

A Long Term Plan
to Address the
Waiting List for
Mental Retardation
Services in
Pennsylvania

**Pennsylvania
Department of Public
Welfare**

**Office of Mental
Retardation**

*Planning Advisory
Committee*

October 1999

The Goal...

*To build a system that
has the capacity to provide
services in a timely fashion
to all persons needing and
requiring services and
supports.*

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The Honorable Feather O. Houstoun
Secretary of Public Welfare
Department of Public Welfare
P. O. Box 2675
Harrisburg, Pennsylvania 17105

Dear Secretary Houstoun:

The following Plan to Address the Waiting List for Mental Retardation Services in Pennsylvania was developed in response to a request from Governor Tom Ridge, made in February 1999, for a long term Plan to address the needs of people with mental retardation and their families who are waiting for community services. The Waiting List Plan was developed by a Waiting List Planning Group convened by the Planning Advisory Committee (PAC) to the Office of Mental Retardation.

The Waiting List Plan is based upon the values underlying the mental retardation service system in Pennsylvania, as reflected in “Everyday Lives” and the Multi-Year Plan. The Plan proposes to continue the commitment of the Department of Public Welfare to meeting the needs of those who still wait.

The Multi-Year Plan included a major goal to realign resources to meet the needs of those on the waiting list. While resource alignment has addressed the need of some people on the waiting list, we have concluded that the realignment of resources alone will not provide sufficient resources to meet the needs of all who are on the waiting list.

We appreciate your consideration of this Plan and the recommendations contained therein to address this important issue across Pennsylvania. This Plan is dedicated to those in Pennsylvania who wait...

Sincerely,

Rocco Cambria
PAC Co-Chair

Michael D. Chambers
PAC Co-Chair

Acknowledgements

This Waiting List Plan would not have been developed without the recognition of Governor Tom Ridge that people with mental retardation and their families are in need of necessary supports and services and his request that a long term Plan be developed to meet those needs. The Plan is the product of the collaborative efforts of a number of persons from across Pennsylvania who participated as members of a Waiting List Planning Group convened by the Planning Advisory Committee (PAC) to the Office of Mental Retardation, including consumers and family members, county and provider representatives, the major associations and interest groups in Pennsylvania, and various state government and legislative officials.

We would like to recognize the efforts of Mr. Mike Chambers and Mr. Rocco Cambria, Co-Chairs of the Planning Advisory Committee, who served to coordinate and facilitate the meetings of the Work Group. Recognition is given to Ms. Celia S. Feinstein and her staff James A. Lemanowicz and Annemarie F. Clarke, of the Institute on Disabilities/UAP, Temple University, whose Waiting List Study served as the foundation for this Plan. Also, special thanks to Mr. John Ashbaugh, Human Services Research Institute, who consulted and guided us throughout this effort.

Special appreciation is extended to the consumers and families who have participated in this workgroup. This process could not have been accomplished without their involvement.

Waiting List Work Group

Rocco	Cambria	PAC Co-Chair
Michael	Chambers	PAC Co-Chair

Consumer/Family Members:

Steve	Dorsey	Consumer - Montgomery County
Karin	Knorr	Consumer - Allegheny County (PAC Member)
Michael	Rhine	Consumer - York County (PAC Member)
Bertin	Springstead	Family Member - Cumberland County (PAC Member)
Maureen	Devaney	Family Member - Philadelphia County (PAC Member)
Kathy	Brill	Family Member - Dauphin County (PAC Member)
Rose Marie	Appel	Family Member - Westmoreland County
Nancy	Murray	Family Member - Allegheny County
Susan	Reese	Family Member - Cambria County
Victoria	Jones	Family Member - Columbia/Montour/Snyder/Union Counties
James	Bradley	Family Member - Delaware County
Lloyd	Burkholder	Family Member - Franklin/Fulton Counties
Bonnie	Miller	Family Member - Franklin/Fulton Counties
Sheila	Stasko	Family Member - Lehigh/Northampton Counties
Robert	Meade	Family Member - Montgomery County
Carol	Csaniz	Family Member - Delaware County
Martin	Murray	Family Member - Delaware County (PAC Member)
Denise	Taylor	Family Member - Philadelphia County
Polly	Spare	Family Member - Bucks County (PAC Member)
Doris J.	Miller	Family Member - Bucks County (PAC Member)

State Organization Representatives:

Martie	Worley	The ARC - PA (PAC Member)
Graham	Mulholland	Developmental Disabilities Council (PAC Member)
Shirley	Walker	PAR (PAC Member)
Nathaniel	Williams	PA Association of Rehabilitation Facilities (PAC Member)
Kris	Ericson	PCPA (PAC Member)
Kevin	Casey	PA Protection and Advocacy, Inc. (PAC Member)
Diane	Bryen	Institute on Disabilities/UAP (PAC Member)
Lynn	Keltz	United Cerebral Palsy of PA (PAC Member)

County MH/MR Programs:

Mary Beth	Mahoney	Bucks County (PAC Member)
Cindy	Zembryki	Cameron/Elk/McKean Counties
Sue	Miosi	Lehigh County
Kathy	Sykes	Philadelphia County
Maureen	Blossey	Schuylkill County

Case Managers:

Linda	Hale	North Star Support Services/Blair County
Cheryle	Brashear	Dept. of Adult Probation/Parole/Philadelphia County

Legislators:

Rep. Dennis O'Brien/Liz Yarnell	Health and Human Services Committee
Sen. Stewart Greenleaf/Eric Pauley	Judiciary Committee
Sen. Vincent Hughes/Niles Schore	Public Health and Welfare Committee

Other Agencies:

Glen	Dunbar	Department of Aging, Division of Policy
Lucia	Roberto	Governor's Budget Office
Steve	Suroviec	DPW, Office of Policy Development

BACKGROUND INFORMATION

A National Perspective

Nationally, the issues surrounding persons on waiting lists for services have become “hot button” topics across the states. Most states currently are engaged in initiatives to reduce or to eliminate waiting lists for services and supports.

