

**NORTHERN VIRGINIA REGIONAL
DUAL DIAGNOSIS (MR/MI) WORKGROUP**

FINAL REPORT; JULY 30, 2003

Background

In July 2002, the Department of Mental Health, Mental Retardation, and Substance Abuse Services (DMHMRSAS) convened a Statewide Dual Diagnosis Steering Committee to address the needs of the citizens of the Commonwealth of Virginia who require services and supports due to the co-occurrence of the conditions of mental retardation and mental illness (MR/MI). The DMHMRSAS Dual Diagnosis Steering Committee Vision Statement is:

The Virginia DMHMRSAS will engage in collaborative partnerships to develop state-of-the-art services and supports for individuals who require care and treatment related to the co-occurrence of the conditions of mental retardation and mental illness. The partnership will seek to (1) identify the prevalence of this dual diagnosis, (2) reduce barriers to treatment, (3) identify best practices models, and (4) train service providers, consumers and families.

The DMHMRSAS Dual Diagnosis Steering Committee goals and objectives are to:

- Determine the prevalence rate of dual diagnosis in Virginia.
- Study the demographics of current cases.
- Improve the accuracy of diagnoses for this population.
- Develop a vision statement that will foster a creative and cooperative service delivery system that values integration of services and stressing that this is a joint project for public and private service providers and specialized agencies (i.e., mental retardation, mental health and substance abuse services).
- Define or identify training needs, standardize training curriculum and requirements, develop a specific dynamic didactic training model.
- Determine the service delivery gaps that exist within the current care or service delivery configurations through a gap analysis.
- Determine incentives for service delivery.
- Identify a good practice model and a list of experts.
- Establish university contacts and liaisons.
- Establish conference planning.
- Identify and seek funding, grants and technical assistance.

The DMHMRSAS Steering Committee also requests that each State Health Planning Region (HPR) create a MR/MI Regional Workgroup to better address regional issues, differences in population and resource allocation. Every regional workgroup is expected to:

- Collaborate with and assure membership from all mental retardation and mental health stakeholders, including consumers, families, advocates, state facilities, community services boards (CSBs), schools, residential and vocational vendors, universities, private community hospitals, etc.
- Conduct service and treatment delivery gap analysis for each region.
- Analyze system capacity for service delivery, including emergency services, crisis prevention, and stabilization.
- Analyze regional strengths and weaknesses; prioritize areas for improvement.
- Define regional priorities.
- Identify regional experts.
- Review and update the regional MR/MI protocols; review other regional protocols for possible items to include in the regional protocol.
- Validate state-derived prevalence data and provide detailed regional data.
- Develop a regional consultation team (PACT team model) or other appropriate program alternatives or treatment options. This team would act as a consultation source for the region.
- Develop topics of regional interest for the upcoming state-sponsored Best Practices Conference.

Northern Virginia MR/MI Workgroup Process

This report represents the HPR II Workgroup's efforts to respond to the expectations for each regional workgroup and to address some of the broader issues identified in the DMHMRSAS Dual Diagnosis Steering Committee's goals and objectives. The MR/MI Workgroup has conducted regular meetings since September 2002. The Northern Virginia Workgroup members are derived from a large group of stakeholders chosen to best represent the interests of consumers, families, advocates, the five (5) Northern Virginia Community Services Boards (Alexandria, Arlington, Fairfax/Fall Church, Loudoun, and Prince William), private residential providers, vocational day placement providers, community behavioral consultants, Northern Virginia Training Center (NVTC), Northern Virginia Mental Health Institute (NVMHI), and George Mason University. Workgroup members are from both mental retardation and mental health service delivery systems.

The process of the Northern Virginia Regional MR/MI Workgroup (hereafter referred to as the MR/MI Workgroup) has been similar to other successful regional collaborations. Members have devoted considerable time and expertise to the Workgroup and significant progress has been made on a number of issues.

