability to assure all providers offer a baseline of appropriate training
  - Need to recognize and address workforce differences of language and culture
  - Need to determine core competencies for training and assistance in coordinating venues for training.
- There is a lack of transitional funding to pay rent/mortgage.

- There is limited availability of accessible and affordable transportation.
- There are limited medical/dental/behavioral supports in community
- There is a near total dependence on MR Waiver funding for the provision of community services to individuals with intellectual disabilities.

Other States' Initiatives to Address Housing Issues

North Carolina – This state has worked to increase the availability of affordable housing for its residents. They have focused on developing new housing units and increasing access to generic housing resources. Successful strategies included:

- Creation of a dedicated Housing Coordinator position and provision of funding for Housing Specialist positions throughout the state.
- Investment of $1 million from the Mental Health Trust Fund combined with $2 million from the NC Housing Finance Agency (NCHFA) to create a project-based rental assistance demonstration program to serve persons with disabilities living in rental units built through NCHFA's Low Income Tax Credit program.

Minnesota - This state provides waiver services using a variety of defined available service options, i.e., caregiver living expenses, caregiver training and education, chore services, housing access coordination. A case manager usually assists in selecting the services. Examples of waiver services that support an individual living in his/her own or family's home:

- Chore services: A service that supports or assists a person or his/her primary caregiver to keep his/her home clean and safe. Examples include washing floors, windows and walls.
- Caregiver living expenses: A service that provides payment for rent and food that may be reasonably attributed to a live-in personal caregiver.
- Housing access coordination: A service that allows an authorized consultant to provide direct housing support to an individual or his/her representatives, to assist them with housing decisions or the implementation of their housing plans, such as making choices about where to live, the type of home desired, the presence and number of roommate(s). This service also helps individuals identify affordable, accessible housing and assures that housing needs are provided for separately from other service needs.

Iowa – Health and Human Service (HHS) recently approved Iowa as the first state to add Home and Community-Services as a permanent feature of its Medicaid State Plan, eliminating the need for repeated requests for time limited waivers (April 2007). This new benefit will provide statewide HCBS case management services and "habilitation services" at home or in day support programs that can include such things as support in the workplace.

Texas – This state assists individuals through the Tenant Based Rental Assistance (TBRA) program and Money Follows the Person, which provides rent subsidies for people with disabilities who live in an institution but want to move to a community living environment. The TBRA is provided through a contract with the Texas Department of

Housing and Community Affairs. Program participants pay about 30 percent of family income for rent and utilities. Participants can receive a subsidy for up to 24 months, and must participate in a plan to achieve long-term self-sufficiency.

Recommended Changes to the System of Services to Improve Virginia's Ability to Address the Housing Needs of Individuals with Intellectual Disabilities

- The elimination of hourly reimbursement units for Residential Support and replacement with **daily or monthly rates** which includes general supervision as a billable activity.
- Combine housing funding and support (Medicaid) funds to develop a mechanism at the Executive level for improved comprehensive and coordinated action by state agencies to reshape the structure and scope of support for affordable and accessible housing choices.
- Develop a Bridge Subsidy supplement program that provides transitional funding to assist in rent payment for those new to the community or living on their own.
- Develop a coordinated housing policy among state agencies with a priority for persons with low incomes who have intellectual disabilities:
    - Implement a demonstration project that is a partnership between the Virginia Housing Development Authority (VHDA), the U.S. Department of Housing and Community Development and other state agencies to develop and implement new housing production strategy linked to rent or operating subsidies that will increase the supply of rental units that are targeted to people with disabilities with SSI level incomes;
    - Create a joint funding review committee to streamline the current housing application process with one uniform application for multiple funding resources;
    - Encourage VHDA to continue to make people with disabilities a priority in the allocation of Section 8 vouchers;
    - Improve connection between housing choices and employment;
    - Develop a consistent philosophy on housing and supportive services across agencies with resource allocation to support principle of furthering independence and choice.
- Develop a plan to increase affordable and accessible housing options, initially targeting individuals transitioning from nursing facilities and ICFs/MR
    - Create a statewide computerized interactive accessible housing registry to assist in the location of affordable barrier-free housing;
    - Revisit the state's homeownership activities to direct resources to people with disabilities and link to Section 8 vouchers for homeownership assistance.
- Medicaid State Plan and/or waiver options could be changed to include:
    - Transition from the dependence on congregate residential services to focus on independent living with supportive services;
    - Expand mental health support services in the home and community;

    - Expand Waiver service options to have a more supported living focus such as chore services, caregiver living expenses, housing access coordination, specialist services, and 24-hour emergency assistance.
- Expand the availability of standardized training for direct support staff, possibly through the College of Direct Support.
- Design a Career Path for statewide use for residential staff.
- Assure that the services of Regional Community Resource Centers (RCSCs) are available throughout the Commonwealth.
- Develop an electronic enrollment and preauthorization system for the MR Waiver to reduce the volume of paper changing hands.
- Provide funding for rental assistance for a specified number of housing units and for development of rental housing

