DOCUMENT RESUME

ED 421 818 EC 306 576

TITLE	An Invitation To Shape the Future: A Multi-Year Plan for Pennsylvania's Mental Retardation Service System.
INSTITUTION	Pennsylvania State Dept. of Public Welfare, Harrisburg. Office of Mental Retardation.
PUB DATE	1997-07-00
NOTE	39p.
AVAILABLE FROM	World Wide Web: http://www.state.pa.us/PA_Exec/Public_welfare/mypomr.html
PUB TYPE	Reports - Descriptive (141)
EDRS PRICE	MF01/PC02 Plus Postage.
DESCRIPTORS	Adults; Advocacy; Children; Community Programs; *Deinstitutionalization (of Disabled); Delivery Systems; *Mental Retardation; Organizational Change; Policy Formation; Program Improvement; *Resource Allocation; *State Programs; *State Regulation
IDENTIFIERS	*Pennsylvania

ABSTRACT

This paper presents a five-year plan for the improvement of Pennsylvania's system of services for people with mental retardation and their families. It was developed over an 18-month period by 70 people, including people with disabilities, family members, advocates, providers of service, legislative staff, and county and state government officials. Resulting recommendations include: (1) restructure the administration of the program to assure quality, efficiency, and positive individual/family outcomes and satisfaction; (2) shift priorities for resource allocation from facility-based programs to services that build on natural supports; (3) create mechanisms for individuals and families to control resources allocated to meet their need; (4) pursue regulatory reform to ensure that regulations support reform efforts; (5) unify funding and eliminate categoricals within the mental retardation system; (6) reinvest savings from system reorganization into community services; (7) provide services and supports in the community for 1,500 people who are currently living in public Intermediate Care Facilities for People with Mental Retardation (ICF's/MR) over five years; (8) transfer the state and federal funding for services for 2,100 people in private ICF's/MR into the community funding system by conversion to the 2176 Medicaid Waiver Program. (CR)

AN INVITATION TO SHAPE THE FUTURE

A MULTI-YEAR PLAN

for

Pennsylvania's Mental Retardation Service System

presented to

the Pennsylvania Department of Public Welfare

by

the Planning Advisory Committee to the Office of Mental Retardation

July 1997

Message from the Co-Chairs of the Planning Advisory Committee

This is a five year plan for Pennsylvania's system of services for people with mental retardation and their families. It represents the efforts of more than 70 people who came together with many different points of view but with a common goal of making life better for people with mental retardation and for their families. These 70 people included people with disabilities, family members, advocates, providers of service, legislative staff, and county and state government officials.

The group worked over an eighteen month period clarifying the objectives of the planning process, gathering and evaluating information, discussing and even debating the findings and then reconciling differences. Through this process, members of the planning group were able to find common ground on which to develop recommendations.

Following publication of the draft plan, 24 public forums were held throughout the Commonwealth. More than 2,200 people attended these forums and over 400 provided verbal or written comments. This significant response to the plan and the substantive comments we received led to significant modification of the original document. The final plan is a result of respectful discussions that often led to compromise on strongly held positions which participants were willing to make as they learned how others felt about the issues. In order to move forward, everyone's point of view was considered and attempts were made to accommodate them.

The most difficult issue we struggled with was that of people leaving state institutions. Reflected in the plan is the recognition that people must be offered the opportunity to leave but that their move to the community must be prefaced by the development of quality services and planned carefully with family members. Additionally, some people will continue to live in state institutions at the end of the five-year period and the services they receive must be of high quality. This recommendation more than any other reveals the commitment of everyone to get past absolute positions and to agree on responsible action.

The planning process and recommendations offered for comment have stirred people to think about what is and what might be. Recommendations for change have generated strong feelings; feelings of concern as well as enthusiasm. This Plan recommends responsible change, at a reasonable pace that will result in higher quality services, more accountability, a stronger role for people with mental retardation and their families in all aspects of the system, and the wise utilization of resources to ensure that all those who need services will find them available.

The Planning Advisory Committee expresses its appreciation to all who in any way were involved in responding to the challenge to help shape the future of Pennsylvania's system of services for people with mental retardation and their families. The real work is now ahead of us.