Mission Statement – Work Group

The mission of MR/MI Workgroup is to advance mental wellness for persons with mental retardation and other related conditions through the promotion of excellence in community-based mental health services and supports.

Vision and Guiding Principles – Work Group

The MR/MI Workgroup fully endorses the Vision and Guiding Principles set forth by the Northern Virginia Regional Partnership and the DMHMRSAS Dual Diagnosis Steering Committee.

Definition of Dual Diagnosis

The MR/MI Workgroup adopted from the National Association for the Dually Diagnosed (NADD) the broad definition of dual diagnosis as *the co-existence of the manifestations of both mental retardation and mental illness.*" Additional detailed clarification on the meaning of dual diagnosis can be found in Attachment 1.

Northern Virginia Regional MR/MI Protocol

The members of the workgroup determined that there are no existing Northern Virginia regional MR/MI protocols for admission and discharge to review or update. The Northern Virginia CSBs, Northern Virginia Training Center (NVTC) and Northern Virginia Mental Health Institute (NVMHI) will use the current DMHMRSAS Admission and Discharge Protocols for Persons with Mental Retardation Served in State Mental Retardation Facilities, the Discharge Protocols for Community Services Boards and State Mental Health Facilities, and the Procedures for Continuity of Care Between CSBs and State Psychiatric Facilities.

Data Analysis and Trends for Northern Virginia

A. Prevalence of Dual Diagnosis

The MR/MI Workgroup experienced difficulty gathering prevalence information from existing Northern Virginia CSB database sources. Data is not easily found or available; the data system is not comprehensive; and data is stored only by specific cases or for crisis incidents. As a result of these limitations, the workgroup was not able to assess prevalence data in Northern Virginia. Therefore, for planning purposes it was decided to use the following clinical assumption based upon the published professional literature to determine prevalence:

Persons with a dual diagnosis (MR/MI) can be found at all levels of mental retardation (mild, moderate, severe, profound). Estimates of the frequency of dual diagnosis vary widely in the published clinical literature; however, many professionals have adopted the estimate that 20-35% of all persons with mental retardation have a psychiatric disorder. The full range of psychopathology that exists in the general population also can co-exist in persons who have mental retardation.

Based upon above assumption and the estimated prevalence of mental retardation from the DMHMRSAS Comprehensive State Plan 2000-2006 for HPR II (N = 16,107), the number of individuals in the Northern Virginia area with dual diagnosis is estimated to be between 3,221 to 5,637 individuals. With current population growth trends, these numbers will continue to increase and put additional strain on the system. Although the Workgroup could not access adequate data to perform an actual prevalence assessment in Northern Virginia, the information that was obtained fell within these estimated prevalence figures. For this discussion, it is also important to note that 85% of individuals with mental retardation fall within the mild range, 10% in the moderate range, 3-4% in the severe range, and 1-2% in the profound range of functioning (Diagnostic and Statistical Manual of Mental Disorders, 4th Edition/TR; DSM-IV/TR).

B. Current Cases of Dual Diagnosis

The above prevalence information can be used for overall planning purposes, however, additional information is needed to determine services currently available, service delivery gaps and other issues. While some individuals with MR/MI issues are served well, there is a general agreement and understanding among treatment professionals and provider agencies that individuals with MR/MI are underserved. It was decided that each CSB, NVMHI, NVTC, and several private providers would review a select group of individual cases currently known to their MR and MH systems. Forty-two (42) cases were reviewed and represented three (3) general categories of treatment outcome:

- (1) Individuals with excellent outcomes and success;
- (2) Individuals who did fairly well but whose outcomes could have been better given adequate or improved services; and,
- (3) Individuals who had poor outcomes and continue not to do well despite tremendous efforts.

Using these three general categories, workgroup members generated individual consumer profiles that provided a summary of services that were critical to a successful outcome, services that could have been improved, services that were lacking, and barriers to service. These services are listed below; they are NOT in order of priority.