Appendix I
Provider Discussion Forum Summary

Eight gatherings of MR Waiver providers (private and publicly funded) were conducted between January and March 2007 across the state at the following locations:

Region	Date of Discussion Group	Discussion Group Location	Discussion Group Facilitator
HPR I	March 7	Valley CSB	Dawn Traver
HPR II	February 20	Service Source Northern Virginia	Ed Gonzalez
HPR III	1) March 8 2) March 26 3) March 16	1) Danville-Pittsylvania CSB 2) Blue Ridge Behavioral Health 3) Abingdon	1) Gail Rheinheimer 2) Gail Rheinheimer 3) Wanda Earp
HPR IV	1) February 15 2) March 21	1) Richmond Goodwill 2) SVTC	1) Dawn Traver 2) Dawn Traver
HPR V	January 30	Virginia Beach	Ed Gonzalez

These events were coordinated by Community Services Board representatives (primarily MR Directors) in each Health Planning Region. A total of 242 provider representatives participated, representing 119 separate agencies. The following is a summary of the most commonly repeated responses to the questions put forth for discussion group participants to consider.

1. How does the MR Waiver have a positive impact on the lives of people with mental retardation?

    - Supports families (e.g., enables parents to keep their jobs) and increases their quality of life
    - Supports individuals in remaining home with their family

- Enables individuals with intellectual disabilities to "have a life"
- Promotes choice and independence
- Supports individuals in their desire to live and receive services outside of an institutional setting
- The funding is portable and remains with the individual
- Promotes skill enhancement for individuals with intellectual disabilities
- Enables individuals to obtain job skills training

2. What are the best things about the MR Waiver that you would not want to see changed?

    - Focus on and opportunities for choice (i.e., choice of providers and services)
    - Slot/funding following the person
    - Wide range of services
    - Responsibility for slot allocation at the CSB level
    - Consultation and training available to providers through OMR

3. Are MR Waiver supports and services person centered? If not, what changes should be made to the MR Waiver to assist in developing person-centered plans and supports.

    - A few felt that the MR Waiver is currently person-centered, but most indicated there is great room for improvement in this area
    - Needed to make the MR Waiver truly person-centered are the following:
        - Increase in staffing ratios (more 1:1 or 1:2 is needed); standardize expected ratio
        - Higher reimbursement rates to support the above staffing ratios
        - Decrease in paperwork
        - Particular need for increase in Supported Employment reimbursement rate to make this service available through the Waiver
        - Change the Residential Support billing unit to one month
        - Provide more person-centered thinking training
        - Raise the competency level of direct care professionals through training and then increase salaries to retain
        - Fund general supervision

4. Is the MR Waiver easy to use? What changes should be made to make it easier to use?
    - There was general agreement that the MR Waiver is NOT as easy to use as people would like. The most common comments and suggested changes were:
        - Preauthorization is cumbersome: long delays & many difficulties; not customer friendly; is it really necessary? Possibility of electronic submissions?

- Need to streamline paperwork & simplify processes
- Need easy access to required forms (i.e., website access)
- Increase information/training for families on how to obtain MR Waiver
- Increase the reimbursement rates to attract/retain quality staff; especially needed for medically involved/behaviorally challenged individuals
- Enable more on the waiting list to get services
- Promote creativity
- Person-centered philosophy doesn't jibe well with medical model
- Update regulations; make consistent (i.e., DMAS & DMHMRSAS); increase consistency of interpretation
- Fund based on cost of plan/severity of need vs. service hours

5. Are there barriers to providing MR Waiver services? What are the barriers?

- Logisticare is viewed as compromises individual's safety. A brokered transportation system (as run by Logisticare) possibly represents a cost savings for DMAS but costs passed on to Day Support providers who expend an inordinate amount of staff resources trying to coordinate with Logisticare only to lose billing regularly when drivers drop off late/pick up early.
- Need some way to bill for needed staff coverage while individuals are in the hospital
- Lack of sufficient number of slots; need for emergency pool of slots
- Insufficient reimbursement rates, especially for medically involved/behaviorally challenged/aging individuals; would like to see per diem for Residential Support; would like rate tied to need; unable to provide 1:1 services under current reimbursement rates
- Outdated LOF Survey
- Too few people interested in direct support positions for the available rate of pay; high turnover
- Lack of funding for general supervision
- Diagnosis issue: DMAS Quality Management Review staff expecting to see the words "mental retardation" on psychological evaluations, but psychologists (especially school psychologists) do not always use this terminology. No funding to get new psychological evaluations.
- Lack of reward for creativity

6. Are there adequate behavior consultation services available through the MR? How can this service be more available?

- No. Not enough consultants available. Some of new PBS-trained consultants only provide consultation within their own agency.
    - Need more flexibility in allowable activities: bill for transportation time/costs

  - Need more flexibility in preauthorized amount
  - Need to be able to do more long-term follow-up with providers regarding particularly challenging behaviors
  - Need increased reimbursement rate. Most consultants hold full-time job in addition to this (decreasing their ability to be available to providers) in order to make ends meet.
  - Need consultants with awareness of best practice (i.e., those doing as psychologists need PBS training too)
  - Permit training centers/RCSCs to provide this service too.

