

Ohio Access for People with Disabilities



Final Report to Governor Taft

February 28, 2001

Table of Contents

I. Executive Summary.....1

II. Overview of Community-Based Long Term Care Services in Ohio.....5

III. Services Offered for Specific Populations.....9

 Department of Job and Family Services 9

 Department of Mental Health 15

 Department of Mental Retardation & Developmental Disabilities 22

 Department of Aging 26

 Department of Health 31

 Department of Alcohol & Drug Addiction Services 34

IV. Public Involvement in the Ohio Access Process37

V. Federal Constraints.....45

VI. Challenges to State Disability Policy.....51

VII. FY 2002-2003 Executive Budget.....61

VIII. Recommendations.....69

IX. Appendices.....77

 Appendix I: Web Sites Containing Related Information 77

 Appendix II: Figures Contained in the Ohio Access Report 79

 Appendix III: Acronyms Contained in the Ohio Access Report 81

Respectfully Submitted

Thomas W. Johnson, Director, Office of Budget and Management (Chair)

Jacqueline Romer-Sensky, Director, Department of Job and Family Services

Michael F. Hogan, Ph. D., Director, Department of Mental Health

Kenneth W. Ritchey, Director, Department of Mental Retardation and Developmental Disabilities

Joan W. Lawrence, Director, Department of Aging

J. Nick Baird, M.D., Director, Department of Health

Luella Fleming, Director, Department of Alcohol and Drug Addiction Services

Executive Summary

In June 2000, Governor Taft announced his continuing commitment to provide community-based alternatives for elders and persons with disabilities. In so doing, he outlined Ohio Access and its three guiding principles:

- 1) Increase Community Capacity: Publicly financed delivery systems should be responsive to consumer demand for choice of services and supports and the need to develop additional capacity in community based services. Current delivery systems must be improved to assist families, communities, and state and local governments in meeting their responsibilities.
- 2) Prioritize Resources: Reform/expansion of any delivery system must be accomplished by balancing competing priorities within the limited resources of families, community based organizations, and state and local governments. Government agencies need to develop a process to determine where reform is most needed and can be achieved. Part of this is seeking cost efficiencies and appropriateness of care, especially in institutional settings, thereby making more dollars available to support community-based care.
- 3) Assure Quality and Accountability: All publicly financed delivery systems must assure clinical, programmatic, and fiscal accountability and compliance at federal, state, local, and provider levels. Responsibility must be clearly defined at each level to ensure significant aspects of program design, including quality assurance, consumer health and safety, and sufficient and appropriate match.

Governor Taft instructed members of his cabinet to conduct a broad review of the state's existing system of services for persons with disabilities, obtain feedback from the public, and make recommendations for improving these services over the next six years, consistent with the three guiding principles. The Office of Budget and Management coordinated this initiative with the participation of the Departments of Job and Family Services, Mental Health, Mental Retardation and Developmental Disabilities (MR/DD), Health, Aging, and Alcohol and Drug Addiction Services.

The review of the system as it exists today, coupled with feedback from consumers and their advocates, lead the agencies involved in Ohio Access to call for a **new vision** of a service delivery system for persons with disabilities. Ohio Access honors the commitment of families who provide care and supports them in their efforts. Eighty percent of all long term care is provided by an informal network of care including family, friends, and neighbors. Government programs should respect and integrate with the family's historic and primary role in care giving. This vision emphasizes consumer choice, control, and autonomy. The cornerstone of the vision is consumer self determination and a person centered planning approach with assistance from family, friends and caregivers. Consumers will be given more **control** over the funds available for their care and be integrally involved in the **choice** of services and caregivers comprising their individual service plan. A holistic approach to person centered planning and care will ensure consideration of each consumer's physical, mental, emotional and spiritual needs.

Executive Summary

Supported employment services programs will be further developed and more widely available and barriers to employment will be removed for consumers able to enhance their financial self-sufficiency.

Expected outcomes of this new vision include enhanced consumer: 1) independence, 2) personal dignity and responsibility, 3) access to community services and decreased reliance on institutional care settings, 4) quality of life, 5) health and safety, as well as 6) the most efficient use of limited funds. This approach will drive the development of home and community based care choices in support of health, wellness and prevention of unnecessary, premature institutionalization. The future array of service alternatives will ensure options, including quality institutional care where it is clinically appropriate and cost-efficient, consistent with each consumer's need and desire. Home and community-based options should be the norm rather than the exception.