Current Services Critical to Achieving Successful Outcomes for the Studied Cases

- Jointly shared responsibility between mental retardation (MR) and mental health (MH) services.

- Collaboration among DMHMRSAS and CSB MR and MH agencies and private providers of residential and day/vocational services.
- Flexible funding and immediate availability based upon levels of support needed rather than diagnosis.
- Intensive case management, with smaller case loads allowing the case manager to take a much more active role in helping the consumer develop and maintain everyday life skills and build natural circles of support.
- Sufficient staff resources in both residential and day/vocational locations; need for 1-1 staffing during crisis and during stabilization periods.
- Well-trained staff that receives specialized training in MR/MI issues.
- Development of strategies to address crisis situations, which is an integral part of an overall treatment or discharge plan.
- Frequent coordination and follow-up with residential and day/vocational placements to ensure adherence to the treatment plan and to prevent slippage and crisis.
- Suitable day placements to meet consumer needs, including vocational and non-vocational options, as well as community college life skills degree programs.
- Psychiatrist with previous knowledge and training in MR/MI issues.
- Accurate psychiatric assessment and diagnoses.
- Significant behavioral consultation hours and more hands-on than the typical behavioral consultation.
- Options for community residential placement with a full range of alternatives such as group homes, specialized foster care, 2-3 bed homes, supervised apartments, mentor roommates, Life Coach, etc.
- Family and consumer education and support groups to recognize dual diagnosis, learn more about treatments, and to offer support for dealing with challenges of a dual diagnosis.

Barriers and Service Enhancements that Would Have Increased Successful Outcomes for the Studied Cases

- Formal agreements for collaboration and jointly shared responsibility between mental retardation and mental health services from both the DMHMRSAS and CSBs.
- Prioritized review of requests/applications for waiver funding for consumers with MR/MI issues.
- DMAS staff is typically not familiar with the specialized needs and supports of the MR/MI population as compared to consumers with only mental retardation.

- Families and consumers are not aware that they can have both a diagnosis of mental retardation and mental illness and sometimes fail to recognize the signs and symptoms of mental illness.
- Financial incentives for residential private providers to keep beds available when consumers are placed out of the home for short durations during crisis.
- Specialized training and supervision in MR/MI issues for all personnel at the clinical, medical, managerial and direct services levels.
- Specialized outpatient services.
- Partial hospitalization option to avoid removing the consumer from their home and as an option to inpatient hospitalization.
- Program for Assertive Community Treatment (PACT) model specialized in MR/MI issues.
- Mobile crisis intervention teams of both clinical and direct care professionals with expertise in MR/MI issues.
- On-going dialogue between regional and local representatives of the CSBs and DMHMRSAS with private residential and day/vocational providers concerning the types of services needed.
- Frequent coordination and follow-up by CSB case management with residential and vocational placements to ensure adherence to the treatment plan and to prevent slippage and crisis episodes.
- Limited number of behavioral consultation providers with knowledge, skills and abilities with MR/MI issues.
- Limited number of psychiatrists with knowledge, skills and abilities with MR/MI issues.

Next Steps and Recommendations

While some individuals with MR/MI issues are served well, there is a general agreement and understanding among treatment professionals and provider agencies that individuals with MR/MI are underserved due to consumer complaints, excessive lengths of inpatient stay, recidivism rates at the MH hospitals, staff turnover, and overall treatment costs. Relatively few individuals with dual diagnosis need institutional-based care; but when it is needed, it should be obtained with minimum bureaucracy. The greatest needs are for community-based mental health services that provide in-home supports, partial hospitalization and crisis stabilization; and for behavioral specialists to support staff working with the MR/MI population in all environments. Community mental health services must be willing to serve people who have mental retardation, willing to work across the various environments that the person requires supports, and willing to work cooperatively with developmental or habilitation specialists. Interdisciplinary assessment and training is needed for staff of both MR and MH agencies with recognition that one profession or service orientation does not have all the answers. Services should be based upon individual

consumer needs and supports rather than disabilities, thus avoiding “problem shifting” that occurs between MR and MH agencies. Much can be accomplished through collaboration with existing community resources rather than creating new resources in response to present limitations of single MR or MH service sectors.