Kevin Casey Ron Rucker

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Table of Contents

At present, more than 3,000 people are receiving state and federal funding for services in private ICF's/MR. Transfer the state and federal funding for 2,100 of these individuals into the community funding system by conversion to the 2176 Medicaid Waiver Program.

INTRODUCTION

In the Summer of 1995, Feather O. Houstoun, Secretary of the Department of Public Welfare,

issued an invitation to the Planning Advisory Committee to participate in reshaping the future of Pennsylvania's mental retardation system. The Planning Advisory Committee (PAC) to the Office of Mental Retardation is pleased to present this report in response to that invitation. It is a plan for realigning existing resources and for redesigning the service delivery system. This report is a recommendation from the PAC to the Secretary of Public Welfare and is presented in the spirit of partnership and cooperation to effect lasting change for the benefit of Pennsylvanians with mental retardation.

These recommendations cover a period of five years beginning with state Fiscal Year 1997-98 and ending with Fiscal Year 2001-02. However, planning for the future of Pennsylvania's program for people with mental retardation must continue well beyond 2002.

The Planning Advisory Committee (PAC) wishes to extend special thanks to those who generously gave of their time to join the planning group and to lend their expertise and valuable experience to the planning process. Special thanks also go to those who attended the public forums and especially to those who provided comment on the plan. The PAC also expresses its appreciation to Mr. John Ashbaugh, Senior Vice-President of Human Services Research Institute, for his research and facilitation of the planning process and his ability to focus so many people on the task of producing a plan that will provide direction to Pennsylvania's service system for many years to come.

WHY A MULTI-YEAR PLAN?

There are an estimated 115,000 citizens in Pennsylvania that have mental retardation. They have a broad range of abilities, with some simply needing opportunities and others needing direct support to participate in their community. They are family members and neighbors who work, go to school, shop in local stores, visit with friends and practice their faith. Each lives an everyday life and enriches the community with his or her presence and participation.

Support from family and friends and access to opportunities in the broader community have been, and continue to be, the critical elements to each person's success in life. At certain times, some individuals and families need additional assistance or support. The Pennsylvania service system exists to provide assistance and support within available resources.

Since the Mental Health/Mental Retardation Act of 1966, publicly-funded supports for people with mental retardation have grown steadily. This year, more than 67,000 people will receive supports from the state's $1.3 billion mental retardation budget. State-operated residential facilities for people with mental retardation serve about 3,000 of those people, while the remaining 64,000 are served in community settings. The majority of those receiving supports—about 60,000 people—are part of the state funded, county administered program created by the Mental Health/Mental Retardation Act. While the program has grown since 1966, the need also has grown. Financial resources are limited, creating waiting lists for services or service enhancements in each of our Commonwealth's 67 counties.

Care must therefore be taken to use resources to support and not supplant the efforts of individuals with disabilities, their family members and communities and to promote personal growth and self-sufficiency. Recognizing that resources are limited requires difficult decisions about how those resources are allocated. Not only is it important to maintain necessary supports and services for those who presently receive them, but also to provide needed supports for those who are on waiting lists. Such decisions must involve those who are most affected. The Department of Public Welfare, therefore, invited individuals from a broad cross-section of stakeholder groups in Pennsylvania's service system, including self-advocates, families, advocates, providers and government officials to participate in shaping the future of our state's mental retardation system.

More than 70 individuals met from October 1995 through July 1996 to create a plan for change and improvement; a plan based on the values and the vision set forth by the Planning Advisory Committee in 1991 through the publication of Everyday Lives.

Representation on the multi-year planning group included:

- People with disabilities
- Parents
- Advocates
- Advocacy Associations
- Providers
- Provider Associations
- Developmental Disabilities Council
- University Affiliated Program
- County MH/MR Administrators
- County MH/MR Program Administrators Association
- State Policy Makers
- Governor's MH/MR Advisory Committee

- Legislative Staff
- Consultants

Public Comment

Following publication of the first draft of the plan in November 1996, twenty-four public forums were held throughout the Commonwealth to provide the broader community with an opportunity to comment. More than 2,275 people attended the forums and more than 400 provided comment on the draft plan. This plan reflects both the thinking of the planning group members and the comments and recommendations received from the public.