7. Are there adequate skilled nursing services available through the MR Waiver? How can this service be more available?

   - No, particularly as more medically fragile individuals exit the training centers
   - Need higher reimbursement rate, especially in view of shortage of nurses
   - Enable nurses to work with providers to facilitate medication administration and ensure individuals' health and safety
   - Educate home health agencies that they can provide skilled nursing under the MR Waiver; create incentives
   - Enhanced flexibility in allowable activities

8. Are there adequate skilled medical services available? How can this service be more available?

   - No. Many physicians do not accept Medicaid due to low reimbursement rates and high paperwork requirements. Those who do usually have a quota and/or little expertise in working with persons with IDs.
   - Training/education is needed for medical personnel on working with people with IDs

9. What additional services and supports should be added to the MR Waiver?

   - Dental services (this was stressed as a critical health need at every single provider discussion forum)
   - Skilled respite
   - Nutritional/dietary consultation (becoming more of an issue with an aging population and increasing levels of obesity)
   - Wellness programs
   - Reimburse general supervision
   - Rates that are viable for 1:1 support
   - Support teams that assist individuals in crisis
   - Transportation services (apart from Logisticare, which is regarded as a broken system), particularly for community access
   - Reimbursement for recreation/leisure/vacation

- A less training-oriented day service for aging individuals
- Vision services

Appendix J
Survey of Virginia's Medicaid Waiver Recipients and Waiting List Members

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I. Purpose

The basis for this study is House Bill 5002, enacted during the 2006 Session of the Virginia General Assembly, which states,

> The Department of Medical Assistance Services, in cooperation with the Department of Mental Health, Mental Retardation and Substance Abuse Services, the Virginia Association of Community Services Boards, the ARC of Virginia, and other stakeholders, shall jointly review the current Medicaid home- and community-based waiver for persons with mental retardation to determine how the waiver program can be improved to provide a person-centered, individualized support focus. In conducting the review, the Department shall assess the need to upgrade availability of therapeutic behavioral consultation, skilled nursing, medical and other specialized supports for individuals who are served through the waiver. Also, the department shall review successful models of waiver funded community supports used by other states to serve individuals with mental retardation for potential application to Virginia. The Department shall report on its review of the waiver program including recommendations for changes and cost implications by December 1, 2006, to the Governor and Chairmen of the House Appropriations and Senate Finance Committees.

The research questions for the Study include the following:

1. How can the current MR Waiver program be improved to provide a person-centered, individualized support focus?
2. Do therapeutic behavioral consultation services need to be more available to MR Waiver recipients?
3. Do skilled nursing services need to be more available to MR Waiver recipients?
4. Do medical services need to be more available to MR Waiver recipients?
5. What other specialized supports do MR Waiver recipients need than those that are currently available?
6. What are other successful models of Waiver funded community supports used by other states to serve individuals with mental retardation?

To address some of these research questions, the Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services (DMHMRSAS) contracted with the Richmond Consulting Group to conduct telephone surveys of representative samples of individuals currently receiving services under the MR Waiver and individuals on the MR Waiver waiting list.

II. Sampling

The two databases provided by DMHMRSAS indicated that the combined number of individuals receiving Waiver services and those on the waiting list totaled approximately 9,900 individuals. A power analysis indicated that a random sample of 340 would be sufficiently representative for generalization of study findings statewide. Assuming that an unknown number of potential respondents would decline to be interviewed, could not be located, had moved, were deceased, etc., the two Waiver databases were over sampled by approximately 30%. In addition, the databases were stratified by Health Services Region (HSR) and by type of service prior to random selection in order to better ensure representation across all Community Service Boards (CSBs) and across the major Waiver services categories.

To protect confidentiality of potential survey respondents, names of individuals randomly selected for surveying were provided to the CSBs, whose staff made initial contacts with the selected individuals or their representatives. The surveyors were to be provided with contact information only for those individuals who consented to be interviewed.

Table 1. Survey samples

Survey group	Self respondent	Other respondent	Total
Waiver recipients	103	133	236
Waiting list members	41	54	95
Totals	144	187	331

Despite over sampling, the combined number of surveys completed was 331, nine surveys short of the target number (see Table 1). In addition to the above-stated reasons for non-responses, phone contacts with potential respondents from at least two CSBs indicated that the individuals had not been contacted prior to the survey so contacts were discontinued with all members of those CSB sub-samples. The surveyors also declined to interview individuals whose responses could only be provided by a provider agency, because of the potential for biased responses.