The term “waiting list” refers to the gap between the demand for publicly-funded services and supports and the availability of such services. In most states, demand exceeds the availability of services that states can underwrite. A recent study has indicated that the number of persons with developmental disabilities who are awaiting services could range from 80,000 to 200,000 across the states (The ARC, 1997). Clearly, efforts to address this magnitude of unmet need will require a substantial expansion of the states’ service systems and a significant investment of resources.

Waiting list campaigns are currently on-going in approximately twenty-three (23) states. It is estimated that another eighteen (18) states have campaigns in the planning stages. According to Mr. Gary Smith of the National Association of State Directors (“Closing the Gap,” 1999), there are various root causes of waiting lists related to demand and demographics, such as:

- longer life expectancy of persons with mental retardation
- the “baby boom” generation presenting itself for services
- aging parents and caregivers
- the aging of the generation that was served by special education and family support services
- widening eligibility in some states

- the complex interaction of these variables
- the lack of entitlement and the need to operate within available funding
- MR/DD budgets “treading water” with little growth from 1980 to 1997 (note that many states refer to their systems as Mental Retardation/Developmental Disabilities systems, rather than mental retardation systems)
- and budget growth not matching the growth in demand.

As a result, waiting lists have grown in most states, and steps to address waiting lists are underway in a large number of states.

Another component of the national perspective relates to litigation. In several states, there has been litigation targeted to address the imbalance between the demand and the available supply of services and supports (e.g., Florida and Massachusetts). Of special importance is the decision in the suit of John/Jane Does v. Chiles in Florida. The State of Florida was directed to make ICF/MR services available to all qualified Medicaid recipients within 90 days of the determination that persons need such services. The implication for states is that the entitlement requirements of Medicaid are potentially in conflict with state practices as related to waiting lists for services.

It is also important to recognize the growing forces across the states, and, in fact, worldwide, related to self determination and increased consumer and family choice and control of necessary resources. Increasingly, consumers and families are expressing their right to services and their proper role in designing, purchasing, and monitoring services and supports and the increased role of individuals and their families in decision-making regarding policies and programs affecting their lives and their futures.

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

persons, 411, or 2.9%, were in the Emergency Needs Group. Another 3,244 persons, or 23.0%, were in the Critical Needs Group. The Planning For Needs Group included 10,428 persons, or 74.0% of the total. The study provided extensive detail regarding the demographics of those persons on the waiting list, including what individuals currently receive and what individuals need. In summary, according to the results of the Temple Study, 411 persons in Pennsylvania were in need of services immediately, and 3,244 persons needed services within one year. The Temple Waiting List Study provided a valuable source of data to serve as a basis for strategic planning and the beginnings of a plan to address the waiting list in Pennsylvania. The study has been cited in some national literature as having produced the best data available across the states regarding the waiting list (Community Services Reporter, July 1999).

In February 1999, Governor Tom Ridge requested that a work group be convened to develop a plan to address the waiting list for mental retardation services in Pennsylvania. Accordingly, the Planning Advisory Committee (PAC) to the Office of Mental Retardation convened a work group that initially met in March 1999. The Work Group was composed primarily of consumers and families from across Pennsylvania who are on waiting lists for mental retardation services. The Work Group also consists of provider and county program representatives and the major provider and mental retardation advocacy associations. Included are staff representatives from various legislative offices and staff from various Department of Public Welfare Offices. The charge of this Waiting List Planning Work Group was to develop a long term Plan by August 1999 to address the waiting list for mental retardation services in Pennsylvania.

Other major factors that are a part of the backdrop for the development of a Plan to address the waiting list in Pennsylvania include the documents, "Everyday Lives," the "Multi-Year Plan,"

and the expanding concept of self determination. "Everyday Lives" was promulgated in 1991 to articulate the values underlying the mental retardation service system in Pennsylvania. These underlying values include choice, control, permanency, security, freedom, prosperity, individuality, relationships, recognition, privacy, citizenship, and passion. "Everyday Lives" represented a vision for the future developed by all the stakeholders across the system. This vision includes self-advocacy, the use of generic community services, competitive employment, and supports for families.

The Multi-Year Plan was developed by the Planning Advisory Committee in 1997, again based upon collaboration with stakeholders across the system. The Multi-Year Plan delivered upon the promises contained in Everyday Lives in terms of concrete recommendations and plans for actions. The Multi-Year Plan reaffirmed the values of Everyday Lives and contained recommendations related to system reform (consumer driven, outcome oriented, and cost efficient), and most relevant for the waiting list, resource realignment to meet the needs of people on the waiting list.

The self determination initiative in Pennsylvania represents a major and a powerful force affecting the future of mental retardation services and supports. The guiding principles of self determination include choice, relationship, contribution and community, roles and responsibilities, control, dreams, dignity and respect, fiscal conservatism, and having the attitude that nothing is impossible. All decisions and actions related to services and supports in Pennsylvania are to be measured against these principles. All individuals have the right to determine the course of their own lives, and they need to be free to exercise this right and to accept responsibility for their decisions. Therefore, self determination is an underlying assumption for Pennsylvania's Plan to address the waiting list.