Several important issues were raised by those providing comment that can be characterized under the headings of Quality, People with Severe Disabilities, Individual and Family Roles in Decisionmaking, and the Waiting List.

Quality of Services and Supports

Quality is a fundamental consideration in providing services and supports to people with mental retardation, regardless of where services are provided or by whom. 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.

The Commonwealth must continue to carry out its responsibility of assuring the basic health and safety of each person in all service arrangements. In addition, there must be a stronger role for people with disabilities and families to measure the quality of services to individuals and in the system as a whole.

People with Severe Disabilities

People with the most severe disabilities need our assistance most. People with serious medical needs, with serious physical disabilities and those with multiple disabilities including mental illness must have their needs met and their health and safety protected as we strive to enhance their opportunities for growth, relationships and participation in family and community life.

Sound values and program philosophy must be coupled with strong programmatic knowledge and expertise. Good planning and attention to unique, individual needs will ensure that people are both safe, cared for, challenged and given every opportunity for personal growth and a fulfilling life.

Individual and Family Choice and Decisionmaking

"...[I]ndividuals with developmental disabilities and their families have competencies, capabilities and personal goals that should be recognized, supported, and encouraged...[and] individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families..." **Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1996**(Section 101(c)3).

People with disabilities have abilities as well as the need for assistance. People have varying capacities to make decisions and to communicate their preferences. Some people are able to make major decisions about their lives and to communicate them clearly. Others need assistance understanding the decisions to be made or in communicating their preferences and are therefore reliant on family members and those who know them well to make or communicate those decisions.

Every person has preferences; preferences for where and how they spend their time, whom they spend time with and for simple things like what foods they eat or what music they listen to. Regardless of the capacities of a person to communicate their preferences, family and care givers know these things and therefore must be involved in all aspects of planning and decision making.

The emphasis of services must be placed on helping each person live a healthy, safe, meaningful, and productive life. This common goal should guide all decision making. Conflict between individuals, their family members and/or caregivers may arise. In such cases no one person can dictate the decisions to be made but all must strive to find what is best for the person and how public services can best achieve the goal.

Once the person's need for supports and services are evaluated, choices in how that need can be met and assistance in making decisions must be made available to the person, their family and others assisting them.

Waiting List

The waiting list consists of many people and families who are receiving services but who require additional services and those who are receiving no services at all. The majority, however, are receiving some service.

The people and families that are of the greatest concern are those who are aging; people with disabilities over 50 being cared for at home by their parents, or often by only one parent. These individuals may be receiving in home supports but are worried about the future.

This plan calls for a realignment of present resources in order to serve people on waiting lists while maintaining necessary supports and services for those who are presently receiving them.

The precise impact of this plan on the waiting list will be defined by the implementation strategies. The amount of savings realized by the proposed resource realignment will depend on who and how many choose to live, work and receive supports differently than now. As resources are realigned according to the plan's recommendations, funds will be made available to reduce the size of Pennsylvania's waiting list.

As this plan is being implemented, the reduction of the waiting list must be given the highest priority by the Department of Public Welfare in its budgeting and allocation of existing and new funds.

Involvement of the Stakeholders

The multi year plan issued for comment in November, 1996 provided a framework for change. With this broad approach, the document was not specific about implementation strategies. Those who provided comment on the plan frequently stated that "the devil's in the details" and that they wanted to be involved in the implementation of the plan.

No system can move forward without the collaboration of all the partners. The recommendations contained in this report emphasize the creation of work groups and processes that engage all of the stakeholders in system design and implementation.

A PLAN FOR THE FUTURE

This plan for the future is intended to accomplish two major goals.

I. SYSTEM REFORM: To restructure the system to one that is:

Consumer-driven—giving the person with a disability and his or her loved ones a decisive voice in formulating individual support goals and determining how public dollars can best be deployed to achieve those goals.

Values-Based—The values articulated in **Everyday Lives** (PAC, 1991) served as the foundation for the plan. The planning group tolerated no compromise of those values. People must be given the opportunity to exercise control over their life decisions. This includes the right to be part of a community, to develop relationships, to have friends, to be with family, to work, and to have real choices about where to live. These opportunities must be provided to all regardless of the type or severity of the disability.