System Issues

- (1) Families and individuals do not understand that they or their loved ones can have both a diagnosis of mental retardation and a mental illness. As a result, treatment and quality of life is compromised for the individual and the family, as they frequently get bounced between systems and face multiple barriers for getting appropriate services.

Recommendation: Develop educational materials that address various symptoms that are associated with a person who may have co-occurring diagnoses.

Recommendation: The CSB intake should be more family and consumer friendly, in that, one case manager should be assigned to help the individual and family negotiate the entire set of services that are available to the individual with MR/MI issues.

Recommendation: Provide opportunities for the families and individuals to receive education and actively participate in treatment planning when an individual is beginning to show signs of decomposition, as well as throughout the crisis period and transition back to the community.

- (2) Service provision, coordination, and oversight should promote and reinforce collaboration and joint responsibility, and lead to the development of statewide, regional, and local solutions.

Recommendation: Develop Formal Memorandums of Agreements (MOA) for MR and MH offices at both the DMHMRSAS and CSB levels. The formats should include the following:

- (a) Regional model for service delivery
- (b) Community-based focus
- (c) Involvement all major stakeholders
- (d) Specified tasks and responsibilities for all parties
- (e) Services based upon individual consumer needs and supports rather than disabilities.

Recommendation: Continued administrative support from DMHMRSAS and the CSBs for the DMHMRSAS Steering Committee and the Regional MR/MI Workgroups. Hold regular meetings with documentation of issues.

- (3) The data was difficult to harvest. The MR/MI Workgroup had difficulty gathering prevalence information from the Northern Virginia CSB database.

Recommendation: Revise the current database or develop system-wide database to improve the efficacy and usefulness of data collected for individuals with MR/MI, the services and supports they receive and the environment in which the supports are provided, and the manner in which costs are reimbursed.

- (4) Case management services need to be enhanced. Intensive case management services were critical to positive outcomes. Case managers must have training in mental health, mental retardation, functional analysis of behaviors, psychosocial treatment, and psychotropic medications. Case managers working for individuals with MR/MI issues must have smaller caseloads and they should provide more hands-on interaction with the consumer, residential and vocational provider so as to advocate for the appropriate services to support individuals in different environments and activities throughout the day. An alternative option of intensive case management relies upon a consultative model, in which several case managers act as specialized consultants and provide technical assistance to other case managers on issues related to MR/MI.

Recommendation: The CSBs should review current case management services and develop a system of intensive case management services that would better address the needs of their MR/MI consumers.

- (5) The existing range of residential options for consumers with MR/MI issues is too limited.

Recommendation: DMHMRSAS and the CSBs should collaboratively develop and fund a fuller range of residential alternatives beyond the typical group home model. Options may include specialized foster care, 2-3 bed homes, individual homes, supervised apartments, mentor roommates, etc. Involvement with local and state HUD should be a critical component of such efforts.

- (6) Behavioral consultation services are currently too limited and insufficiently funded. Effective behavioral consultation is critical to positive outcomes and successful crisis resolution. However, the current waiver consultative model is not sufficient. Consumers require more direct, hands-on service from the behavior specialist for successful clinical outcomes than is currently allowed. In addition, DMAS and DMHMRSAS have frozen the development of any new behavior consultation contracts under the waiver.

Recommendation: DMHMRSAS and DMAS should establish clinical skill criteria for new behavior consultation contracts for MR/MI consumers.

Recommendation: DMHMRSAS and DMAS should review the current waiver consultative model and consider a more direct, hands-on service delivery approach for the behavior specialist working with persons who demonstrate MR/MI issues. The funding should also support on-going training for direct care and managerial staff from pre-admission throughout the crisis period.