DATA COLLECTION AND ANALYSIS

Assessing Need—The Waiting List Study

In the Fall of 1998, the Temple University waiting list study data collection phase began through the statewide implementation of the Prioritization of Urgency of Need for Services for Persons with Mental Retardation (PUNS) form. Each county program was requested to complete a PUNS form for each of the individuals within the county program who was identified on the waiting list. By April 1999, Temple University had collected, edited, entered, and analyzed data from all 45 county programs across Pennsylvania.

Definitions for the urgency of need and intensity of services were established for the purpose of the study:

Emergency - person needs services immediately

Case Management - only case management services and nothing else

Critical - person needs services within one year

Low Intensity Service - support or ancillary services (therapies, F.S.S., transportation) in addition to case management services

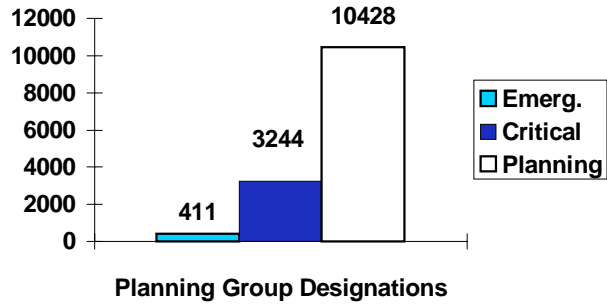
Planning - person with needs more than one year away

Medium Intensity Service - vocational/day services, possibly in addition to support/ancillary services and case management

High Intensity Service - residential services, possibly in addition to vocational/day services, ancillary/support services, and case management

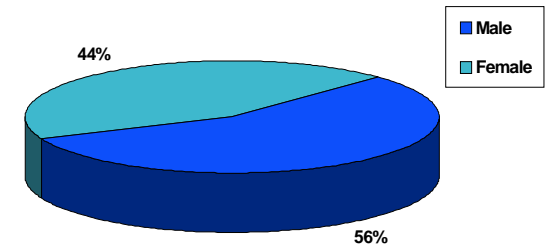
THE TOTAL WAITING LIST - 14,083 PERSONS

Waiting List Distribution Among Planning Groups

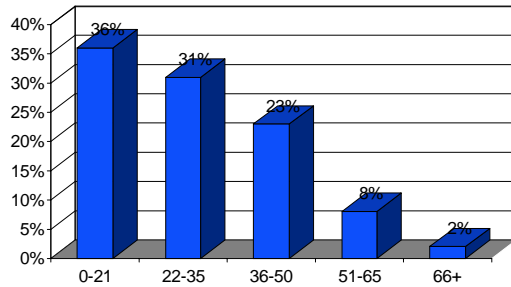


Emergency -	411
Critical -	3244
Planning -	10428
TOTAL -	14083

GENDER



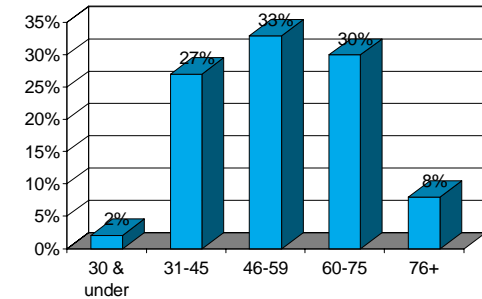
AGE



CURRENTLY LIVING IN...

- 🏠 Own home or relative's home 78.2%
- 🏠 Some type of supervised living 4.1%
- 🏠 Family living and home-based 2.0%
- 🏠 Private ICF/MR 1.7%
- 🏠 State Operated Facility 2.2%
- 🏠 Other Arrangement 11.9%

AGE RANGES OF PRIMARY CAREGIVER



EMERGENCY AND CRITICAL NEED - TOTAL OF 3,655 PERSONS

Within the EMERGENCY NEEDS Group...

- ☞ 12.4% were dropped on the county doorstep
- ☞ in 22.9% there was a death of a caregiver
- ☞ in 41.4% there is an illness of a caregiver
- ☞ for over 25% either the court has ordered this placement, it is temporary, or other additional reasons are noted

Within the EMERGENCY Group People Are Receiving...

- ☞ 21.0% Case Management Only
- ☞ 21.8% Low Intensity Services
- ☞ 32.8% Medium Intensity Services
- ☞ 21.0% High Intensity Services

Within the EMERGENCY Group People Are In Need Of...

- ☞ .5% Case Management Only
- ☞ 7.4% Low Intensity Services
- ☞ 7.7% Medium Intensity Services
- ☞ 70.3% High Intensity Services

Within the CRITICAL NEEDS Group...

- ☞ 32.7% have an aging caregiver
- ☞ 3.6% have an ill caregiver
- ☞ 32.5% have a diminished capacity of caregiver to provide support
- ☞ 27.2% have graduated and need either a day or residential placement
- ☞ 13.2% are behaviorally unmanageable

Within the CRITICAL NEEDS Group People Are Receiving...

- ☞ 23.3% Case Management Only
- ☞ 22.8% Low Intensity Services
- ☞ 29.7% Medium Intensity Services
- ☞ 21.3% High Intensity Services

Within the CRITICAL NEEDS Group People Are In Need Of...

- ☞ .3% Case Management Only
- ☞ 9.1% Low Intensity Services
- ☞ 20.1% Medium Intensity Services
- ☞ 55.2% High Intensity Services

PLANNING GROUP - 10,428 PERSONS

Within the PLANNING FOR NEED Group...