Outcome-Oriented—Services and supports must emphasize helping each individual live a healthy, safe, meaningful, and productive life and they must be tailored to the needs and aspirations of each person.

Cost-Efficient—The ability to reach out to all those who need help depends on how wisely resources are used. Services must foster the development and use of natural support networks as well as strong ties to the community. Paid supports must be directed to those aspects of a service plan that are deemed essential to achieving the person's life goals and that cannot be accomplished by the individual's natural support network.

II. RESOURCE REALIGNMENT: To realign existing resources to meet the needs of those on the waiting list while maintaining necessary supports and services for individuals

currently receiving them.

A PLAN FOR THE FUTURE

Eight recommendations, with implementation strategies for each, support the goals of this plan.

Recommendation #1:

Restructure the administration of the program to assure quality, efficiency, and positive individual/family outcomes and satisfaction.

In deciding who will manage the program at the local level, the planning group recommends that counties be provided the opportunity to act as the local managing entity through a formal written arrangement (e.g. contract, grant agreement or other bilateral arrangement). If a county does not wish to act as the local managing entity or cannot meet state established standards, then the state would seek another agent to act as the local managing entity.

In the current mental retardation system, the state allocates resources to counties in the form of a grant. Although the state, over the years, has restricted the use of certain funding to particular services through "categorical allocations" to start new programs or to comply with directives from courts, there has never been a formal agreement between the state and the county that spells out the expectations for the use of those resources. **A formal agreement must be established between the state and the county, or a local management entity** receiving state funds, that must spell out clear expectations regarding the services to be provided, the role of individuals and families in decision making, the benefits to individuals and families, the cost of services, and local program administration.

The state must enter into a contract with the county/local managing entity. The contract should contain specific outcomes and performance standards for the county/local managing entity. In addition to specific program outcomes, the contract should require the creation of **an independent team at the local level to monitor the quality of services** delivered under the contract. This team should be comprised of individuals, family representatives and/or advocates acceptable to the individuals and families so as to assure independence from the parties to the contract. The county/local managing entity must provide adequate training for these teams and charge them with the responsibility for assessing the quality of supports and services being provided to individuals and families. Quality should be measured both in terms of **outcomes** for the individual and family as well as the level of **satisfaction** of the individuals and families with the services received.

To address the benefits of services received under the contract and to promote **efficiency** in the use of services, the contract should also establish standards that address the types of services to be provided, the criteria to determine a person's need for them, and to what extent individuals and families exercise control over the resources allocated to them. The contract should clearly identify responsibility for cost overruns and for assuring that emergency needs are met quickly and effectively.

The administrative functions related to the service system, such as intake, eligibility determination and financial responsibility, must be separate from the **service brokerage** function. The contract must specify that individuals and families have the option to choose who will perform these service brokerage functions. Such services may include providing information and community connections to individuals and their families, assisting in the development of their person-centered plan and budget within the limits of capability and resources, and assuring that individuals and family members have real choices to make.

The Office of Mental Retardation must require that the administration of the local mental retardation program by the county/local managing entity be governed by **a board that is comprised of at least fifty-one percent individual/family representation.** This is to assure that individuals and families have a deciding voice in the local administration of the program. The Mental Health and Mental Retardation Programs are a single administrative unit at the county level and the MH/MR Board functions in an advisory capacity to the county commissioners. Where counties elect to be the local managing entity, this board would continue to be appointed by and be responsible to the county commissioners, and would be charged by the commissioners to make decisions and give direction to the program administrator.

- The Office of Mental Retardation must develop reliable standards and measures for monitoring system performance.

- The Office of Mental Retardation must involve stakeholders in the design and development of the mechanism chosen to establish the relationship between the Commonwealth and the county/local managing entity.

- The Office of Mental Retardation must conduct a self assessment to determine the appropriate organizational structure, staffing and expertise necessary to manage a contract system.