To achieve this new vision, it is recommended that Ohio adopt the following goals:

- Elders and persons with disabilities live with dignity in settings they prefer.
- Elders and persons with disabilities receive safe, high-quality long-term care, services, and supports wherever they live.
- Relatives, neighbors, and friends who care for and support elders and persons with disabilities receive the information and services they need to plan for their future and support their caregiver role.

The report begins with an overview of state supported community-based long-term care services in Ohio. Section III describes the currently offered community services for persons with disabilities and is organized by agency. Section IV summarizes several different public processes that were used to gain consumer feedback on Ohio's system and the call by consumers for a new vision in how Ohio provides services to persons with disabilities. More specific recommendations are available through each agency's website. Section V addresses federal constraints that have contributed to the current institutional bias present in publicly funded programs. Section VI discusses specific challenges to state policy that exist and must be addressed for the vision articulated in this report to become reality. Section VII discusses short-term priorities that are contained in the FY 2002-2003 budget recently submitted by Governor Taft to the Ohio General Assembly. These recommendations, in a period of constrained growth and in light of present budget realities, serve as markers toward the new vision detailed in the final section of the report. Specific recommendations in Section VIII include:

A. Match capacity with demand. Put simply, expenditures for publicly funded care in Ohio are misaligned with the expectations and desires of Ohio's consumers. This misalignment has been created by federal and state reliance on institutional services over many years, including statutory reimbursement methodologies for institutional services, and the absence in most systems of a comprehensive state policy (such as Ohio Access) in favor of community-based services. The Governor's budget is an important first step in that it proposes adjustments to the current reimbursement system for institutional care that will slow the growth

in the cost of these services, while at the same time investing an additional \$145 million dollars in the expansion of home and community-based services for persons with disabilities. The state must work with existing private institutions and institutional providers to examine ways to transition to new models of community-based care and in diversifying their businesses.

B. Generate and sustain the necessary resources to expand community services.

A review of successful system realignment efforts here in Ohio, as exemplified by the Mental Health Act of 1988, and in other states makes evident how essential comprehensive structural reform is in achieving a balanced and sustainable delivery system. Isolated program initiatives alone will not be effective. Financing, statutes, regulations, local infrastructure, and the support of affiliated public agencies must be strategically aligned to achieve the intended results. A sustained reduction of institutional capacity and funding will not occur without a comprehensive, strategic focus. Without a shift of some funding to community settings, alternative community services will not grow and be sustained.

C. Overcome federal policy constraints.

With a new administration on the federal level comes a new opportunity for Ohio to realign its public support for services for elders and persons with disabilities. Ohio must work with the National Governors' Association and other national groups to lobby for more flexible regulations. At the same time, state policy makers must continue to be responsive to the Health Care Financing Administration and the federal Office of Civil Rights to assure Ohio's compliance with the mandates of the Americans with Disabilities Act (ADA), allowing consumers to choose the most integrated settings for services.

D. Address the health care workforce shortage.

Ohio must encourage public and private efforts to reengineer the direct care workforce and improve efficiency. Good management techniques and the adoption of best practices can create a work environment in which people are treated fairly and professionally. Job satisfaction is more than just wages and benefits. More emphasis should be placed on training and supporting supervisors who make the transition from direct care. The state should encourage the creation of demonstration projects to increase workforce efficiency.

In addition to increasing its workforce development efforts, the state must create strategies to examine innovative responses to the direct care workforce shortage. These initiatives may be aligned with the principles detailed in President Bush's New Freedom Initiative, which he proposed to Congress on February 1, 2001.

E. Overcome policy constraints on self-sufficiency and personal responsibility.

A consistent theme throughout the public process that surrounds the development of the Ohio Access report, was that there are currently far too many policy barriers that inhibit persons with disabilities from achieving self-sufficiency. To the extent that such barriers exist, the state has an important role in developing mechanisms to remove those barriers.

Also, while the state plays an important role in financing and organizing long-term care services, the fact remains that the vast majority of long-term care, services, and supports is provided informally by relatives, neighbors, and friends. The state has an important role in supporting, not replacing, this informal network.

