

	<b>MENTAL HEALTH AND SUBSTANCE ABUSE SERVICES BULLETIN</b> <b>MENTAL RETARDATION BULLETIN</b> COMMONWEALTH OF PENNSYLVANIA * DEPARTMENT OF PUBLIC WELFARE
	<b>SUBJECT</b> Coordination of treatment and support for people with a diagnosis of serious mental illness who also have a diagnosis of mental retardation
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**SCOPE:**

County Mental Health/Mental Retardation Administrators Base Service Unit Directors

**PURPOSE:**

The purpose of the Bulletin is to provide a framework to establish capacity for the delivery of coordinated treatment and care for adults with co-occurring mental illness and mental retardation.

**BACKGROUND:**

Estimates of the frequency of people with a diagnosis of mental retardation and a co-occurring mental illness vary widely; however, many professionals have estimated that 20 - 35 percent of all persons with mental retardation have a mental illness <sup>1</sup>. A much smaller number of people with mental retardation would meet the criteria of a "serious mental illness", as defined by the federal government <sup>2</sup>, and meet the definition of the Adult Priority Group established in the OMHSAS Bulletin OMH-94-04 <sup>3</sup>. This number is estimated to be 8-10 percent of the number of people with mental retardation. The number of adults who meet the criteria for a serious mental illness in the general population is approximately 5 percent. The individuals represented by these statistics, while a small number, can have frequent hospitalizations and be difficult to serve.

1. NADD An Association for persons with developmental disabilities and mental health needs; Fletcher (2002)
2. Adults with serious mental illness are persons age 18 and over, who currently or at any time during the past year, have a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified in the DSM-IV that has resulted in functional impairment which substantially interferes with or limits one or more major life activities. (See references for additional detail)
3. In order to be in the Adult Priority Group, a person: must meet the federal definition of serious mental illness; must be 18+ (or age 22+ if in Special Education); must have a diagnosis of major affective disorder, psychotic disorder Not Otherwise Specified (NOS), schizophrenia or borderline personality disorder (DSM-IV or its successor documents as designated by the American Psychiatric Association. (See References for additional detail)

The issues related to the difficulty of effectively completing a comprehensive review and identification of symptoms of mental illness, as well as the creation of treatment plans for this population, pose many problems for both the mental health (MH) and the mental retardation (MR) systems when people with mental retardation require mental health treatment.

Traditionally, if persons had a diagnosis of either serious mental illness or mental retardation, their access to services was the responsibility of one or the other of the service systems. However, over time it has become increasingly clear that persons with both serious mental illness and mental retardation need the treatment and support provided by both systems. It has become clear that there must be a closer and more coordinated response by both MH and MR systems to effectively meet the needs of those who are "dually-diagnosed". It is critical that locally coordinated MH treatment and MR supports are individualized, timely, cost-effective, occur in the most integrated setting, and are provided in accordance with principles established in the OMHSAS Community Support Plan and the OMR Everyday Lives document.

Therefore, this bulletin has been created to describe a framework to provide treatment and support to people with co-occurring mental retardation and mental illness through cooperative efforts of both the MH and MR systems.

## **COORDINATION OF SERVICES**

The County Mental Health and Mental Retardation Administrator shall assure the development of a cross-system approach between the county mental health and mental retardation services to support and to treat people with mental retardation and mental illness by:

- Establishing written protocols/procedures in both the mental health and mental retardation programs that will identify, assess, plan for and serve people with co-occurring mental retardation and mental illness.
- Identifying and/or recruiting providers that have the demonstrated specialization, experience and ability to accurately assess, diagnosis and treat or support people with co-occurring mental illness and mental retardation.
- Designating either the mental health or the mental retardation program as the lead in the coordination of services for each specific person and determining payment responsibilities.
- Promoting and sponsoring cross-system trainings to enhance collaboration and expand the knowledge base within each system, as well as sponsoring training for providers who are treating or supporting people with mental illness and mental retardation.
- Developing individual plans that meet the needs of people, to ensure effective treatment is provided in the least restrictive environment, and to avoid inpatient stays.
- Ensuring the county's involvement in effective discharge planning upon admission to a private or state mental health hospital.

Each county should identify two administrative staff, one each from mental health and mental retardation, to serve as Mental Health and Mental Retardation (MH/MR) "Dual Diagnosis" Coordinators. Their responsibilities include:

- Informing and educating county staff and providers on the local protocols and procedures that identify, assess, plan for and serve people with co-occurring mental illness and mental retardation.
- Overseeing and ensuring the implementation of the county protocols to serve people with co-occurring mental illness and mental retardation.
- Ensuring MH case managers and MR support's coordinators and other appropriate staff are trained in basic and advanced treatment and supports approaches for people with co-occurring mental retardation and mental illness

(It may be beneficial to designate and/or identify specific mental health case managers and mental retardation supports coordinators who would receive additional intensive training in promising practices for treating and supporting people with co-occurring mental illness and mental retardation.)