The PAC recognizes that the ability of the state to enter into a contract with the county to administer the mental retardation program may require statutory change. This would then require a different implementation strategy that would involve the Pennsylvania General Assembly and a time table that must be consistent with legislative priorities. Also potentially requiring statutory change is the recommendation that the county MH/MR Board become a governing board whose responsibilities currently are defined by statute as being advisory to the county commissioners [Mental Health and Mental Retardation Act of 1966, Section 303(4)].

While the PAC urges that this recommendation be implemented, alternative strategies that would not require statutory change are suggested. Each of these alternatives maintain the present role of county government in managing the program locally. They make no provision for change in the local managing entity and are presented only as secondary recommendations.

Alternate A: The state may revise its **Annual Plan and Budget** process with the county to create a bilateral agreement that would require the county to comply with the same requirements as would be included in a contract. The Annual Plan would contain assurances that specific standards would be met and a formal approval process should be established by the Office of Mental Retardation that would constitute the Annual Plan and Budget as a formal agreement with the county/local managing entity.

Alternate B: The state may enter into a grant agreement with the county that would contain these same requirements.

Alternate C: The Department of Public Welfare may develop and implement regulations that would require counties to comply with the same requirements as a condition for receiving grants from the state.

Recommendation # 2:

Shift priorities for resource allocation from facility-based programs to services that build on natural supports.

Over the years, different kinds of program models have been developed and funding has been provided to implement those programs. These programs became the choices for people with mental retardation.

Funding must now be allocated, not to programs and facilities, but for the supports that people need to live healthy, safe, meaningful and productive lives. These supports must not replace the informal support network that consist of family and community but instead should foster the development and use of informal networks.

Formal services made available should be those that are deemed essential for the person to achieve his or her life goals and ones that are not available through the informal support network.

- The Office of Mental Retardation must, through policy development and training, promote models of support that strengthen informal support networks.
- The Office of Mental Retardation must measure progress toward developing support models as part of contract

  monitoring.
- The Office of Mental Retardation must continue to promote person-centered planning.
- All those who want a job should be offered an opportunity to work. The Office of Mental Retardation must monitor contracts against this principle. Of the 11,000 people receiving services in facility based vocational and developmental programs, 3000 must be offered the opportunity of a real job over the next five years.
- The Office of Mental Retardation must discontinue the development of new facility based adult day programs and must work with providers to develop broader options for people to participate in community life.
- The Commonwealth agencies that have responsibility for preparing children for adult life must strengthen planning processes for the transition from school to adult life. Interagency collaboration must be strengthened at the local and the state level.

Recommendation # 3:

Create mechanisms for individuals and families to control resources allocated to meet their need.

Family support pilot programs throughout the Commonwealth have demonstrated that, with appropriate structure, information, and training, individuals and families make good decisions about the supports they need.

The Office of Mental Retardation should require, as a condition for receiving funds, that counties/local managing entities have a process in place to provide individuals and families control over the resources allocated to them. This may include vouchers or cash payments, individual budgets, or other methods.

- The Office of Mental Retardation must provide a training program to prepare individuals and family members to take an active part in exercising control over the future as it relates to the lives of family members with mental retardation. This training should prepare families to develop a plan that supports the person's achieving his/her life goals; provides information on what services and supports are available to enhance their informal networks; and enables them to deal effectively with the local managing entity regarding funding decisions.

- The Office of Mental Retardation must expand its current self determination initiative begun under a grant from the Robert Wood Johnson Foundation so that in five years time all local programs will have systems that provide individual/family choice and decisionmaking in the types of supports they receive to enhance their natural support system.

Fiscal Year 1997-98 (Year 1): + 6 county programs

Fiscal Year 1998-99 (Year 2): +10 county programs

Fiscal Year 1999-00 (Year 3): +10 county programs

Fiscal Year 2000-01 (Year 4): +10 county programs

Fiscal Year 2001-02 (Year 5): + 6 county programs

- The Office of Mental Retardation, in conjunction with the County MH/MR Programs, must develop funding strategies that allow for individual budgets, choices for individuals and families, and individual/family purchase of supports.

- The Office of Mental Retardation must continue to explore all opportunities for expanding choices for people with mental retardation, particularly in the area of housing, transportation and jobs.