- ☞ 66.8% are currently eligible for services but will only need services if something changes
- ☞ 26.7% want increased supports
- ☞ 6.6% have a known need for service more than one year away
- ☞ 2.1% live in a large setting and are interested in moving

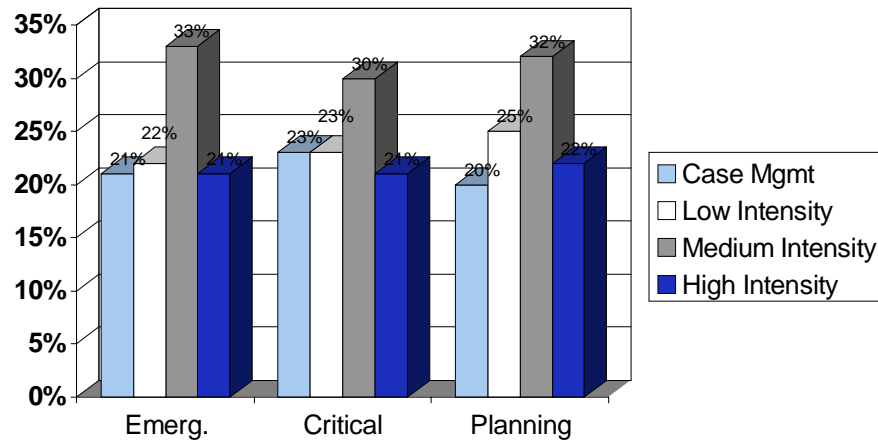
Within the PLANNING FOR NEED Group People Are Receiving...

- ☞ **20.2% Case Management Only**
- ☞ **24.8% Low Intensity Services**
- ☞ **31.6% Medium Intensity Services**
- ☞ **22.0% High Intensity Services**

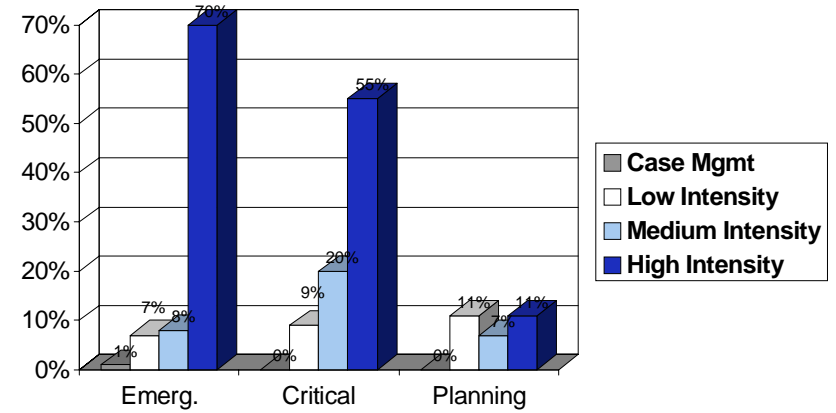
Within the PLANNING FOR NEED Group People Are In Need Of...

- ☞ **.4% Case Management Only**
- ☞ **10.6% Low Intensity Services**
- ☞ **7.1% Medium Intensity Services**
- ☞ **10.9% High Intensity Services**

Service Received By Group



Need for Service By Group



The Costing-Out of Services

In accordance with the consensus of the Waiting List Work Group, it was agreed that the focus of this Plan should be to address the needs of persons on the Emergency and the Critical Need lists (411+3,244=3,655 persons), plus an estimated 411 persons (“shadow” waiting list), for a grand total of 4,066 persons. The estimated 411 persons for the “shadow” waiting list is based on the finding in Phase I of the Temple Study that approximately 49% of persons coming into service in the year were not previously on the waiting list. The 4,066 total was later modified by extracting 139 people who reside in State Centers. The provision of community opportunities for people in State Centers has its own budget initiative. Therefore, to avoid duplicate funding, these persons have been removed from the list. The revised total number of persons is 3,927.

The Waiting List Study broke out the levels of service needed into case management only, low intensity, medium intensity, and high intensity services. Low intensity services are individual or family support services. Medium intensity services are “day services,” including Adult Development Training, Vocational Rehabilitation, and Community Employment. High intensity services are Residential services. The Residential services were further broken down into services not requiring 24-hour staff (e.g., Home-Based and Family living), and those that do need 24-hour staff. The study also broke out whether a person needed a service they were not receiving, or they needed more of a service that they were receiving.

In order to develop cost projections based on the types of service(s) requested and whether it was new or an expanded service, the Emergency and Critical Need lists, minus the State Center persons, were placed in one of 24 groups. Cost projections were then applied to these 24 groups.

The cost projections were originally based upon actual costs reported by the counties on the Annual Income and Expenditure (I&E) Reports for Fiscal Year 1997-98. Based upon the recommendations of the Waiting List Work Group, cost estimates were modified in certain areas. Case management costs were changed to reflect an average ratio of 1:50. Residential service costs were modified based on current provider information regarding the average cost of residential services. Day service costs were modified based on information provided by the counties to ensure that costs reflected estimated costs for full rather than partial day services.

The following chart shows the estimated costs for both residential and non-residential services to meet the needs of the 3,927 persons. For the 3,516 persons who were on the Emergency and Critical Need lists, the number of people and the estimated costs are shown by the 24 different groups. For the “shadow” list, the costs were estimated based on the cost to serve the 411 persons on the Emergency list.

“I want my grandson to live in the community like everybody else, but he can’t right now because he can’t make good choices for himself for daily living. Help him now, to obtain residential placement and day support services, so he can have the opportunity to make his own decisions and live his own life with pride in the future.”