Executive Summary

The recommendations are intentionally general in nature and must be further developed and refined with consumer, family, provider, and community input over the next six years.

The Ohio Access report is a blueprint for Ohio's future. In order to achieve the new vision for elders and persons with disabilities, the state must work with consumers and their families, local funding partners, and providers to overcome the barriers and constraints identified in this report. The implementation of the strategies outlined in Section VIII will require the commitment of all of these stakeholder groups, as well as the realignment of limited resources to purposefully and efficiently match capacity to demand.

The agencies recognize that the new vision cannot be achieved quickly. Ohio's current system of long-term care and services has evolved over many years and the issues highlighted in this report will not be resolved in the near term. However, Ohio Access marks a beginning, not an end point, and with the concerted efforts of all affected Ohioans, a vision based on self-determination and person-centered planning will be realized for our futures.

Overview of Community-Based Long Term Care Services

Community-based services provide long-term support for people who need help with activities of daily living outside of large state institutions or nursing homes and in their own homes and communities. Community-based care grew from the choices of elders and people with disabilities to emphasize quality of life issues: staying in the community; health and safety; personal growth and opportunity; and self-determination.

Depending on program eligibility requirements, available resources, and the specific needs of the individual, the following types of assistance and support may be available to elders, people with disabilities and their family caregivers:

- Residential services and supported living facilities, including subsidized independent housing, community-based residential placements in supervised apartments, or group homes with case manager visits;
- Income support through Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI);
- Personal assistance services, including a range of human and mechanical assistance for those people of any age who require help with routine activities of daily living and health maintenance;
- Care planning and case management, including a comprehensive assessment by a case manager of their individual needs and the network of aid agencies and programs appropriate for providing care;
- Day programs, including activity centers, habilitation and adult skills programs;
- Vocational services, including supported employment programs, vocational evaluations, job training and placement, and work adjustment programs;
- Treatment services including medical, psychiatric, and rehabilitation programs; and/or
- Other quality of life services, such as recreation and leisure activities, transportation and early intervention programs.

Ohio Medicaid and Other Services. Ohio's publicly funded community-based long term care delivery system is administered by a number of state and local agencies using federal, state, and local funds. Medicaid is the principle funding source for long term care in Ohio, and the Ohio Department of Job and Family Services (ODJFS) is recognized as the single state Medicaid agency. ODJFS establishes relationships with other state agencies to administer Medicaid services as appropriate, and, in some cases, these agencies establish similar relationships with their local systems.

Overview of Community Based Long Term Care Services

While most publicly funded community long term care services are available through Ohio's Medicaid program, a variety of non-Medicaid services are offered by state and local agencies as well. These services include housing (which is not covered by Medicaid outside of institutional settings), home and community based waivers, and other services listed above. These services are sometimes used as "wraparound" services for a Medicaid consumer or stand-alone services for an individual who, when receiving the service, can live successfully in the community.

Additional community based benefits to consumers may include assistance from the Ohio Rehabilitation Service Commission, Veteran's Administration, or other federal, state, or local agencies.

Long term care services are provided in both institutional and community settings.

The Ohio Medicaid health plan provides two benefit packages: comprehensive primary and acute care medical services, and long term care services. The acute care benefit package is available to all Medicaid consumers according to their medical necessity. The long term care benefit package provides additional services for persons who have chronic or disabling conditions and meet certain "level of care" criteria. Long term care includes both community-based and facility-based long term care services.