Table 2 provides information regarding respondents' self-reported impairments. These total more than 100% because individuals could indicate multiple impairments. Descriptions and/or examples of these impairment types were provided. As would be expected, almost all of the respondents indicated that they or their family member had intellectual impairment. Among both groups, the second most frequently impairment was medical, which included seizure disorders, asthma, diabetes, and other diseases and health-related conditions.

Table 2. Self-reported impairments of consumers

Impairment	Waiver recipients	Waiting list
Intellectual impairment	97.0%	95.8%
Autism spectrum disorder	3.8%	1.1%
Mobility impairment	32.0%	22.1%
Hearing or visual impairment	30.1%	18.9%
Communication impairment	5.9%	13.7%
Behavioral impairment	22.0%	17.9%
Medical impairment	45.0%	44.2%
Mental disorder	8.9%	7.4%

Table 3 shows the age groupings of the two sub-samples. A substantially larger proportion of the waiting list sample was under the age of 22 as compared to the recipient sample. One possible explanation for this anomaly is an increased awareness of the Waiver for special education students in transition on the part of their teachers and parents, and a corresponding increase in applications by parents of youth with disabilities.

Table 3. Self-reported age of consumers

Age range	Waiver recipients	Waiting list
Under 22	28.2%	55.2%
Between 22 and 30	13.7%	7.4%
Between 31 and 40	20.9%	12.8%
Between 41 and 50	26.1%	11.7%
Between 51 and 60	10.7%	12.8%
Over age 60	0.4%	0.0%

III. Procedure

Instrument development. Two surveys were developed, one for current Waiver participants and one for waiting list members. Wording of the items allowed for the participant or potential participant as respondent or an alternative respondent. The survey instruments were originally drafted following the research questions and directives from the Virginia General Assembly. The drafts were reviewed by DMHMRSAS staff and by staff of the Virginia Board for People with Disabilities and revised according to their recommendations. The initial set of interviews were used to pilot-test the instruments, with no subsequent modifications.

Survey procedures. As indicated previously, the CSBs made the initial contacts with potential respondents who provided verbal consent to be interviewed. The CSBs then provided the names and contact information to the surveyors. All surveys were completed by telephone. Three attempts were made to contact each respondent to either complete the survey or schedule for a more convenient time. The surveyors were requested to obtain information directly from the Waiver consumer or waiting list member rather than an alternative respondent when feasible. Approximately 43.5% of surveys were completed by the participant.

Several items from both surveys related to services that the individual did not currently receive but might need. Because it was likely that a respondent would not understand the nature of a service from the name alone, a list of simple descriptions of all possible Waiver services was available to the surveyor to read to the respondent when requested.

Data were entered into a database and analyzed using STATA statistical software. Primary means of analysis included frequency counts across response options.

IV. Findings

Waiver Consumer Survey

Respondents were requested to provide an assessment of the services they receive with regard to the helpfulness of those services to the individual with disabilities and his or her family. Because the Waiver database provided by DMHMRSAS included the services each person received, the surveyors only requested this assessment from individuals receiving the particular service. Table 4 summarizes ratings of helpfulness of the major Waiver services (services having fewer than five respondents were excluded).

Table 4. Ratings of Service Helpfulness to Consumer and/or Family

Service	Total Respondents[8]	Extremely helpful	Somewhat helpful	Not helpful
Residential	137	89.8%	9.5%	0.7%
Day support	121	81.0%	18.2%	0.8%
Prevocational	31	45.2%	54.8%	0.0%
Respite	70	91.4%	7.1%	1.4%
Therapeutic consultation	47	59.6%	40.4%	0.0%
Personal assistance	45	93.3%	4.4%	2.2%
Supported employment	45	57.8%	40.0%	2.2%

Table 4 indicates that most frequent ratings of "extremely helpful" were for personal assistance (93.3%), respite (91.4%), and residential services (89.8%). Lowest ratings of helpfulness were for prevocational services (45.2%) and therapeutic consultation (59.6%), although it is notable that ratings of "not helpful" were very low across all services. Individuals who indicated that a service was "not helpful" were asked to provide an explanation for their rating. Three respondents indicated that they were not utilizing a service in which they or their family member was enrolled, and two indicated that a service was not helpful because of disagreements or dissatisfaction with the service providers.

Respondents were also requested to rate the degree of individualization with the services they or their family members were receiving, either the service was fully individualized, somewhat individualized, or not individualized at all. Table 5 shows responses to these items. As with the prior question, highest ratings were found for personal assistance (88.9%), respite (87.1%), and residential services (84.7%). Lowest rates of individualization were given for prevocational services (38.7%), supported employment (53.3%), and therapeutic consultation (63.8%). As with the prior item, only a small minority of respondents indicated that services were not individualized at all.

