

Addressing Pennsylvania's Waiting List

Pennsylvania, like most other states, has waiting lists for mental retardation services. In recent years, it was estimated that approximately 22,000 to 28,000 persons were on such waiting lists in counties across Pennsylvania.

Initiatives begun from Fiscal Year 1996-97 through Fiscal Year 1999-2000 will expand services to more than 3,000 persons and will result in an annualized amount of approximately \$134.1 million to reduce Pennsylvania's waiting list for mental retardation services. This has included expanded funding through the Home and Community-Based Waiver, increased in-home and family support services, and expanded out-of-home residential services.

However, without a standard definition of the waiting list, and county MH/MR programs following different processes in maintaining waiting lists, it was difficult to measure the scope of need and the impact of expanded services.

In an effort to further study this phenomenon and to enable the Department of Public Welfare to initiate strategic planning to address the waiting list across the state, during Fiscal Year 1996-97, the Office of Mental Retardation commissioned a study of the waiting list for services in Pennsylvania by the Institute on Disabilities/University Affiliated Program (IOD/UAP) of Temple University in Philadelphia. Phase I of the study involved documentation of how large the waiting list is, as well as what services are being requested. Also, the study gathered information to document how counties across the state report, track, and control their waiting list data.

Several major issues were raised. It became clear that counties did not employ a uniform procedure to capture waiting list data in

support of annual county plans. Individual counties varied widely in their reporting. There was a lack of a clear definition of the waiting list. As a result, it was recommended that the Office of Mental Retardation develop consistent definitions and data collection methods for determining the size of the waiting list and the characteristics of persons on the waiting list.

Counties also reported using various methods of tracking and controlling their waiting lists. The study identified five main methods used by counties. In order to develop a consistent definition of the waiting list and to develop a uniform data collection and tracking procedure for the waiting list, Temple University worked with a subcommittee to develop a data collection instrument entitled, "Prioritization of Urgency of Need for Services for Persons with Mental Retardation (PUNS)." Following a pilot test, phase II of the study began with a statewide distribution of the PUNS form to be completed by each of the 45 county MH/MR programs on each individual designated by the county to be waiting for service.

By April 1999, data was received from each county program on each person identified on a waiting list. Data was then analyzed by Temple University regarding three broad categories used to classify need: Emergency (persons needing services immediately); Critical (persons needing services within one year); and Planning For (persons with needs greater than one year away). Services were grouped according to four major categories as case management only; other ancillary and support services; vocational and other adult day services; and residential services. Individuals were grouped by low, medium, and high intensity services and categorized in terms of services being asked for; needed; currently receiving; and in need of more.

In May 1999, results of the survey revealed that a total of 14,083 persons were on waiting lists for services in Pennsylvania. Of these