Mr. Lloyd K. Burkholder, Grandfather

“My mother died when I was seven years old. I have no brothers or sisters. I have lived with my Grandfather for the past 15 years and now he has cancer and is 68 years old. What will happen to me if he dies and leaves me like my mother did? Please don’t make me wait any longer for a residential home or day support services. We need to know what will happen to me and what my future will be like before Pappy leaves me too.”

Darryl L. Burkholder, Pappy’s Grandson

The Costing-Out of Services

Summary of People and Cost to Provide the Services for the Emergency and Critical List (Excluding State Center Residents) by Service Package

	Need "Other" Services Only	More Individual Support Services	Need Individual Support Services	Day Services Only	More Residential (but not 24 Hr Staff)	Need Residential (but not 24 Hr Staff)	More 24 Hr Staff Residential	Need 24 Hr Staff Receiving Other Res	Need 24 Hour Staffing
No Day Services									
# of People	530	172	103		66	283	58	80	581
Avg/Person Cost	\$307	\$1,880	\$2,906		\$7,384	\$21,725	\$39,207	\$59,701	\$88,505
Total Cost	\$162,487	\$323,389	\$299,326		\$487,370	\$6,148,277	\$2,274,023	\$4,776,114	\$51,421,204
More Day Services									
# of People		51	27	101	31	74	41	32	195
Avg/Person Cost		\$9,187	\$10,725	\$6,692	\$15,248	\$33,708	\$46,155	\$76,477	\$101,161
Total Cost		\$468,525	\$289,570	\$675,941	\$472,684	\$2,494,392	\$1,892,344	\$2,447,260	\$19,726,339
Need Day Services									
# of People		95	141	277	16	133	31	28	370
Avg/Person Cost		\$15,612	\$18,170	\$14,048	\$26,997	\$39,278	\$48,117	\$75,410	\$103,906
Total Cost		\$1,483,144	\$2,562,004	\$3,891,178	\$431,956	\$5,224,036	\$1,491,613	\$2,111,492	\$38,445,273
						People	Costs		
						3,516	\$149,999,938		
						411	\$ 22,232,066		
						3,927	\$172,232,004		

The Planning Process—A Summary

The Waiting List Planning Group initially met on **March 25, 1999** in Harrisburg, Pennsylvania. The Work Group learned about the national perspective, including the root causes of waiting lists across the states and brief presentations on the waiting list initiatives in other states. This was followed by a detailed presentation by representatives from Maryland on the Maryland Waiting List Initiative. Finally, the Work Group was oriented to the Pennsylvania Waiting List Study by Temple University and the work to be done in Pennsylvania as addressed in the Multi-Year Plan under the goal of resource realignment to realign existing services to meet the needs of those on the waiting list, as well as recommendations regarding the movement of persons out of State Centers. It was emphasized from the start that the Plan to address the waiting list is both a plan to address the needs of particular people and an effort to establish a system and a process to address the management of the waiting list over time.

The **second meeting** of the Waiting List Work Group was held on May 5-6, 1999, and it represented the first real working session of this group. During the May meeting, the Work Group defined the purpose and the scope of the Plan and developed an outline of the waiting list Plan.

Purpose: The purpose of the waiting list planning effort is to develop a plan and a budget to address the needs for services including both persons currently on the waiting list for services and persons not on the waiting list but expected to request services.

Scope: The plan will include all persons other than those needing early intervention supports and services. The plan will examine state policies and procedures and their implications at the county level.

Next, OMR presented initial information on people served and

associated costs. Temple University then presented the results of the Temple Waiting List Study. The data indicated that a total of 14,083 persons were waiting for mental retardation services across Pennsylvania, including 411 persons, or 2.9% of the total in the Emergency Needs Group (individual needs services immediately); 3,244 persons, or 23.0% of the total in the Critical Needs Group (individual needs services within one year); and 10,428 persons, or 74.0% of the total in the Planning for Needs Group (individuals' projected needs are greater than one year away). The study grouped services by category and grouped persons by Low, Medium, or High Intensity Services. One important finding was that an average of 49% of the individuals who came into service during the year under study was not on waiting lists. This began to be commonly referred to as the "shadow waiting list." In summary, the Temple Waiting List Study revealed that there are 411 persons in Pennsylvania who need services immediately (Emergency Need); and 3,244 persons who need services within the next year (Critical Need).

Following the presentation of the Temple data, the Work Group began to review and to discuss service and support packages and associated costs. The Work Group identified issues and priorities and began to structure resource groups that could be used to inform the Work Group members and to assist in their deliberations for the next meeting.

The **third meeting** of the Waiting List Plan Work Group was scheduled for June 14-15, 1999. The June meeting focused on the capacities of families, providers, counties, and the state to expand services to meet the needs of persons on the waiting list. Numerous issues related to capacity were identified for discussion and review by the Work Group for possible recommendations to be included in the Plan. The Work Group then began to identify priorities for services and supports within broad categories of service; for example, family support services, day supports, residential supports, etc. It was agreed that for the next meeting, members would vote

The **fourth meeting** occurred on July 12-13, 1999. Initially, the Work Group reviewed the capacity issue from the provider and the county perspectives. It was announced at the start of the meeting that the Health Care Financing Administration (HCFA) approved the new Consumer Directed Supports Waiver for Pennsylvania, effective July 1, 1999. It is anticipated that services under the new Waiver will commence effective January 1, 2000, and approximately 3,300 people will be enrolled. Significantly, this new Waiver allows Pennsylvania to reach out to many persons who are currently underserved, as well as a significant number of unserved persons, and it will impact on a large part of the waiting list. Also of significance is that in approving this Waiver, HCFA recognized and accepted the principle of state government allowing a county to put in place an administrative service to make payments to anyone that the county uses to provide services at the local level; for example, this could be a family, providers, etc. This development has enormous implications in facilitating self determination and the control of resources by consumers and families in Pennsylvania.