Table 5. Ratings of Degree of Individualization of Services to Consumer

Service	Total Respondents[9]	Fully	Somewhat	Not

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[8] Because many respondents received more than one Waiver service, this column total exceeds the total number of respondents.

[9] Because many respondents received more than one Waiver service, this column total exceeds the total number of respondents.

Residential	137	84.7%	13.9%	1.5%
Day support	121	73.6%	25.6%	0.8%
Prevocational	31	38.7%	61.3%	0.0%
Respite	70	87.1%	10.0%	2.9%
Therapeutic consultation	47	63.8%	36.2%	0.0%
Personal assistance	45	88.9%	8.9%	2.2%
Supported employment	45	53.3%	44.4%	2.2%

Respondents were asked to indicate if there were any services they needed but were not receiving. Eighteen of the 236 respondents (7.6%) indicated that they needed additional services, including the following:

- Assistive technology
- Physical therapy
- Residential services
- Supported employment
- Training
- Dental care
- Sign language

Finally, respondents were requested to indicate need for the three specific services indicated in the General Assembly directive within the next two to five years: Behavioral assistance, nursing care, and assistance with medical needs. Responses are summarized in Table 6. Only a small percentage of respondents indicated a need for these services.

Table 6. Self-reported need for specific Waiver services within 2 to 5 years

Service	Percent
Behavioral assistance	3.4%
Nursing care	2.5%
Assistance with medical needs	0.0%

Waiting List Survey

A total of 95 surveys were completed for individuals on the Waiver waiting list or a family member respondent. At the time of the survey, the members of this group had been on the Waiver waiting list for an average of 831 days, or approximately 28 months. Time on the waiting list ranged from 3 days to 5,534 days.

Respondents were read 13 reasons for requesting Waiver services, and to indicate which reasons applied to their particular situation. Table 7 below summarizes their responses. Four reasons were applicable to over half of the respondents, including:

- Need for behavioral assistance,
- Need for medical supports,
- Desire to avoid out-of-home placement, and
- Need for financial support.

Table 7. Self-reported reasons for seeking Waiver services	
We need help with behavioral problems in the home	88.4%
Our family member with disabilities needs medical supports	75.8%
We want our family member with disabilities to continue to live at home	71.6%
Our family member with disabilities needs financial support	68.4%
We want to improve the overall quality of life of family member with disabilities	38.9%
We want to provide education or training for our family member with disabilities	36.8%
My family member with disabilities needs to be involved in something productive during the day	28.4%
We need respite or breaks for caregivers	20.0%
My family member with disabilities wants to increase his/her independence	14.7%
A family caregiver wants to go to work or increase hours of work	13.7%
My family member with disabilities needs an alternative living setting	13.7%
We want to improve the overall quality of life for family caregivers	9.5%
We need environmental or technological modifications for our family member with disabilities	9.5%

Respondents were also requested to indicate need for specific Waiver services. Again, a description of each service was available to the respondent if needed to understand the nature of the services. As shown in Table 8, over half of respondents indicated a need for six Waiver services: Residential services, respite services, personal assistance, day support, assistive technology, and companion services.

Table 8. Self-reported services needed	
Residential services	86.3%
Respite services	72.6%
Personal assistance	71.6%
Day support	68.4%
Assistive technology	55.8%
Companion services	55.8%
Environmental modifications	47.8%
Skilled nursing services	45.3%
Therapeutic consultation	45.3%
Supported employment	28.4%
Prevocational services	26.3%
Personal emergency response systems	23.2%
Crisis stabilization	13.7%

As with the Waiver recipient survey, respondents were requested to indicate a need for the three targeted Waiver services within the next two to five years, behavioral assistance, nursing care, and assistance with medical needs. As with the recipient survey, a small minority of respondents indicated a need for these services (see Table 9).

Table 9. Self-reported need for specific Waiver services within 2 to 5 years

Service	Percent
Behavioral assistance	3.2%
Nursing care	2.1%
Assistance with medical needs	2.1%

Respondents were requested to indicate how they learned of the availability of Waiver services. Responses were categorized and presented in Table 10. Written information from the CSB or other sources (such as the Department of Medical Assistance) accounted for 44.6% of responses. Over one-fourth (27.6%) indicated that they learned of the availability of Waiver services by word of mouth from other parents or non-professional sources. A smaller percentage (13.8%) learned of the Waiver from a professional, such as the individual's case manager, teacher, etc.