- The Office of Mental Retardation must require that the county/local managing entity establish a formal appeal process to assure individuals and families an opportunity to resolve disagreements regarding all aspects of service delivery, including intake, eligibility, and the types of services and supports offered.

Recommendation # 4:

Pursue regulatory reform.

As discussions continue regarding changes to the service system, regulations must be reviewed to make sure they support reform efforts. The following recommendations are made regarding regulatory reform:

- The Office of Mental Retardation must convene a work group made up of fiscal officers from selected county programs, as well as provider representatives and other Department representatives to identify needed changes to the County MH/MR Fiscal Manual (PA Code, Chapter 4300), known as the **4300 Fiscal Regulations.** Revisions to the regulations should be driven by the need to promote the principles of self-determination, particularly individual and family control of resources. Consideration must be given to the recommendations made in this plan regarding contracts, agreements and issues of fiscal accountability throughout the system.

- The Office of Mental Retardation, in conjunction with the Planning Advisory Committee and the Department of Public Welfare's Cross Systems Licensing Work Group, must continue to pursue the recommendations made by the Regulatory Reform subcommittee regarding revisions to the licensing regulations. Particular attention must be given to the health, safety and rights of individuals who are receiving services and supports.

- In addition to the fiscal and licensing regulations, the Department of Public Welfare must review the current financial liability regulations for adults receiving services and the financial liability requirements for families of children who are under the age of 18 receiving services. A review of these regulations should determine their appropriateness and fairness. This review must not result in an imposition of financial liability on any family member of an adult who is receiving services and supports, but should not discourage or impede any individual or family member who wishes to contribute in any way to the supports and services provided.

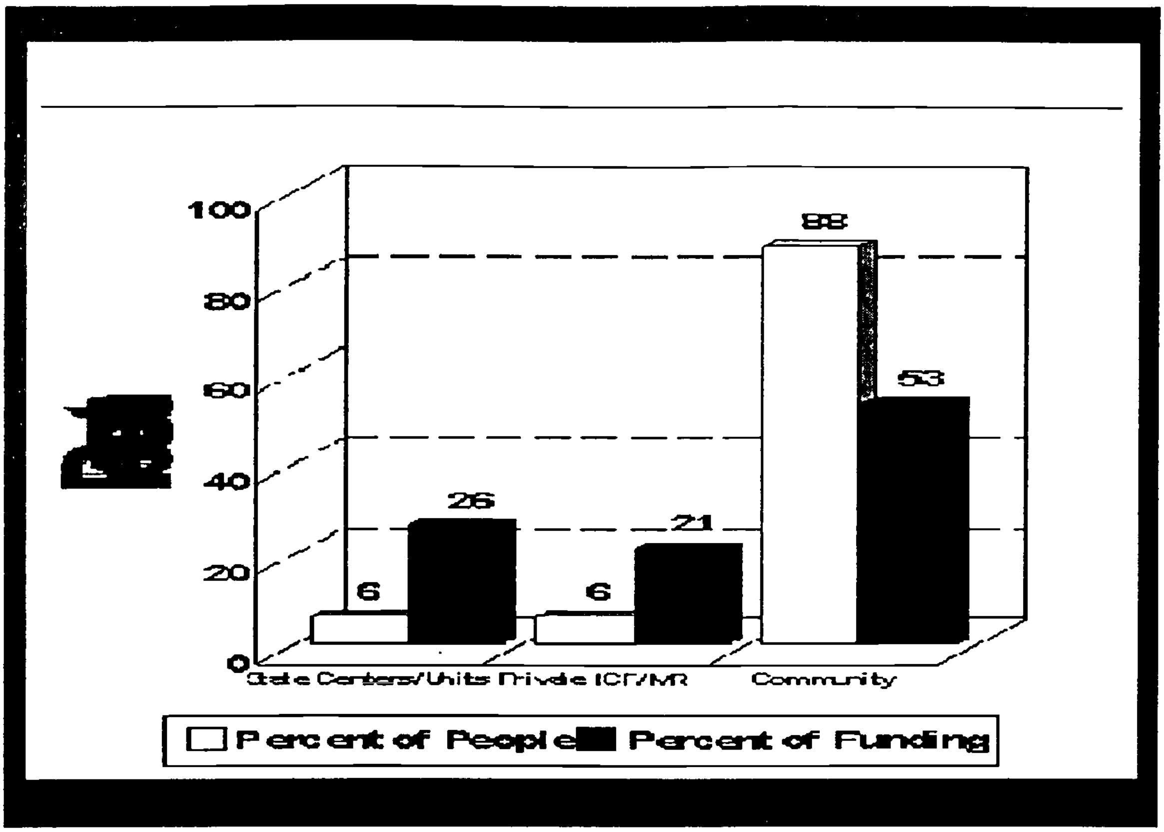
- Included in this recommendation for regulatory reform is a recommendation that the Office of Mental Retardation review all other applicable DPW regulations and office policies in the light of the recommended system changes addressed in this plan.