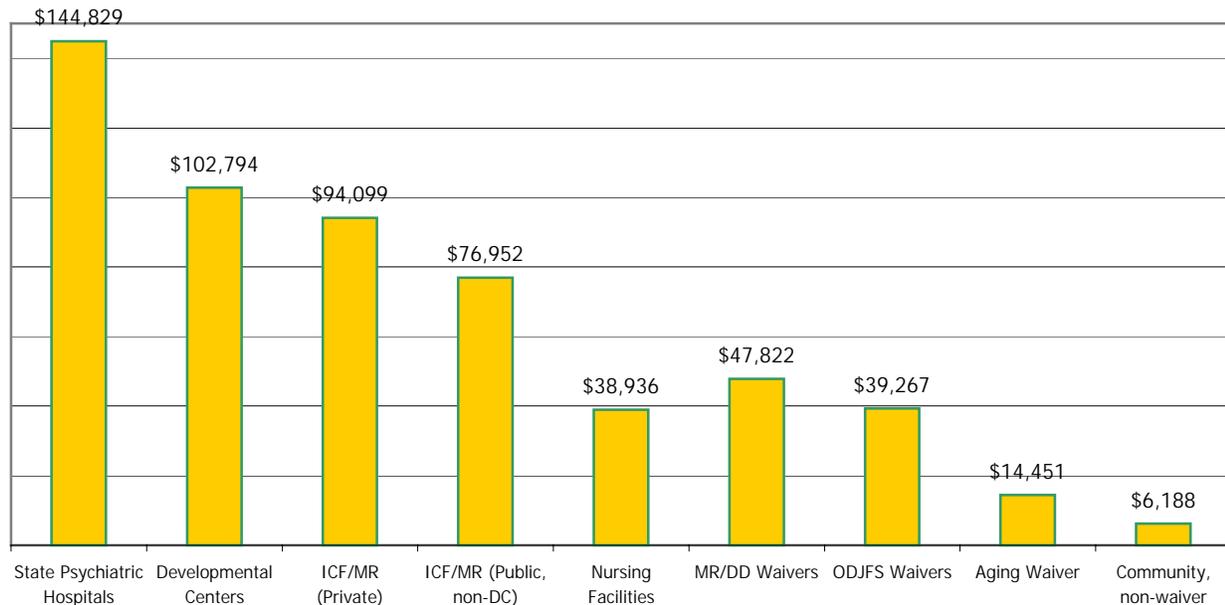
The federal government requires state Medicaid programs to extend a broad range of mandatory services to Medicaid consumers. Nursing home care is an example of a mandatory service for consumers who are eligible for long term care. If a state chooses to offer additional, optional services, those services become entitlement services for all eligible consumers, as well. Intermediate care facilities for the mentally retarded (ICFs/MR) are an example of an optional service that Ohio offers to eligible consumers.

The Health Care Financing Administration (HCFA) allows states to seek waivers, or exemptions, for various regulations including these entitlement institutional care settings. In the home and community-based waiver process, the federal government essentially "waives" the comparability of services requirement in order to allow states to provide certain services to targeted individuals to enable them to live safely and successfully outside of an institution. Under Ohio's waiver programs, certain consumers can receive such services as personal care, adult day care, and home delivered meals, even though these services are not available to all Ohio Medicaid eligibles.

The federal government requires that all home and community-based waiver services offered to individuals must be less expensive than the institutional entitlement options, either on a per-person basis or in the aggregate. Figure 1 compares the average annual costs of various institutional and waiver settings. Note that these average costs include consumers' Medicaid acute care service costs.

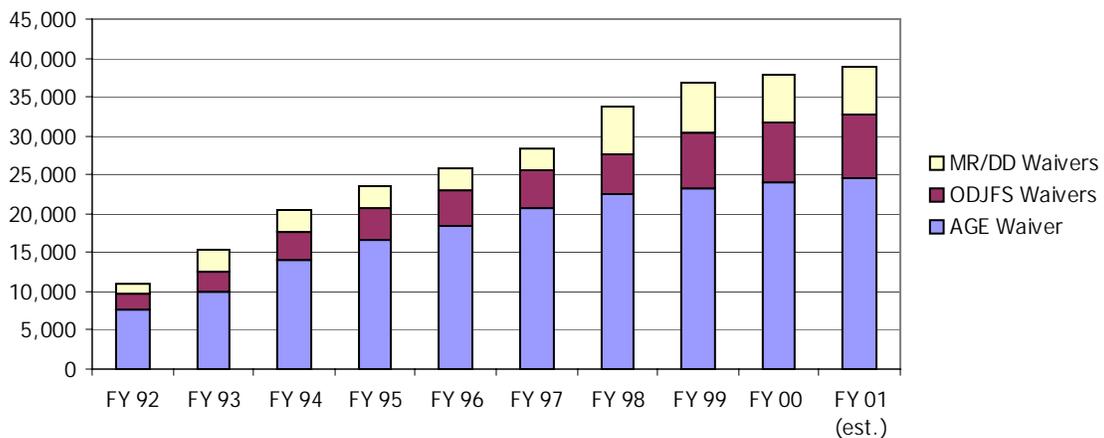
Overview of Community Based Long Term Care Services