The results of the priority criteria vote were discussed. Priorities were then listed by rank order and costs of service packages were displayed. For example, it was shown that for 3,655 persons (Emergency plus Critical Need) and 411 persons on the “shadow” waiting list (a total of 4,066 persons) costs are projected to be \$25.8 million for non-residential services. The Work Group had previously reached a consensus to recommend that day services be provided to all persons needing this from the Emergency and Critical Need Groups. There is significant evidence from national research, plus anecdotal evidence heard from the comments of families as part of these meetings, indicating that if day services alone were made available, the need for persons to go on the Emergency or Critical Need waiting lists for residential services would be avoided to a significant extent.

Detailed discussions followed regarding the capacities of families, providers, county programs, and the state, as well as the overall capacity of the mental retardation system to grow by the magnitude of the expansion in services required to meet the needs of persons on the waiting list. It was discussed that other developments and initiatives occurring as a result of the Multi-Year Plan must also be factored into the capacity deliberations; for example, the number of persons coming out of State Centers in the plan years. Along with the capacity discussion, the timetable proposed for the waiting list Plan was debated. Based upon the recommendations of the Work Group, an overall capacity increase for the mental retardation system of approximately 11% would be required (20% growth in the community program). The Work Group consensus was that the Plan should be proposed to be implemented over a period of two fiscal years, beginning in Fiscal Year 2000-01.

Finally, on **July 13, 1999**, the Work Group reviewed and refined a listing of issues and possible recommendations related to the themes of waiting list management, system efficiency and effectiveness, provider capacity, county program capacity, state capacity, consumer and family capacity, the waiting list implementation plan, new and alternative models of services and reinvestment to strengthen the infrastructure, financial management, and transition (young persons leaving school and entering adult life). Most importantly, the Waiting List Planning Group began to formulate some overall goals related to directing resources to address the waiting list.

A special one-day meeting of the Work Group was held on **July 22, 1999** to review and to refine the goals and to formalize recommendations to be included in the Plan.

A final meeting of the Work Group was held on **August 11, 1999** to review the draft Plan to address the waiting list. The final Plan was then submitted to the PAC and discussed and voted on at a joint meeting between the PAC and the Waiting List Work Group on September 28, 1999.

“I live with my mother, and I am afraid of what will happen to me when my mother passes away.”

*Mr. Steven Dorsey, during the Waiting List
Work Group Meeting on July 12, 1999*

“I am able to make up my own mind and do what I want. My mom cares about me and worries about me; she does not run my life.”

*Mr. Michael Rhine, during the Waiting List
Work Group Meeting on August 11, 1999*

THE PLAN

Principles

Following are the Principles that provide the foundation for the Plan to address the waiting list in Pennsylvania. All decisions and actions related to the provision of mental retardation services and supports are to be weighed against these principles.

Everyday Lives

Everyday Lives, published in 1991, expresses the values upon which the Pennsylvania Mental Retardation Service System is based. Everyday Lives presented what people with disabilities said is important to them.

Choice - in the decisions of life; choice of jobs, friends, recreation, where and with whom to live.

Control - of relationships, money, transportation, services, medicine and staff.

Permanency - with a life in the community among family and friends; no fear of returning to the institution.

Security - and protection for those who have difficulty in communication; competent services; and safety in the community.

Freedom - of movement, and from stigma.

Prosperity - freedom from poverty and a chance to be successful.

Individuality - by having a name and a personal history and by making a difference; having dignity and status.

Relationships - with friends, family and partners.

Recognition - of abilities, capacities and gifts.

Privacy - of records, files and histories; protection from being labeled and the option of living alone.

Citizenship - as part of the community, having a feeling of connectedness, partnership in dreams and beliefs; playing a part in decisions which affect you.

Passion - in advocates and self-advocates to fight and dream together.

Multi-Year Plan

The Multi-Year Plan, published in 1997, builds on the promise of Everyday Lives in terms of goals, recommendations, and action steps. The Multi-Year Plan is a plan for the future which provides a backdrop for recommendations to address the waiting list in Pennsylvania. It included a major goal to realign resources to meet the needs of those on the waiting list. While resource realignment has addressed the need of some people on the waiting list, we have concluded that the realignment of resources alone will not provide sufficient resources to meet the needs of all who are on the waiting list.

Two major goals:

System Reform: restructuring the system to one that is: Consumer-Driven, Values-Based, Outcome-Oriented, and Cost-Efficient.

Resource Realignment: realigning existing resources to meet the needs of those on the waiting list while maintaining necessary supports and services for individuals currently receiving them.

Recommendations contained in the Multi-Year Plan include:

1. Restructuring the administration of the program to assure quality, efficiency, and positive individual/family outcomes and satisfaction.
2. Shifting priorities for resource allocation from facility-based programs to services that build on natural supports.
3. Creating mechanisms for individuals and families to control resources allocated to meet their need.
4. Pursuing regulatory reform.
5. Unifying funding and eliminating categoricals within the mental retardation system.
6. Reinvesting savings from system reorganization into community services.
7. Provide services and supports in the community for 1,500 people who are currently living in State ICFs/MR over 5 years.
8. Transfer state and federal funding for 2,100 persons who live in non-state ICFs/MR into the community funding system by conversion to the Medicaid Waiver.