Recommendation # 5 :

Unify funding and eliminate categoricals within the mental retardation system.

The current system is really three systems: **state centers/units, private ICF's/MR, and community programs.** Each is managed separately and there is little movement between them. These systems have developed independent of each other in response to a need in time. Each of these systems has its own eligibility criteria for enrollment in services and its own rules for the kinds of services that can be provided, as well as its own regulations and reporting requirements. A significant portion of these funds are limited to services provided in licensed facilities and therefore restricts their use for family and community supports.

The following chart shows the three systems:



This arrangement has created problems for individuals and family members who try to access needed services. **Funding for these three systems must be brought together and managed by a single entity.** Funding unified under one managing entity will increase flexibility, efficiency, and responsiveness to people.

Steps should be taken toward the unification of funding and the elimination of categorical allocations:

- The Office of Mental Retardation must create a work group to identify strategies that achieve unified funding and address any statutory, regulatory, or policy issues at the federal and state levels regarding this recommendation. The Office of Mental Retardation should make available any additional consultation as may be necessary to the work group and provide the necessary linkages to the Health Care Finance Administration to accomplish the task.

- The Office of Mental Retardation must identify all categorical funding streams currently in place and work with the counties to streamline them.

Recommendation # 6:

Reinvest savings from system reorganization into community services.

- The Office of Mental Retardation **must establish the size of the waiting list and define the level and urgency** of the need it represents. Those on a waiting list receiving no services should be distinguished from those who are receiving some services.

- **Reinvestment decisions must take into account local need** as it relates to the size and urgency of the county waiting list and the funding provided to the county for current services.

Recommendation # 7:

Provide services and supports in the community for 1,500 people who are currently living in public Intermediate Care Facilities for People with Mental Retardation (ICF's/MR) over five years.

Counties have reported in their annual plans an estimated 1,500 people living in state facilities who would prefer, and would benefit from, community living. Recognizing this, it is recommended that these individuals be provided opportunities to live in the community. The following schedule should be considered for implementing recommendation # 7:

State Facility Residents Residents Remaining

Moving to the Community in State Facilities

FY 1997-98 (Year 1): 400 2,600

FY 1998-99 (Year 2): 300 2,300

FY 1999-00 (Year 3): 300 2,000

FY 2000-01 (Year 4): 300 1,700

FY 2001-02 (Year 5): 200 1,500

It is estimated that, at the end of the five year period, the state center budget will be reduced by an amount ranging from $105 million to $140 million. These resources must be made available from the state center appropriation to provide community-based supports for those moving into the community. The actual amount will be determined by how many individuals move and from which facilities. Depending on the needs of the individuals, an estimated 875 to 1,750 additional people could be served from the waiting list.

This schedule requires that the Office of Mental Retardation continue its budget planning in a way that assures successful implementation of the recommendation. Also, as a result of this schedule, this plan envisions that a significant number of people will continue to be served in state operated facilities at the end of the five-year plan period.

Successful implementation of the above recommendation will require action in several areas:

Involving Individuals and Families in Decision Making:

- Individuals with disabilities and their family members must be involved in all planning activities and in the decisions affecting them.

- The Office of Mental Retardation must work with individuals, families, advocacy organizations, and counties to provide training to enable individuals and families to be active and effective participants in the individual planning process.