Recommendation: Each CSB should have a behavioral consultant either on staff or as a specific consultant for MR/MI issues.

Recommendation: In order to meet the current demand and future needs, DMAS and DMHMRSAS should begin approving new behavioral consultation providers under the MR Medicaid waiver program. The lack of an approval process for additional behavioral consultants over the recent years has resulted in a significant resource shortage for service providers and creates a reliance on staff resources without sufficient expertise in the field.

Treatment

- (1) Current assessment and diagnostic protocols and treatment programs are not standardized or appropriate. The co-existence of mental retardation and a psychiatric disorder can have serious effects on the person's daily functioning by interfering with educational or vocational progress, by jeopardizing residential placements, and by disrupting family and peer relationships. In short, the presence of behavioral and emotional problems can greatly reduce the quality of life of persons with mental retardation. Misdiagnosis also can result in additional stigma and inappropriate treatment (and thus poor outcomes) for the person. It is imperative, therefore, that accurate diagnosis and appropriate treatment are obtained.

Recommendation: Develop a uniform set of standards for assessment and treatment programs for persons with MR/MI. Assessment tools would be based upon levels of support needed and encompass the entire "circle of need."

- (2) Individuals with MR/MI issues may also need individualized supports in specialized areas of geriatrics, forensics, and/or substance abuse. The MR/MI Workgroup has noted that like the general population, there is a large aging MR/MI population who faces the prospects of age related physical health and mental health issues (e.g., depression, senility, and dementia issues).

Recommendation: CSB case managers and other treatment professionals need to recognize and address appropriate supports in these specialized sub-areas to ensure stability of placements.

Recommendation: Increased cooperation and shared responsibility for service provision across single service agencies (e.g., MR, MH, geriatrics, forensics, and substance abuse) will be needed to address these complex treatment issues.

Recommendation: A global assessment and treatment plan covers all service areas and interdisciplinary teams encompass all specialized areas so the person can be treated in a holistic manner.

- (3) A small number of the MR/MI population will require care in an ICF/MR. The development of inpatient psychiatric ICF/MR programs should be approached cautiously and only as one small component of a larger community-based initiative involving NVTC and NVMHI.

Recommendation: The focus of care should be community-based, with a range of treatment options, including specialized outpatient services, in-home supports, partial hospitalization, crisis stabilization, and inpatient treatment.

- (4) Community-based residential alternatives with adequate supports for consumers with MR/MI are very limited. The vast majority of persons with mental retardation function in the mild to moderate range of mental retardation. These consumers are best served in a small, supportive community-based residence. Placement in a State Training Center is not appropriate for several reasons: ICF/MR level of care criteria will not be met; Training Centers serve predominately persons with severe and profound mental retardation; and mental health agencies and facilities have the psychiatric and psychosocial rehabilitation services most appropriate to meet the needs of persons with mild to moderate mental retardation.

Recommendation: Persons with severe and profound mental retardation who also have mental health issues will be served in community-based options when possible. If inpatient care is needed, they will be served only in the Training Centers, not in State Mental Health Hospitals.

- (5) Placement at a Mental Health Facility is appropriate for higher functioning individuals with mild and moderate mental retardation, but many persons with mental retardation do not “fit in” with the typical mental health population. At mental health facilities, some individuals with mental retardation are easily victimized and/or they frequently do not benefit from the treatment milieu. These individuals pose more serious treatment and safety issues for Training Centers who serve predominately persons with severe and profound mental retardation.

Recommendation: Persons with mild and moderate mental retardation who also have mental health issues will be served in community-based options when possible. If inpatient care is needed, they will be served only in the specialized units of the State Mental Health hospital, not in the Training Centers.

Recommendation: Some individuals may lack a mental health diagnosis and will not meet criteria for admission to a public or private Mental Health Hospitals. However, their serious behavioral challenges prohibit effective and safe treatment in their current community setting. A crisis stabilization residential program can meet this need for more intensive services until an effective treatment program can be developed.