Table 10. Means by which respondents learned of Waiver services	
Written information from the CSB or other sources	44.6%
Word of mouth	27.6%
Case manager, teacher, other professional	13.8%
Don't know/remember	14.0%

Respondents were requested to assess the level of difficulty they had encountered in accessing Waiver services, either "not difficult at all," "somewhat difficult," or "very difficult." Responses to this item are summarized in Table 11. Over three-fourths of respondents indicated that they had not experienced difficulty in accessing services, with 4.3% indicating that the process was very difficult.

V. Summary

How can the current MR Waiver program be improved to provide a person-centered, individualized support focus?

Findings from the Waiver recipient survey show that the overwhelming majority of recipients of services believe that the services they received were either fully or somewhat individualized to meet their needs. In addition, the overwhelming majority of service recipients believed that the services they or their family member were receiving were helpful to them. Certainly, this is an area in which all service providers and funding agencies can make improvements; however, with the exceptions of prevocational services and supported employment, participants seem to be satisfied with the degree to which services are individualized for themselves or their family members. Furthermore, over three-fourths of the members of the waiting list stated that they had not encountered any difficulty applying for and accessing Waiver services.

Table 11. Self-reported level of difficulty in accessing Waiver services

Service	Percent
Not difficult at all	76.6%
Somewhat difficult	19.1%
Very difficult	4.3%

Do therapeutic behavioral consultation services need to be more available to MR Waiver recipients?

Only a small number of current Waiver service recipients indicated an unmet need for behavioral consultation services. However, 88.4% of the waiting list respondents indicated that they needed assistance with behavioral problems in the home, and 45.3% indicated a need for therapeutic consultation services. It would appear that there is indeed a need for behavioral consultation for individuals on the waiting list.

Do skilled nursing services need to be more available to MR Waiver recipients? Do medical services need to be more available to MR Waiver recipients?

As with behavioral assistance, there does not appear to be an unmet need for skilled nursing or medical services among current Waiver recipients. However, there does appear to be a greater need for nursing and medical services among the waiting list members. When asked specifically about skilled nursing services, 45.3% of respondents indicated that they or their family member would need the service. In addition, over three-fourths of respondents indicated that they were interested in the Waiver because they or their family member required medical supports. There does appear to be a discrepancy between this item and the follow-up item, which found that only 2.1% would be in need of nursing care and medical assistance within the next two to five years. This discrepancy may be due to the temporal nature of the second question; respondents may feel that they will ultimately need nursing and medical assistance but do not foresee needing within the next few years.

What other specialized supports do MR Waiver recipients need than those that are currently available?

This survey did not reveal a significant need for other specialized supports for Waiver recipients, other than those currently available. There is certainly a need for expansion of service capacities statewide to shorten time spent waiting for services. It is notable that the average time on the waiting was 28 months and for many individuals was significantly longer than that. Time spent waiting for services can result in the erosion of previously learned skills, inactivity and boredom (which may in turn lead to criminal or self-destructive behaviors), and financial and emotional burdens on the family. It is also notable that many individuals from the waiting list sample could not be located. CSBs can make the time that individuals and families spend on the waiting list productive by maintaining frequent contact with individuals and families, keeping contact information current, and assessing needs for specific types of Waiver services and supports.

Appendix K
Results of Research Regarding Other States' Practices

In developing the recommended changes to our system's **Behavioral Consultation issues** the focus team learned that Vermont totally eliminated their state institution system several years ago. When they accomplished this, they set up a community network of professionals that are equipped to provide crisis stabilization in the community. At the core of this system is a team that meets weekly to review the status of each individual throughout the state who has been identified as being in crisis and his/her recent progress. Other states, such as New Mexico, have developed mobile teams of professionals that can be dispatched to any part of the state when needed to help stabilize individuals in the community. While their focus is to stabilize the individual in their present home environment, there are back-up systems in place to remove them to another residence if needed.

The **Housing focus team** discovered that our neighbor, North Carolina, has worked to increase the availability of affordable housing for its residents with intellectual disabilities. They have focused on developing new housing units and increasing access to generic housing resources. Successful strategies included:

- Creation of a dedicated Housing Coordinator position and provision of funding for Housing Specialist positions throughout the state;

- Investment of $1million from the Mental Health Trust Fund combined with $2 million form the NC Housing Finance Agency (NCHFA) to create a project-based rental assistance demonstration program to serve persons with disabilities living in rental units built through NCHFA's Low Income Tax Credit program.

Minnesota provides waiver services using a variety of CMS service options not yet utilized in Virginia:

- Chore Services: A waiver service that supports or assists a person or his/her primary caregiver to keep his/her home clean and safe. Examples include washing floors, windows and walls.

- Caregiver living expenses: A waiver service that provides payment for rent and food that may be reasonably attributed to a live-in personal caregiver. The live-in person also provides one of the following waiver services, i.e., personal assistance.