Assuring Quality, Health, and Safety:

- All county MR Programs, or local managing entities, must be required to have in place a **local monitoring team** that is independent of the local service system and that is made up of a majority of individuals/family members. Outcomes for people

and individual/family satisfaction should be the major focus

of the assessments.

- All state operated facilities must be required to have in place a **facility monitoring team** made up of residents/family and friends. Outcomes for people and individual/family satisfaction should be the major focus of the assessments.

- The Department of Public Welfare must review and revise, where necessary, its current **licensing regulations** to assure necessary health and safety protections for individuals receiving supports in the community.

- The **planning processes** for all individuals must assure that health and safety issues are adequately addressed in all service arrangements.

- The Office of Mental Retardation must provide the following to all individuals receiving services in the community and facilities, and their family members:

- assurances of **regular monitoring visits** by the county or the local managing entity

- a list of names and telephone numbers **providing access to key people** in the community program (e.g. county mental retardation staff, case managers, state regional office staff, provider organizations, advocacy organizations)

- **a toll free telephone number that provides direct access to the Office of Mental Retardation**

Building Capacity:

- The Office of Mental Retardation, in conjunction with the stakeholders of the program, must develop and implement an **education and training program for individuals and families** to provide information on the community program and the supports and services available.

- The Office of Mental Retardation must continue to provide **training on best practices in community services** including:

- person-centered planning/self determination
- supports for people with ongoing medical needs
- access to physical health care
- assistive technology and services
- interventions for individuals with mental retardation and

  mental illness

- positive approaches
- communication training and technology
- employment training and support
- individual and family support strategies
- cultural competency
- service brokerage and service coordination

- The Office of Mental Retardation must develop strategies to **develop a qualified and trained work force** to provide community services and supports in the future.

- The Office of Mental Retardation recognizes that each local community faces its own unique challenges in developing and providing quality supports for all citizens with mental retardation, particularly those with severe and/or multiple disabilities. The

Office of Mental Retardation must work with the counties or local managing entities to ensure that each community in the Commonwealth has the competencies to support people and, where assistance is needed, work with those communities by providing technical assistance.

- The Office of Mental Retardation must continue to provide **training to staff in state facilities on best practices** in caring for and supporting people with disabilities.

Recommendation # 8:

At present, more than 3,000 people are receiving state and federal funding for services in private ICF's/MR. Transfer the state and federal funding for 2,100 of these individuals into the community funding system by conversion to the 2176 Medicaid Waiver Program.

The implementation of this recommendation must take into account two important considerations:

- Individuals and family members must be involved in any change that will affect the services they receive.

Under current Medicaid law, the role of private ICF/MR providers must be recognized and, consequently, program changes and enrollment in the 2176 Medicaid Waiver Program can occur only with the cooperation of the provider.

To implement the above recommendation, the following must

occur:

- All planning for individuals that occurs as a result of this recommendation must involve the individuals and family members.

- Since ICF/MR programs serving 10 people or fewer will require no changes in living arrangement, the Office of Mental Retardation must begin working with the private ICF/MR providers, the ICF/MR task force and the counties to convert funding for these programs from the ICF/MR program to the Medicaid Waiver.

- For ICF/MR programs serving more than 10 people, the Office of Mental Retardation must work with the private ICF/MR providers, the ICF/MR State Task Force, and with the counties to demonstrate new service models.

- Specific plans must be developed by the Office of Mental Retardation, in conjunction with the affected providers, to address the future of private ICF/MR programs that serve ten or more people. These plans must address how services and supports will continue, how the provider agency can successfully restructure the program, and how the restructuring will affect the agency's ability to continue to support people with disabilities.

The Office of Mental Retardation must maintain its current policy of no new ICF/MR development.

It is the belief of the PAC that the implementation of the above recommendations will result in providing more beneficial service to more people through a realignment of current resources. It is also the belief of the PAC that a redesign of the system to one that is person and family driven and outcome oriented will result in a more cost-efficient and accountable system that is necessary for the future stability of the program.

EC 306579

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Title: An Inventation to Shape the Future: A Multi-Year Plan... System

Author(s): PA Dept of Public Welfare, Office of Mental Retardation

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Publication Date: July 1997

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