- (6) There exists an insufficient provider network of specialized outpatient services in Northern Virginia. The NVTC Regional Community Support Clinic provides specialized outpatient services but additional resources are required to provide adequate number of appointments to satisfy current demand and address future needs.

Recommendation: Provide additional targeted funding to the NVTC Regional Community Support Clinic to provide specialized outpatient services to consumers with

MR/MI. In addition, provide funding to NVMHI to create and support a Regional Community Support Clinic model program based at that location.

Recommendation: On-going collaboration between NVTC and NVMHI will be essential to any specialized outpatient effort.

- (7) A Partial hospitalization option does not exist in the Northern Virginia region. Partial hospitalization is less artificial than an inpatient unit, since the person spends nights and weekends in a community residence. This model can accommodate a shorter psychiatric inpatient length-of-stay by providing step-down level of care upon discharge from an inpatient facility. Partial hospitalization can also provide an alternative to inpatient care for those patients who do not require the restrictive security of a locked environment, but who are experiencing new onset of psychiatric symptoms or acute exacerbation of chronic psychiatric conditions.

Recommendation: Create and fund a community-based specialized partial hospitalization option that can be used as both a step-up and step-down treatment location.

- (8) Each CSB should have a PACT model of care. The treatment literature indicates that participation in PACT for persons with MI/MR was associated with fewer admissions, higher social functioning, greater patient satisfaction, lower symptomatology, lower cost, and shorter length of inpatient and partial hospitalization stay.

Recommendation: Create and fund a CSB PACT model specializing in MR/MI for all the Northern Virginia CSBs. Currently only Arlington and Fairfax-Fall Church CSBs have PACT teams, but none specialize in MR/MI issues.

- (9) Many community residential and day/vocational providers do not have the necessary staff resources to handle crisis situations or to provide the necessary staff supports for the short-term to meet supervision needs.

Recommendation: Train current CSB-based mobile crisis intervention teams of both clinical and direct care professionals to assure expertise in MR/MI issues. Expand this training to more traditional emergency response teams, such as police and fire department.

Recommendation: Allow flexibility in staffing and funding so that staff resources can stay in the residential and day/vocational locations for enough time to provide needed stabilization.

- (10) Individuals with MR/MI issues who live independently frequently miss follow-up appointments with psychiatrists and other treatment professionals. Failure to adhere to prescribed medication and other treatment plans typically result in crisis incidents and emergency room visits.

Recommendation: Develop and fund a personal support network, mentor or life coach program to assist discharged individuals in following treatment plans. Under a model developed by Sentara Health, individuals are assigned a Life Coach who assists in applying for benefits, keeping appointments, and accessing other needed services. Data collected by Sentara during the first year of a pilot program showed that persons assigned a Life Coach kept more appointments, had fewer emergency room visits, and had lower inpatient readmission rates than individuals without a Life Coach. The Arc of Northern Virginia has a Personal Support Network program that provides a similar set of services.

Education and Training

- (1) Cross training in MR and MH issues are needed for both service agencies in order for collaboration and joint responsibility to occur. This training is also necessary to develop MH service expertise among MR personnel and MR service expertise among MH personnel who have enduring or recurring contact with persons with MR/MI issues.

Recommendation: In order to develop the “next generation” of MR/MI direct care professionals, DMHMRSAS should develop a Commonwealth of Virginia Curriculum in Mental Retardation program. In a joint venture with the Virginia community colleges and universities, DMRMRSAS should provide funds and programmatic support to develop: a) training on mental retardation at the undergraduate level for college students; and b) a post-graduate training program for individuals interested in developing supervisory skills necessary to provide quality services to individuals with MR/MI.

Recommendation: Cross training of MR and MH personnel at the clinical, medical, managerial and direct services levels is needed.

Recommendation: Develop uniform system-wide training for State Mental Health Hospital psychiatric staff on assessment, evaluation, and treatment of MR/MI issues.