- Housing access coordination: A waiver service that allows an authorized consultant to provide direct housing support to an individual or his/her representatives, to assist them with housing decisions or the implementation of their housing plans, such as making choices about where to live, the type of home he/she wishes to have, who will be a roommate(s), if any. This consultant also helps identify affordable, accessible housing and assures that housing needs are provided for separately from other service needs.

Health and Human Service (HHS) recently approved Iowa as the first state to add Home and Community-Based Services (HCBS) as a permanent feature of its Medicaid State plan, eliminating the need for repeated requests for time limited waivers (April 2007). This new benefit will provide statewide HCBS case management services and "habilitation services" at home or in day support programs that can include such things as support in the workplace.

Connecticut's Department of Mental Retardation operates a "Community Based Housing Subsidy Program," which assists persons in intellectual disabilities to meet the housing costs attributable to the acquisition, retention, use and occupancy of a personal home in the community. Any person eligible for residential services provided by the DMR, who does not have sufficient income and assets to pay for his or her total housing costs may receive the housing subsidy. Costs that may be subsidized include but are not limited to rent, security deposits, utilities, insurance, and costs related to "routine" maintenance and repair.

Texas provides rent subsidies for people with disabilities who live in an institution but want to move to a community living environment through the Tenant Based Rental Assistance (TBRA) program and with its Money Follows the Person demonstration project. The TBRA is provided through a contract with the Texas Department of Housing and Community Affairs. Program participants pay about 30% of family income for rent and utilities. Participants can receive a subsidy for up to 24 months, and must participate in a plan to achieve long-term self-sufficiency.

As the **Medical Oversight focus team** made recommendations about adding Dental services to the MR Waiver, research was conducted into other states' coverage of dental needs. Tennessee includes dental services for adults in their Self Determination Waiver. Funded services include fillings, root canals, extractions, the provision of dentures and other dental treatments to relieve pain and infection including anesthesia services provided in the dentist's office. Oklahoma defines this service in their Waiver as including "maintenance or improvement of dental health as well as relief of pain and infection." The dental services in Oklahoma's Waiver include oral examinations, limited X-rays, prophylaxis and are currently limited to 5 visits per 12 months at a reimbursement rate of $83.50 per visit, though this will be amended to $1000 per year. Texas has a similar $1000 per individual per year limit in their Waiver. They cover emergency dental treatment, preventive dental treatment, therapeutic dental treatment, and is fairly unique in covering orthodontic treatment. Texas states that they "recognize that basic dental treatment is an essential element in overall health care and therefore, is necessary to protect and promote the health status of participants in their Waiver." They further state, "access to basic dental care enhances the ability of people with mental retardation to fully participate and be accepted in everyday community activities such as employment opportunities or social activities." Colorado's SLS Waiver covers dental services not available through the Medicaid State Plan and is intended to provide, at a minimum, routine preventative dental care, but also includes treatment of injuries and elimination of infection or life threatening oral conditions. Nebraska covers dental services for all Medicaid recipients under the Medicaid State Plan, not the DD Waivers. Indiana similarly provides State Plan dental coverage, but for a time its Waiver included a service called "Enhanced Dental," which was designed to ameliorate more generalized disease due to infection or improper nutrition which would require institutionalization. The following states do not report covering dental services under their Waiver programs: Connecticut, Delaware, Louisiana, Massachusetts, North Carolina, North Dakota, South Dakota, Utah, Wisconsin and West Virginia.

The **Person-Centered Practices focus team's** research into other states' models revealed that the current medical, clinical, programming model in Virginia's system does not align with the more progressive person-centered models available in many other states. It was discovered that some states (such as Wyoming, Maine, Kansas and Connecticut) have been forced to expand community services due to lawsuits. Several have used this opportunity to expand person-centered practices at the same time.

Others, such as Maine and North Carolina have created a formal role within their system for a professional to act as an assistant to the individual with disabilities in order to ensure that person-centered planning occurs as it should. Massachusetts ensures a person-centered approach to service delivery through a two-part process that includes both a licensure and certification process. The licensure process, similar to Virginia, gives legal authorization to provide services and supports, and is based upon the presence of essential safeguards in areas relating to health, safety and rights. The certification process reviews the outcomes in individuals' lives, in addition to health and safety, such as relationships, community connections, individual control, growth and accomplishments.

The introduction of an individual budget (a.k.a. individualized resource allocation) helps individuals develop plans for services and supports that best meets their unique needs and preferences. Individual budgets design supports around an individual rather than a service setting, funds are portable across providers, and individuals gain authority and flexibility over a variety of the most useful services and supports tailored to their needs and preferences. Wyoming's DOORS and Maryland's New Directions Waiver are good examples of true individual planning and self-direction of support.

In a few states (Kansas, Wyoming, Wisconsin), individuals have a choice of traditional or independent case management services. Case management services may vary based on need as is seen in Maryland, or may be time limited as in New York's Waiver. Several states (such as Kansas, Wyoming, Wisconsin, New York, Maine and Connecticut) limit caseload size to regulate the workload, improve quality of service, facilitate person-centered planning, ensure regular monitoring of individual needs and services provided, and finally, decrease the frequent case management turnover.