Figure 1: Average Annual Cost by Setting, FY 1999



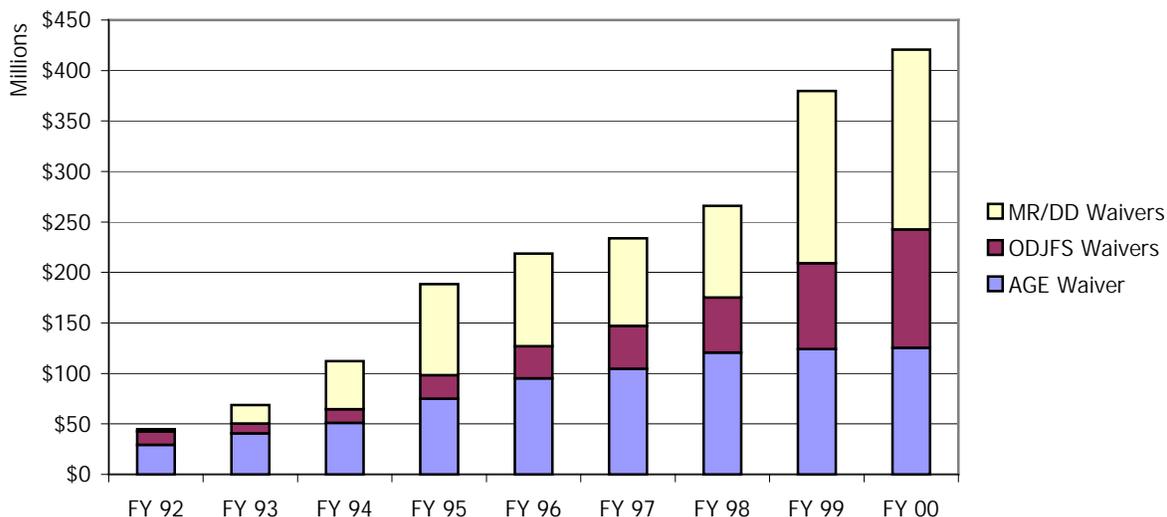
New growth in Ohio's long term care system has been focused in the community for nearly a decade. A certificate of need moratorium on licensing of new nursing home and MR/DD institutional beds was established in FY 1994. This policy decision enabled the state to better manage long-range growth of institutional expenditures and focus on expanding the availability of community-based services. During the late 1980s and early 1990s, the Departments of Job and Family Services, Aging, and MR/DD developed home and community based waiver programs as alternatives to institutional care. These programs grew throughout the decade: across all delivery systems, the number of waiver slots approved by HCFA increased from 11,064 in FY 1992 to nearly 38,000 in FY 2000. This represents a 242% increase over FY 1992 levels.

Figure 2: HCFA-Approved Home & Community Based Waiver Slots, FY 1992-2001



Overview of Community Based Long Term Care Services

Figure 3: Home & Community Based Waiver Expenditures, FYs 1992-2000



The Department of Mental Health took a different approach to expanding community based care. Home and community based Medicaid waivers are not available as a practicable means of funding mental health community care since Medicaid does not reimburse institutional care in mental health facilities. Mental health reform emphasized transferring full responsibility for care to local boards, which then plan and finance care for all local residents in both state facilities and community services. As boards de-emphasized use of state facilities, the Department reduced the number of state psychiatric hospital campuses from seventeen to nine and transferred the closed hospitals' operating dollars, as well as substantial savings attributable to administrative consolidation of services and re-engineering, to local boards to provide community care. During the period FY 1990 to FY 1998, funding for community based mental health care increased by approximately \$397.5 million. Much of this growth may be attributed to the redistribution of resources within the system. Additionally, an increased reliance on Medicaid fee for service billing for those community mental health services and clients that are eligible helped expand community care.

Under the umbrella of publicly funded long term care in Ohio, state and local agencies have developed a wide variety of innovative service packages to assist consumers and their families. Section III contains information regarding specific delivery systems, including a snapshot of the client population, services provided, community infrastructure, a chronology of key events within each system, and current challenges.