Recommendation: Develop uniform system-wide training for State Training Center psychiatric staff on assessment, evaluation, and treatment of MR/MI issues.

Recommendation: DMHMRSAS should sponsor and provide funds for a series of Continuing Education presentations on MR/MI issues based upon statewide and regional priorities for training.

Recommendation: DMHMRSAS should support and provide funding for a Best Practices Conference to obtain information from outside Virginia about state-of-the-art treatment and service delivery models.

Recommendation: The Northern Virginia MR/MI Workgroup will develop topics of regional interest for the State-sponsored Best Practices Conference.

- (2) The Northern Virginia area does not have sufficient psychiatrists with MR/MI treatment experience. Accurate assessment and diagnosis is critical to positive treatment outcome.

Recommendation: Develop a continuing education program for currently practicing psychiatrists who are interested in acquiring new skills necessary to provide expert services to individuals with MR/MI.

Recommendation: In order to develop the “next generation” of MR/MI psychiatrists, DMHMRSAS should develop a Commonwealth of Virginia Fellowship in Mental Retardation program. In a joint venture with the three (3) Virginia medical schools, DMRMRSAS should provide funds and programmatic support to develop: a) additional training on mental retardation at the required curriculum level for all medical school students; and b) a post-graduate training program for psychiatrists who are interested in acquiring skills necessary to provide expert services to individuals with MR/MI.

- (3) Education and training efforts in the public sector should be widespread in order to develop and provide awareness of MR/MI issues, individual needs and service delivery options.

Recommendation: Provide an education and training within the Public School Special Education apparatus (both administrators and teachers). This will aid early identification and treatment efforts and possibly prevent later challenging problems when the individual has grown physically.

Recommendation: Provide education and training to family members because they need to understand treatment issues and service options in order to advocate for needed services and supports.

Funding Issues

- (1) Department of Medical Assistance Services (DMAS) staff are typically not familiar with the specialized needs and supports of the MR/MI population as compared to consumers with only mental retardation. This lack of knowledge and training results in excess red tape, delays the funding of necessary supports and services, and prevents the funding of some needed supports.

Recommendation: Representatives of the CSBs and DMHMRSAS should work with DMAS to educate them about the special needs of this population. DMAS should consider establishing a specialized MR/MI utilization review team who could review service and funding requests and then issue a recommendation to approve or deny services.

Recommendation: Prioritize review of requests/application for Waiver funding. DMAS should assign specific person(s) with expertise in the special needs and supports of MR/MI population. This DMAS group would conduct cooperative reviews with CSBs of

requests for services and supports submitted by the CSB case manager. This would promote coordination of services based upon information from specialists with intimate knowledge of the individual.

- (2) Legislative support for funding proposals and reinvestment initiatives will be critical to success.

Recommendation: Representatives of the CSBs, DMHMRSAS, and DMAS work with Legislators to educate them about the special needs of this population. Knowledge of MR/MI issues will aid Legislative support of crucial funding proposals and potential appropriation of State funds.

- (3) Flexibility of funding and immediate availability of funding was identified as crucial to successful outcomes. Current funding mechanisms are not flexible and a delay in availability of funds has created gaps in service and supports needed for crisis management and stabilization.

Recommendation: Funding should be based upon levels of support needed rather than on diagnoses or service area.

Recommendation: Increased Medicaid Waiver slots for individuals with MR/MI issues are needed to address the large numbers of individuals statewide who have urgent needs, yet who remain on waiting lists for services until they are in crises. In addition, there is a need to identify funding for the growing number of individuals with MR/MI statewide who are waiting for services but who do not meet eligibility requirements for Medicaid waiver services.

Recommendation: Develop flexible specialized programs and services to meet the training and treatment needs of MR/MI persons in residential and day/vocational placements.

Recommendation: On-going dialogue between regional and local representatives of the CSBs and DMHMRSAS with private residential and vocational providers concerning the types of services and supports needed.

