PENNSYLVANIA'S HEALTH RISK ASSESSMENT PROCESS

Introduction

More than 70,000 children and adults with mental retardation are living in the community and receiving some type of support services from the Commonwealth's community mental retardation service system. Over 15,000 individuals are living in licensed community residences. This number increases each year as individuals move from state-operated facilities to the community and as services expand for those on the waiting list.

It is critical that both health care and mental retardation professionals are aware of and knowledgeable about the health care needs of people with mental retardation and that they provide them with support to maintain optimal health.

The Office of Mental Retardation, as part of its ongoing commitment to assure the health and safety of individuals receiving services and to improve the quality of those services, began planning the Health Risk Assessment initiative in late 1997.

Establishing Goals

The Health Risk Assessment initiative was designed to collect health care information on people who had moved, or were in the process of moving, from state-operated facilities into community settings. In addition to gathering a wide variety of health care information, the project was designed to meet the following goals:

- To ensure optimal health care for people with mental retardation living in the community *and* for people moving from a state facility into the community.
- To understand and strive to improve individual health care within the community mental retardation system.
- To assist with building community capacity for the best possible health care supports.

From the beginning, the major focus was to study the information gathered and move forward to "make it better." This report provides the results of assessments of the health status of 584 persons receiving services from the mental retardation service system.

How Were the Health Risk Assessments Conducted?

An initial draft of a Health Risk Assessment measurement tool - a 21-page evaluation instrument - was developed by Office of Mental Retardation staff with assistance from a variety of health care professionals both in Pennsylvania and from other states. While a comprehensive instrument could not be found that could be applied to the sample population, many states and agencies had valuable components which were used to form Pennsylvania's own Health Risk Assessment tool. Several drafts were completed, reviewed, and revised before the final tool was developed.

The final product was formatted to include a variety of information under several topics:

- Basic identification information
- General health information
- Residential health supports and use of support services
- Detailed dental information
- Detailed nutritional and dietary information
- Major and minor physical and behavioral health issues
- Communication and mobility
- Prescription and non-prescription medications and issues related to their use
- Health risk rating scale and level of management
- Face-to-face interview/assessment by a registered nurse
- Diagnoses and chronic conditions and recommendations for follow-up

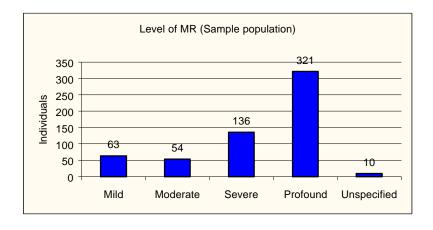
Who Are the People Being Assessed?

The Office of Mental Retardation initially focused on completing Health Risk Assessments for people who were already living in the community, having previously been served in Western, Torrance, and Embreeville Centers. These are state-operated institutions in both the southeastern and western parts of the state. Assessments were also conducted for people who were in the process of moving from these same facilities into the community.

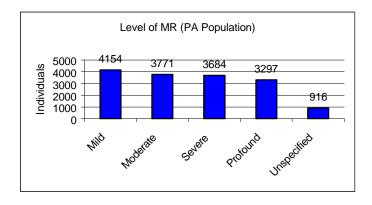
A total of 584 Health Risk Assessments were completed from June through October 1998. This 'snapshot' revealed the following general characteristics:

- Individual ages ranged from 26 to 85 years, and the average age was 48 years.
- There were 384 males and 200 females in the sample.

The majority of the sample (55%) was made up of people with profound mental retardation. The following graph depicts the sample group by level of retardation:



This graph contrasts with the following graph depicting the 15,822 Pennsylvania citizens who have mental retardation and who live in various types of licensed residential settings:



(Source: Community Residential Facility [CRF] state-wide database)

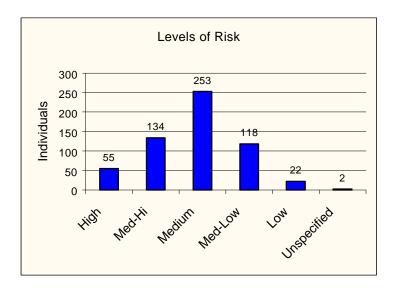
A comparison of the two graphs notes a skewed sample. There are a higher percentage of people with severe and profound mental retardation in the sample group than in the group of people living in residential settings. Many in the sample have severe physical and/or behavioral disabilities and were awaiting the building of adequate community supports before moving into the community.

Are They at Risk?

The registered nurses who completed the Health Risk Assessment assigned a 'risk rating' in the following manner:

- *High:* Indicates the person had at least one diagnosis needing at least monthly visits by medically-licensed personnel.
- *Medium-High:* Indicates the person had at least one diagnosis needing review by medically-licensed personnel five or more times per year.
- *Medium:* Indicates the person had at least one diagnosis needing review by medically-licensed personnel 2-4 times per year.
- *Medium-Low*: Indicates the person had at least one diagnosis needing medication but it does not affect activities of daily living.
- Low: Indicates the person had at least one diagnosis which has minimal to no affect on activities of daily living.
- *Unspecified:* Indicates the diagnosis could not be rated.