Services Offered for Specific Populations

Department of Job and Family Services

The mission of Ohio's Medicaid program is to assure access to comprehensive health care services for targeted populations in order to improve the health status of Ohioans and their communities and to support the self-sufficiency and care of covered populations. Medicaid acts as a value purchaser in the health care market place, seeking improvements in access, cost, and quality while being accountable to consumers and taxpayers. Ohio Medicaid is structured such that services are provided under two benefit plans; acute care services (such as physician, hospital, laboratory, and prescription drugs), and long term care services (including home and community based care, waivers, and services obtained through long term care facilities.) Medicaid consumers enrolled in home and community based waiver programs access primary and acute care services through the Medicaid fee-for-service delivery system, and access long-term care services through home and community based providers, and long term care facilities.

The Ohio Medicaid program, as mandated by federal law, provides services such as inpatient hospital, outpatient hospital, prescription drugs, durable medical equipment, physicians, laboratory and x-ray, nursing facility, home health, and Early Periodic Screening and Diagnostic Treatment (EPSDT) services. These services are mandatory services which all state Medicaid programs must provide to eligible consumers. Each state also chooses optional services it may include in its state plan. In Ohio, optional covered services include pharmacy, dental, private duty nursing, physical therapy, occupational therapy, speech and hearing, psychology, podiatry, community behavioral health care services, and others. Also, federal law requires these state plan services to be available statewide. Consumers on Medicaid have the freedom to choose from among the qualified eligible providers. Medicaid may offer additional services to persons with disabilities enrolled in a home and community based waiver. Ohio covers waiver services such as emergency response systems, home-delivered meals, supplementary equipment/adaptive devices, home modification, out-of-home respite, adult day care, supported employment, and homemaker/personal care services.

Persons with disabilities who are eligible for Medicaid are able to participate in the standard Medicaid plan and, if enrolled, waiver services. Persons with disabilities may also use services from other sources such as the Rehabilitation Services Commission and the Bureau of Vocational Rehabilitation. Persons with disabilities may avail themselves of services through advocacy organizations such as the Ohio Development Disabilities Council, the Governor's Council for People with Disabilities, and Traumatic Brain Injury Community Support Network. Additionally, a person with disabilities typically has income from Supplemental Security Income or Supplemental Security Disability Income.

Ohio Home Care Program

As of July 1, 1996 the Ohio Department of Human Services (ODJFS name prior to FY 2001 merger with Ohio Bureau of Employment Services) revised its home health services under a program known as the Ohio Home Care Program. The purpose of the program is to provide home care services to Medicaid eligible consumers who are in need of such services due to their

Services Offered for Specific Populations

functional abilities and/or medical condition. The Ohio Home Care Program is a term used to describe the following benefit packages: Core Benefit Package; Core Plus Benefit Package; Home Care waiver (administered by ODJFS); PASSPORT waiver (administered by the Department of Aging); Individual Options (IO) waiver (administered by the Ohio Department of Mental Retardation and Developmental Disabilities); and Residential Facilities (RFW) waiver (also administered by the Ohio Department of Mental Retardation and Developmental Disabilities).

The portion of the Ohio Home Care Program described below focuses upon the benefit packages administered by the Ohio Department of Job and Family Services, specifically the Core Benefit Package, the Core Plus Benefit Package, and the ODJFS Home Care waiver.

Core Benefit Package. Core services include nursing and daily living services up to 14 hours per week, and skilled therapies (physical therapy, occupational therapy, and speech) as medically necessary. Daily living services may include personal care services, assistance with activities that directly support skilled therapies but do not require the skills of a therapist, routine care of prosthetic and orthotic devices, performance of general household activities that are essential to the consumers health and safety, and some short-term relief for care givers.

Core Plus Benefit Package. Services include all the services listed in the Core Benefit package, plus additional nursing and daily living services in excess of 14 hours per week. However, the total amount of services, including skilled therapy services, must be prior-approved by ODJFS and must fall within the individual "cost cap" (spending limit) assigned to the consumer by ODJFS. ODJFS, in a face to face meeting with the consumer, establishes the services he or she may access.