- Facilitating cross-system planning teams and assisting in problem-solving between these teams.
- Developing a plan for resource training of County MH/MR staff as well as providers to increase their capacity to provide required services.

The Regional Office of Mental Health and Substance Abuse Services and the Regional Office of Mental Retardation will each identify a staff person to serve as mental health and mental retardation coordinator for its region. Their coordinators' responsibilities shall include:

- Serve as a liaison between the county mental health and mental retardation coordinators and the state offices.
- Be available as needed to facilitate cross-system planning teams and assist in problem-solving.
- Help to identify training, technical assistance and promising practices.

## **COMPREHENSIVE REVIEW PROCESS**

There is general agreement that there are complicating factors that impact on making an effective diagnosis and providing treatment and support for people with mental illness and mental retardation. Some of these factors are:

- Symptoms of mental illness are often misinterpreted as a characteristic of mental retardation.
- Many people cannot report their subjective experiences due to limitation in communication.
- Some people cannot participate in verbal models of therapy at the level offered in traditional mental health outpatient or partial hospitalization.
- Caregivers often do not recognize symptoms of mental illness and therefore do not report possible signs and symptoms.
- There is a short supply of specifically trained, skilled and experienced staff in both systems who know how to provide treatment and support for this population.
- Personal and medical histories are often incomplete and not integrated into a holistic summary.

To assist the clinicians in completing the assessments so all the information necessary to diagnosis a mental illness and develop an effective treatment and support strategy, a comprehensive review of the current and historical status of biological, socio-cultural and psychological factors should be completed. Several tools may be used to assist the clinicians/professionals in gathering this information. An example of a comprehensive review is attached to this bulletin. While this tool focuses primarily on the psychological and the biological factors, the socio-cultural factors and personal consideration also need to be considered. These factors can be obtained from interviews or planning meetings with the person, their family or other caregivers. These factors should reference how the person interacts and relates to the world around them. This format, or a format similar to this, should be completed for persons with mental retardation who are suspected of having a mental illness. If the person has a mental illness, the format should be updated annually.

A comprehensive review involves collecting data and information through interviews of the person and any others who know, support, or treat them. Such a review also involves record reviews and a coordinated team process. The comprehensive review should include a review of the following data and information:

- Chronic and/or acute medical conditions
- Developmental disability and other learning and perceptual differences
- Central nervous system involvement (neuropsychological status, attentional, memory, executive functioning)
- Trauma, life experiences and losses
- Mental health symptomology
- Substance abuse diagnosis

- Family history of medical/mental health issues
- Current status
- Forensic history
- Method in which the person communicates
- Medications history
- Genetic conditions

The comprehensive review should be completed when the person enters the MH/MR system. The comprehensive review should be updated whenever the person requires mental health treatment.

The comprehensive review may also be helpful for people who have a history of mental illness, but are not experiencing active symptomology.

The people who know the person best (the person's family members and caregivers) will gather the information needed to complete the review and the form. In addition, the information from the review may need to be summarized in a format that is helpful for the clinician and to expedite the interview process between the clinician and the person.

When a person with mental illness and mental retardation is unable to share his/her history, the people that know the person best must share their knowledge of the person's history with clinicians and other professionals as part of the assessment process. The person should always be part of the conversation with the clinician and as much as possible the person's wishes should be respected. In addition, caregivers familiar with the person will be available to answer questions for the clinician during the interview process if the person has difficulty in communicating with a clinician. The clinician should tailor the interview based on the person's ability to communicate and the importance of relying on those who accompany the person to serve as a resource for information about the person. The comprehensive assessment, once completed, will also serve as a reference tool for the caregivers and family and should be periodically updated.

#### **CONCLUSION:**

People with a diagnosis of mental retardation who also have a diagnosis of serious mental illness are entitled to and should be afforded a comprehensive coordinated plan of treatment and supports. The person's plan should be coordinated by the County Mental Health and Mental Retardation Office and, if necessary, with regional office staff assistance and monitoring. To assist the professional and other caregivers in developing an effective plan a comprehensive review of both the current and historical status of biological, sociological, psychological and psychiatric factors must be completed. Effective treatment and support depends on a coordinated plan that utilizes available resources in both the mental health and mental retardation service systems.

#### **COMMENTS AND QUESTIONS REGARDING THIS BULLETIN SHOULD BE DIRECTED TO:**

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