Some states use a support broker/services facilitator to help individuals with developing their plans and managing their services. The primary functions of a support broker/services facilitator include specialized help to the individual and family with developing a person-centered plan, developing an individual budget, managing that budget, developing emergency back-up plans, managing services, as well as recruiting, hiring, and terminating staff. In Maryland, Connecticut, and Vermont, this service is funded under the individual budget, is selected by the individual from among friends, certain family members, or other approved providers.

The **Waiting List focus team** examined information about a number of states that have also grappled with waiting list issues. Information was reviewed about 17 different states with more in-depth information gathered about 10 of these states. It was learned that while one of the examined states has no waiting list (South Dakota), many others have significantly higher waiting lists than Virginia.

All of the states reviewed had determined that part of their approach to lowering waiting list numbers was to adopt a Supports Waiver (geared toward preventing out-of-home placement through offering less than 24-hour supports and involve capped costs for each individual – at significantly less than the average ICF/MR rate) for persons with intellectual disabilities, *in addition to* their comprehensive waiver (such as our MR Waiver). Nearly half of the states currently operating Supports Waivers (eight of the 17 reviewed) were further nudged toward this solution by litigation over their waiting lists, which were perceived by advocates as barriers to community access.

Another factor related to decreasing the Statewide Waiting List that was examined in other states was their eligibility processes/tools. The committee theorized that one reason there are so many individuals in need of services in Virginia and unable to even get on the Statewide Waiting List is that the criteria for gaining access to the MR Waiver is stricter than other states. Eligibility criteria in Alabama, Tennessee, Florida, Oklahoma, Texas and Nebraska were investigated. While there was great variability in these states' criteria, none seemed to have as "institutionally focused" a functional eligibility tool as Virginia has in the Level of Functioning Survey.

The Employment focus team reviewed supported employment waiver programs in Colorado, Tennessee, Minnesota and Maryland and compared them against Virginia's programs under the MR Waiver. The definition for waiver supported employment programs for all five states is very similar. Each state stresses various program objectives. For example, Colorado, Minnesota, Tennessee and Virginia stress that supported employment is paid employment. Maryland, Colorado, Tennessee and Virginia require supported employment work to be in community settings where persons without disabilities are employed. The MR Waivers for Colorado, Minnesota and Virginia stress that supported employment services are for persons for whom competitive employment at or above the minimum wage is unlikely due to the nature and complexity of their disabilities.

Under the area of service activities, Virginia's allowable activities appear to be targeted to the generic program consumer as compared to the other states. A consumer may receive training in specific skills or specialized supervision or transportation to/from work sites, but the choices made for or presented to the consumer could better recognize a consumer as an individual. On the other hand, the Maryland, Tennessee and Colorado MR Waivers are focused on the individual's preferences and needs that form the basis for the service plan. Allowable activities in Colorado, Maryland and Minnesota stress the individual. Whether individualized assessment, individualized counseling, individualized job development or appropriate job matching for the individual, all three states seem to recognize the importance of the individual as a consumer of services. Colorado appears to allow the most flexibility and does not impose any service limits and only imposes a financial limit of $35,000 per year per recipient. The individual can receive as many services as can be negotiated with the provider. Services are oriented toward long-term support.

Tennessee's *Employment First* initiative has recently made employment a top priority for individuals with disabilities. In order to increase the number of individuals served by their Department of Mental Retardation Services (DMRS) who are employed, *Employment First* establishes employment as the first day service that is considered in an individual's service plan. Supported employment may be combined with other day services. *Employment First* also strives to increase the service capacity of day service providers. *Employment First* creates three critical elements to achieving their plan: 1) clear and effective communication between DMRS, Vocational Rehabilitation (VR), the Council on Developmental Disabilities and advocates; 2) each person served by DMRS in the community must have a least one job site assessment every three years; and, 3) to develop tools and resources that serve as the basis for an in-depth discovery proves – including site assessments that match the needs, wants and interests of the job seeker. Success is reliant on Home and Community-Based Services Waiver funded SE, favorable rates for SE, Money Follows the Person, blended VR and DMRS funds, Social Security work incentives, training and Community Work Incentive Coordinators, and natural supports.

A review of unit types and reimbursement rates include wide ranges for both categories. The smallest unit is 30 minutes in Minnesota. The largest reimbursement rate was a maximum spending limit of $35,000 per year for an individual in Colorado. States contacts showed the unit type most used is a "day." Whatever the reimbursement rate or unit type, paid claims were only made to licensed or certified providers and/or certified vendors as each state so identified them. All states were billed monthly. Only Virginia reported a specific fixed rate for enclave or work crew work.