ODJFS Administered Waiver Benefit Package (Ohio Home Care Waiver.) This waiver, called the Ohio Home Care waiver and described in greater detail below, was implemented July 1, 1998. It combined the former Disability waiver and the Medically Fragile waiver and added an additional 2,000 slots for eligible consumers. The revised waiver allows greater flexibility in certain service areas and permits greater consumer choice in directing and designing their care. Income and asset eligibility standards are also more flexible under the waiver. The amount, duration and scope of services provided under this waiver are established in an "all services plan" and fall within an individual cost cap that is assigned to the consumer by ODJFS. Services under this waiver include any of the core services of nursing, daily living skills and/or skilled therapies. Services not normally covered in the Core Benefit Package, such as home modifications, home delivered meals, center-based day health services, out-of-home respite, supplemental transportation, supplemental adaptive and assistive devices, and emergency response systems, are also included.

A. Client Population

Numbers and Distribution. On July 1, 2000, the Ohio Home Care (OHC) waiver had 6,537 persons enrolled, 517 new slots approved by HCFA and 1,024 slots that had become available due to disenrollments during FY 2000. An additional 130 slots were granted through legislative action yielding a total of 8,208 slots for FY 2001. As of February 21, 2001, 7,343 consumers were currently or had been enrolled on the Ohio Home Care waiver. Numbers of enrollees across the four OHC service regions were comparable, with approximately 1,800 to 2,500 consumers per region. All of the 1,671 slots opening up for FY 2001 were either filled or reserved. The waiting

Services Offered for Specific Populations

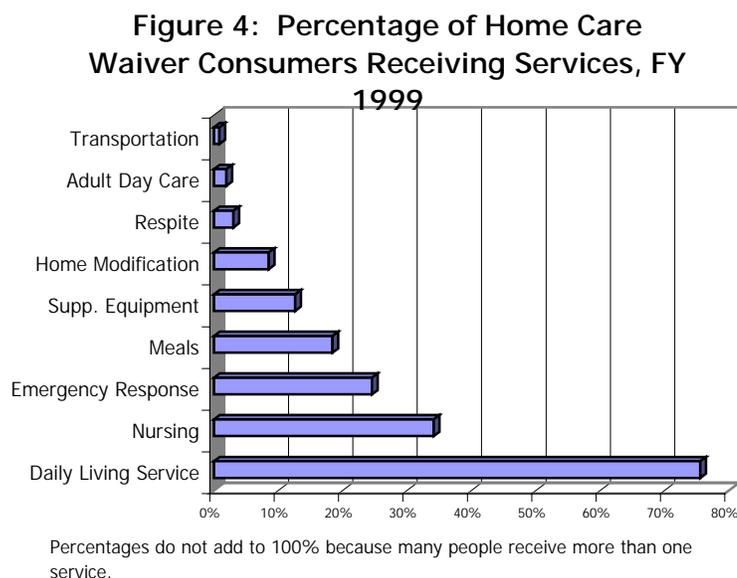
list is maintained statewide by date of application. As of February 2001, ODJFS had a total of 2,366 individuals on the OHC waiting list. Please note that the OHC Waiver slots are not filled when opened by disenrollment (e.g., death, nursing home placement) during the fiscal year.

Characteristics of Enrollees. The intent of the OHC Waiver is to avoid institutionalization through the provision of home and community-based services. Thus, each OHC Waiver enrollee must be assessed to have "level of care" requirements comparable to those of residents institutionalized in nursing facilities (NF) or hospitals. The OHC Waiver is targeted toward people under age 60 who, without waiver services, would require nursing facility level services and people of any age who, without waiver services, would require long-term care in a hospital. Characteristics of current waiver enrollees are described based on a random sample of 893 OHC/Core Plus enrollees interviewed through quality assurance reviews during the months of March-August 2000. Eighty-seven percent of the sample was enrolled in the OHC Waiver. Analyses of demographic characteristics indicated that 56% of the sample were female and 44% were male; 77% of the sample were white, 20% were African-American, and 3% were other racial/ethnic groups. The age distribution, shown below, indicates peaks in age at 10 years or less and at 50 to 60 years. Approximately 30% of enrollees were under 18 years of age.