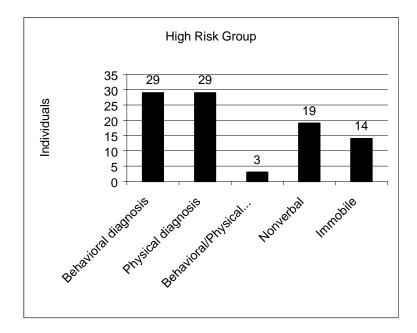
Risk ratings for the sample are noted in the following graph:



As shown in the graph above:

- Though 78% (457) of the sample displayed severe and profound levels of impairment (see graph on page 4), 90% (529) of the sample were found to need less than monthly visits by medical personnel.
- 9% (55) of the sample were found to be at high health risk; i.e., needing at least monthly visits by medical personnel.
- 32 of the 55 people were listed as having a profound level of mental retardation.
- 524 medications are listed for this group which averages to 9.5 medications per person.
- 663 diagnoses are listed for this group which averages to about 12 diagnoses per person.
- Two people from this group were rated as 'appears major needs unmet.'

Additional characteristics of this group are shown in the following graph:



The most prominent behavorial diagnosis in the 'high risk' group was bipolar disorder, and the most prominent physical diagnoses were dysphagia, a swallowing disorder, and seizures. Also, a person was listed as 'Nonverbal' if they were unable to communicate their thoughts and desires verbally, through gestures, or through an assistive device. A person was listed as "Immobile' if they were immobile without the assistance of another person; i.e., a person to push the wheelchair or support the person in movement or physical/mechanical transfer.

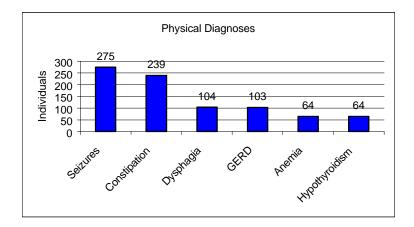
The two people who were rated as 'appears major needs unmet' had an immediate plan of action developed by the individual county and provider agency to determine what steps should be taken to better meet their health care needs. As a result of the recommendations from the Health Risk Assessment, both individuals had medication changes and currently are doing well. One is being seen monthly by a psychiatric specialist, and the other individual has a new behavior plan.

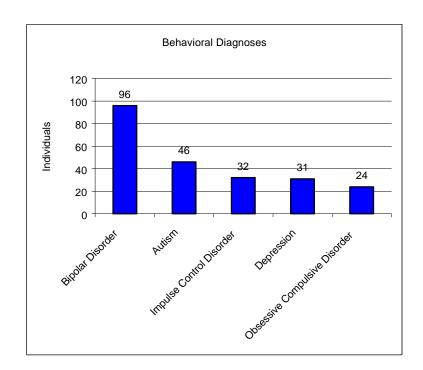
Following the Health Risk Assessments, a plan of action to address each of the 55 individuals assessed as 'high risk' was developed. Each county reviewed individual plans of action submitted by the provider agencies and followed up to ensure plans were completed accurately. Additional follow-up occurred when Office of Mental Retardation staff also reviewed some of the plans and focused additional attention on people in the 'high risk' group by contacting the appropriate county program to ensure follow-up actions were completed.

How Is The System Performing?

What Are The Needs?

The major physical and behavioral diagnoses from the sample of 584 are shown in the following graphs:





Are The Needs Being Met?

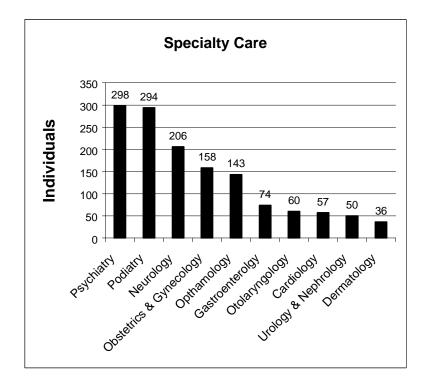
Given the follow-up actions to ensure health care needs were met, the 'high risk' group and the rest of the sample group appear to have their health care needs met on a regular basis.

Access to primary health care ...

- 98% (572) of the people in the sample group have a Primary Care Physician.
- 100% (584) have seen a physician at least once in the past year.

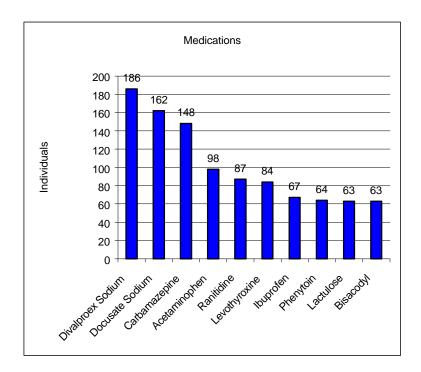
Access to specialty health care ...