Self Determination

The principles of self determination hold that all individuals have the right to determine the course of their own lives. All individuals need to be free to exercise this right and to accept responsibility for their decisions. It is recognized, however, that some individuals require a greater degree of support in doing this than others. Family members and friends provide support and have a role in helping

individuals determine and achieve their life goals. In this process, government plays a supportive role as necessary.

Self determination means:

- ...freedom to decide
- ...support and information to make decisions
- ...control over resources
- and...responsibility for decisions and actions.

Quality Services and Supports

Quality is a fundamental consideration in the provision of services and supports. People receiving services and their families deserve the highest quality and they must be assured that quality is continually measured by people who are knowledgeable, trained and independent.

Quality means:

- Maintaining health and safety...
- Achieving optimal service outcomes for people...
- Providing to consumers and families value for the dollar.

Goal

To build a system that has the capacity to provide services in a timely fashion to all persons needing and requiring services and supports.

Recommendations

1. Service Expansion

Service capacity must be expanded in the short term to address the needs of people who have been waiting for services for many years and in the long term, to assure that waiting lists do not grow again.

- Serve all persons who are and have been identified on the waiting list in emergency and critical need within the next two years (by June 30, 2002).
- After June 30, 2002, expand services each year to all persons who are identified through the annual planning process as needing services and supports.

The wait for in-home services and day services and supports will not be longer than 90 days from initial request for services.

Planning for residential services for people on the emergency and critical waiting list will be completed and funding identified and requested within 30 days to include specific time frames agreed upon with consumer/families.

- Assure an adequate infrastructure at the provider, county program, and state levels to improve quality services to people currently receiving services and to assure quality in new services.

2. Establish an On-going Process to Review and Respond to the Waiting List

The plan is not only to address the needs of the people identified by the Waiting List Study in December 1998, but to establish a permanent mechanism to identify those waiting and plan for

their services long into the future.

- Adopt an annual planning and budgeting process to address the needs of individuals.

- Institute the PUNS form as a requirement for county annual plans and use in program budgeting.

- Adopt the Priority for Urgent Need definitions as the basis for responding to requests for service.

- Require that PUNS form be completed by case managers with consumers and families.

- Provide ongoing training on PUNS form to case managers, families and consumers.

- Develop a method to track individuals who present for services who were not previously known to the system.

- Develop a Management Information System capacity for PUNS data to be utilized by the state and counties.

- DPW will publish an annual report on the size of the waiting list based on the PUNS form and a comparison to the size of the waiting list in previous years.

- Establish an on-going advisory group to advise the Office of Mental Retardation on the waiting list.

3. State and County Capacity

State and County Leadership will be necessary to carry out the Waiting List Plan

- Develop and implement plans to enhance staffing capacity in both state and county government to manage growth and to ensure the highest quality of services and accountability.

- Build and maintain a comprehensive and integrated information system between the state and counties to improve the management and evaluation of the program, including the ongoing management of the waiting list.
- Expand training and technical assistance activities to assist counties and providers to implement consumer directed supports and to provide quality services.
- Create mechanisms to allow individuals and families to control resources with a minimum amount of red tape.
- Expand case management/service coordination commensurate with the increase in the number of people receiving services to assure that case managers/service coordinators can meet individual need, protect health and safety and support participation in community life.
- Develop agreements with other appropriate agencies and systems to address the availability and coordination of generic resources; e.g., transportation, aging services.

4. Consumer and Family Outreach and Education

Consumers and families need to know about the availability of services.

- Initiate an aggressive, face to face, outreach program, through a partnership of state/county/consumers/families to inform consumers and families about :

Self Determination;
 the types of supports available and how to create other options;
 the service system;
 the Priority for Urgency of Need form;
 transition to adult life

- Develop & maintain a web site that provides information to consumers and families.
- Provide technical assistance to existing parent, self-advocacy and disability groups to disseminate information, provide education to consumers and families, and provide peer supports.
- Inform communities of the Waiting List Plan through all available media.
- Develop an information/education program, with parent input, for use by the counties and consumer/parent groups on Self Determination.
- Develop information for health care providers and other groups to encourage referral to the county MH/MR program.
- Coordinate the resources and the efforts of early intervention, local task forces, and transition groups in sharing information and training.

5. Reinvestment to Improve the Quality of Services and Supports

While expanding to meet the needs of those waiting for services, we must address issues affecting all people, including those already receiving services.

- Permit savings from efficiencies to be reinvested into improving the quality of services and supports for people already receiving them.
- Create mechanisms to provide more administrative flexibility to free up resources to reinvest in improving quality.
- Enhance the ability of all stakeholders to develop new and alternative services and funding models.

6. Self Determination

Consumers and families are not just waiting for services, they want to determine how they will live their lives and to have more control over what services and supports they receive. In taking that responsibility, they can assure that public funds are used to the maximum benefit of the person and the family.

- Create efficient policies and procedures to allow individuals and families to control the use of resources without unnecessary restrictions and red tape.
- Develop a local MIS to track individual budgets and expenditures in a timely manner.
- Designate a state and county staff lead person who will coordinate and provide leadership in the evolving implementation activities of self determination.
- Engage Support Brokers who understand and implement self determination principles and develop non-traditional supports.
- Develop individual budgets: change contractual arrangements from County with Provider to County with the Individual/Family.
- Provide transitional support system to assist Providers to move from County contracts to individual contracts.
- Provide organized approach to education and outreach on self determination with the outcome that all participants understand and practice self determination principles.
- Share success stories that depict self determination.