Recommendation: Funding should address the actual costs associated with services and staff supports the individual truly needs to maintain stability in his current environment and at the same time, affording protection to other individuals. Medicaid funding must be flexible rather than static to address specialized needs for support and ensure stability of placement.

Recommendation: Higher reimbursement rates for “complex” psychiatric outpatient visits and the recognition that the majority of services (particularly psychopharmacological services) to individuals with MR/MI qualify for the higher rate.

Recommendation: DMHMRSAS and the CSBs to develop financial incentives for residential private providers to create new beds and to keep beds available when consumers are placed out of the home for short durations during crisis.

- (4) Since the start of Medicaid Waiver services in Virginia in 1990, there have been no regular rate increases to adjust for inflation, and there is no rate differential to adjust for the demonstrated higher cost of providing services in Northern Virginia, unlike other Medicaid reimbursable programs.

Recommendation: DMAS and DMHMRSAS should consider addressing the need for a rate increase for both residential and day/vocational placement Medicaid waiver providers that reflect the actual costs of services.

Recommendation: A rate differential to adjust for the higher cost of providing services in Northern Virginia programs should be considered also.

The Northern Virginia Regional MR/MI Workgroup appreciates the opportunity to present these findings and suggested recommendations for consideration.

Respectively submitted,

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APPENDIX 1

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APPENDIX 3

DEFINITION: DUAL DIAGNOSIS (MR/MI and MI/MR)

Most broadly ... Dual Diagnosis is *the co-existence of the manifestations of both mental retardation and mental illness*" (from the National Association for the Dually Diagnosed (NADD), 2003).

The Diagnostic and Statistical Manual of Mental Disorders, 4th Edition/TR (DSM-IV/TR) defines Mental Retardation by three criteria:

- Below average intellectual functioning, as measured by an intelligence quotient (IQ) obtained by an individual assessment (usually a score of 70 or below);
- Onset before age 18 years; and
- Concurrent deficits or impairments in adaptive functioning.

DSM-IV/TR also specifies different levels of severity - Mild, Moderate, Severe and Profound.

However, there are definitional differences between the DSM-IV/TR and the new *American Association on Mental Retardation (AAMR) Definition, Classification and Systems of Supports Manual (2002)*.

- AAMR uses the IQ score of 70-75 as the marker for below average intellectual functioning, in order to take into account measurement errors (+/- 5 points) in testing;
- AAMR classifies persons with mental retardation based on "Patterns and Intensity of Supports Needed". The levels are Intermittent, Limited, Extensive and Pervasive.
- AAMR does not specify the four (4) levels of severity used by the DSM-IV/TR.

Mental Illnesses are "severe disturbances in behavior, mood, thought processes and/or interpersonal relationships" (DSM-IV/TR). Common types include: Affective Disorders, Psychotic Disorders, Depression, Personality Disorders, Anxiety Disorders, and others (per DSM-IV/TR).

[Adapted from the website of National Association for the Dually Diagnosed (NADD, www.thenadd.org)]

Based on the most significant factor contributing to functional impairment, Dual Diagnosis includes two major Sub-Groups:

- MI/MR: Persons for whom a serious mental illness is the most significant factor in their functioning and who has either mild or moderate mental retardation. Problems in daily living are primarily the result of the mental illness; or manifestations of the mental illness are creating the most difficulty in successful community living. Although some cognitive impairment exists, they have limited impact as compared to the mental illness. Example: a person with Schizophrenia and Mild MR.
- MR/MI: Persons for whom mental retardation is the primary basis for problems in daily living. Usually the level of mental retardation is severe or profound, and level of supports needed is extensive and pervasive. In general, the developmental delay was an issue for

supports prior to development of a serious mental illness. Example: a person with Severe MR and Major Depression.

Differential diagnosis between these two groups is critical in determining the most appropriate placement, supports and therapeutic interventions.