One critical factor influencing quality health care is access to various specialty providers. The graph below represents the number of people who have seen these specialists at least once in the past year:



Medications ...

The 10 most used medications for the sample of 584 are graphed below:



The graphs note that the top physical and behavioral health diagnoses correspond with the top medications. Divalproex sodium, carbamazepine, and phenytoin are commonly used for seizure disorders. Divalproex sodium and carbamazepine are also used as mood stabilizers for bipolar disorder and other behavioral disorders. Ranitidine and levothyroxine are used to treat dysphagia/GERD, which are swallowing disorders, and hypothyroidism, respectively. Acetaminophen and ibuprofen are commonly used to treat minor aches and pains.

It might appear unusual that constipation occurs as the second most common physical diagnosis. However, certain types of medications such as seizure, anti-anxiety, and psychotropic medications have a tendency to slow down the intestinal peristalsis which moves waste materials, and this slowing causes constipation. Other factors contributing to constipation include a sedentary lifestyle, lack of proper hydration, and megacolons (commonly referred to as "institutional bowel") which have been stretched due to enema dependency. Docusate sodium, lactulose, and bisacodyl are common medications used to alleviate constipation.

Access to dental care ...

In the area of dental care, statistics from the sample noted:

- 90.8% (530) of the people in the sample group will either complete routine dental care or allow it to be performed.
- 74.3% (434) of the people in the sample group were noted to have routine care effective in removing plaque and debris.
- 87.2% (509) of the people in the sample group have all their dental needs met.

How Can We Improve?

While the results of the Health Risk Assessments indicate that individuals leaving stateoperated facilities have access to necessary health care and their needs are being met, the process of quality improvement for the health and safety of people being served is an ongoing effort. The Office of Mental Retardation has launched a number of initiatives aimed at resolving issues and improving health care for people with disabilities.

There is a need to continually monitor the health care needs and the availability and quality of health care for people with disabilities.

Planning for the expanded use of the Health Risk Assessment tool has already begun and the tool will be improved and applied to a broader sample including individuals living in licensed community residences who have never lived in a state-operated facility.

Health care throughout the service system requires high quality and full time medical leadership.

The addition of a medical office with a full time medical director and nursing administrator in Harrisburg, along with a registered nurse in each of the four Office of Mental Retardation regional offices, will enhance the Commonwealth's ability to monitor and improve the quality of the health care delivery system.

* There is a need for local oversight and clinical expertise to be responsive to specific health care issues.

Health Care Coordination Units (HCCU's), currently under development in county mental health/mental retardation programs, will serve as the entity responsible for the overall health status of people receiving services in each county program.

Specialized training programs are required to address specific health needs of people with disabilities.

The Office of Mental Retardation has intensified ongoing training efforts in the areas of proper positioning, dysphagia, assessing health risk, and health care decision making.

* The availability and quality of dental care are issues that require continual monitoring.

Although people in the sample are receiving adequate dental services, the Department of Public Welfare is continuing efforts to assure the availability and quality of dental care for people with developmental disabilities. A 'dental summit' was held by the Department in May to discuss and to resolve the dental needs of Medicaid recipients including people with mental retardation. Some of the strategies considered at the dental summit include the possibility of developing a state-wide quality improvement dental program; educating consumers; addressing fees; and simplifying the paperwork process for enrollment and reimbursement of dental providers.

Like the general population, some people with mental retardation require treatment for behavioral health needs.

A major thrust to improve behavioral health services is currently underway through trainings, seminars, and technical assistance for residential and health care providers to effectively treat people with mental retardation who also have mental illness.

There is a need for collaboration within service systems networks to address the spectrum of health care needs of people with disabilities.

The Office of Mental Retardation continues to participate in joint planning and training sessions with the Office of Mental Health and Substance Abuse Services (OMHSAS) and the Office of Medical Assistance Programs (OMAP). These cooperative ventures maintain the communication lines and create a venue for exchanging ideas and resolving health care issues as they arise.

❖ The community health care delivery system must be used fully to assure quality health care is available to people with disabilities.

The implementation of mandatory managed care in southeastern and southwestern Pennsylvania has already begun to make an impact on improving the quality of health care. Each person has a Primary Care Physician (PCP) who focuses on providing a consistent quality of physical and behavioral health care in cooperation with the Managed Care Organization (MCO). Each Managed Care Organization has a Special Needs Unit (SNU) which complements overall health care by meeting individualized health care needs. The Special Needs Unit is effective in identifying and coordinating medically necessary services for each individual.



The information here represents only a portion of the many pieces of data obtained through the Health Risk Assessment process, but demonstrates that the Office of Mental Retardation has taken some positive steps in an effort to improve overall health care. The information obtained from the Health Risk Assessments will be used in its entirety to examine all facets of health care and to make improvements as necessary. An internal examination of all data collected will be instrumental in addressing specific areas of concern and in building further on the positive steps already taken.

The ultimate goal is to ensure people with mental retardation are as healthy as they can be so they can enjoy all aspects of their lives, their families, and their communities.