7. Preparing for School to Adult Life Transition

Planning the future begins early. Learning about and planning for the responsibilities of adult life must be part of the educational experience. Good preparation for adult life during the school years will result in better outcomes for people, and a reduction in the demand for services.

- Require agreement between county and schools to assure that:
 - information about the county MH/MR program is provided to everyone who is 14 years and older and to their families
 - assistance in registering with the County MH/MR program is offered to all students and their families
 - counties are invited to participate in transition planning for each student
 - children in school but living outside the county are identified to their responsible MH/MR program
- Counties inform/educate school age consumers and families about transition; i.e., the need to prepare for adult life and about transition planning in the school.
- Case managers attend student transition meetings.
- Build a Circle of Friends around the student within the school community.
- DPW, with the Department of Education, will take leadership at the state level in strengthening, clarifying, and defining roles and responsibilities of the transition process.
- Build a partnership with the Department of Education and schools, advocates, families, students, and county programs locally for school to adult life transition.

8. People living in state operated facilities

- Continue to provide people living in state operated facilities the opportunity to live in the community as recommended in the Multi-Year Plan:

1999-2000 300 people

2000-2001 300 people

2001-2002 200 people

Implementation

This Plan to expand services and supports to meet the needs of persons on the waiting list is proposed to be as follows:

- Fiscal Year 1999-2000
People to be served by June 30, 2000

Residential	363
Non-residential	1,964
- Fiscal Year 2000-2001
People to be served by June 30, 2001

Residential	973
Non-residential	1,963
- Fiscal Year 2001-2002
People to be served by December 31, 2001

Residential	973
Non-residential	N/A

Growth in the capacity of the services system is necessary to respond to people waiting for services. Speed in the development of services is necessary to respond to the urgency of need. However,

services must also be of the highest quality, and individuals and their families must have control over those services.

The rate of service expansion must account for the need to develop high quality services. The Waiting List Planning Group consensus was that a growth rate of approximately 15% per year was a reasonable rate of expansion across the counties. However, some county programs, due to the size of their waiting list, need to grow more than others. Therefore, while the rate of growth may be the same across all counties, the length of time it will take to fully expand services to the needed level will vary by county.

As reflected in the goals and the recommendations of this Plan, meeting the needs of persons on the Emergency and Critical Need waiting list involves non-residential and residential services. The Waiting List Work Group established as a priority that all persons in Emergency and Critical need who need day services, should receive appropriate day services as quickly as possible, but no later than 90 days from requesting services. Families indicated the need for residential service could be delayed for some people if necessary day services were available. Other persons in Emergency and Critical Need require the development of appropriate residential services. This involves time, resources, and the capacities of counties and providers at the local level.

Throughout this Plan, a combination of new funds and the re-configuration of existing services, as well as the use of new models in the development of additional services and supports has been incorporated. This is consistent with Everyday Lives as well as the recommendations of the Multi-Year Plan.

The expansion of community services and supports will occur through the increased use of Medicaid Home and Community based Waivers. The following chart displays the implementation of this Plan in terms of persons and dollars through Fiscal Year 2002.

SUMMARY AND CONCLUSIONS

- The Plan to Address the Waiting List in Pennsylvania represents a significant expansion in the capacity of the service system for mental retardation services.
- The system must grow to accommodate the needs of those waiting for services.
- The Plan represents a combination of new funding and the reconfiguration of existing services to move the system towards new models of services and supports.
- Dollars in the plan do not include costs for statewide Management Information Systems (MIS), administrative staffing at the state and county levels, or the enhancement of salaries for direct care staff in existing services.
- Without this initiative, the waiting list will continue to grow across Pennsylvania.

“I want my daughter, Karrie, to have a full productive life, living within her community with the same opportunity, dignity and freedom to choose what she wants to do with her life as you and I do.”

Ms. Bonnie Miller, Mother

“A friend of my mother made a comment to me about my daughter, Jackie, who is 13 and has Down Syndrome. She said, “You never coddle her, she just amazes me.” It never occurred to us to “coddle” her. Jackie is learning to think independently so she can choose where she wants to live, who she wants to live with, and where she wants to work.”

Ms. Carol Csaniz, Mother

DEFINITIONS

Categories of Need

Emergency	Persons needing services immediately.
Critical	Persons needing services within one year.
Planning For	Persons with needs more than one year away.

Categories of Service

High Intensity	Persons receiving residential services, possibly in addition to vocational/day services, ancillary/support services, and case management
Medium Intensity	Persons receiving vocational/day services, possibly in addition to support/ancillary services and case management
Low Intensity	Persons receiving support or ancillary services (therapies, F.S.S., transportation), in addition to case management services

Types of Service

Day Services	Non-residential services to people with mental retardation including adult developmental training, vocational rehabilitation, and community employment
Residential Services (24 hour staff)	Services necessary to maintain a person in their home or in some other residential setting by providing staffing support 24 hours a day.

Residential Services (Not including 24 hour staff) Services to people who require some degree of staffing support to maintain them in their home, but do not require staffing on a 24 hour/day continuous basis.

Fiscal Year The 12 month period from July 1 to June 30 on which Commonwealth budgets are based.

Infrastructure The basic foundation that must be in place for an organization to function properly (administrative, information systems, staffing).

PUNS Prioritization of Urgency of Need for Services for Persons with Mental Retardation—Data collection instrument developed by Temple University to assess the need of individuals waiting for services.

The Goal...

To build a system that has the capacity to provide services in a timely fashion to all persons needing and requiring services and supports.