OHC Waiver enrollees typically have multiple complex diagnoses. The most prevalent diagnoses among the quality assurance sample described above were in the ICD-9 classification of 'Diseases of the Nervous System and Sense Organs', with 62% of the sample having diagnosed conditions of this type. Within this category, the most frequently reported condition was cerebral palsy, reported for 18% of the sample. Slightly over one-third had diagnoses of "Mental Disorders", with 17% of the sample diagnosed with conditions of mental retardation or developmental delay. Other frequently occurring diagnoses included diseases of the musculoskeletal system, cerebrovascular diseases, and diabetes mellitus.

B. Services

The OHC Waiver provides nine types of services designated to assist disabled consumers to remain in the home/community setting. These services include daily living assistance (DLS) (e.g., bathing, meal preparation), skilled nursing, emergency response systems (ERS), home-delivered meals, supplementary equipment/adaptive devices, home modification, out-of-home respite, adult day care, and transportation. Needs for daily living assistance predominate within this population as shown in the following graph. Referring again to the quality assurance sample of 893 individuals enrolled on the OHC Waiver or Core Plus, over 75% required assistance with daily living and 33% required skilled nursing services. (Core Plus services are limited to Daily Living Services and Nursing). An estimated 31% required emergency response systems and 22% required home-

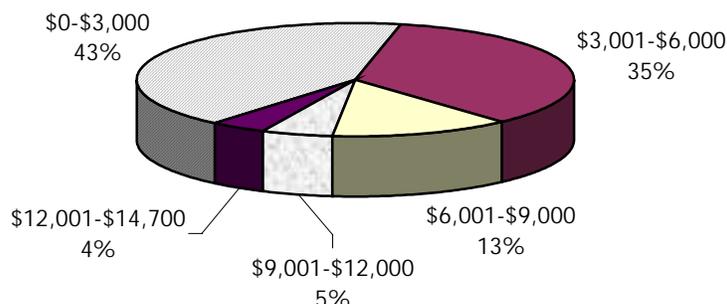


Services Offered for Specific Populations

delivered meals. The remaining OHC Waiver services were used less frequently. In some cases this was due to the absence of a service provider in the area.

Costs of Services. Monthly cost levels for services are estimated for each consumer at the time of enrollment, and updated through routine service visits and at annual recertifications, with consumer costs 'capped' within the designated range. Cost level data for the 7,343 consumers active on the OHC Waiver as of February 21, 2001, are shown below.

**Figure 5: Home Care Waiver Cost Levels
(7,343 consumers as of 2/21/01)**



C. Community Infrastructure

In order to administer the Ohio Home Care waiver program, ODJFS contracts with four Home Services Facilitation (HSF) agencies to manage the day to day operations in designated portions of the state. Each HSF agency is responsible for collecting consumer specific information to determine eligibility (e.g., functional ability, services needs, support system, and medical condition) and on-going service facilitation (e.g., case management, care coordination).

ODJFS uses the information gathered by the HSF agencies to enroll, make level of care decisions, and monitor the work of the HSF agencies through monthly quality assurance reviews. These reviews involve face-to-face interviews with a random sample of Home Care waiver consumers, interview with and chart reviews of providers involved in the care, and chart reviews of HSF agency documentation. The individual review may result in additional contact with the HSF agency work manager to resolve any outstanding issues or concerns. Collectively, the data from the review are analyzed and used to create HSF agency performance profiles related to health and safety, consumer rights, care coordination, etc.

The services covered by the Home Care waiver program are provided by independent and agency providers. Consumers can choose to receive services through: 1) the traditional service delivery method (i.e., choosing among the qualified agencies) or 2) the new, consumer directed care option (i.e., recruiting a friend or neighbor to serve as an provider of daily living services).

D. Key Chronology

In the late 1980s and early 1990s, ODHS operated several small waivers targeting specific populations. For example, from 1988 through 1993, "Waiver 2" targeted persons with AIDS who were in the hospital at the time of application. In September 1993, the AIDS waiver ended and

the consumers served on that waiver were enrolled on other programs such as the Disability and Medically Fragile waivers. The Disability waiver, which served consumers 60 years of age and under, began in July 1990 and was renewed for five years in 1993. The Technologically Dependent waiver, which began in 1989, targeted consumers under the age of 22 who required some type of technology support. In 1993, the Department renewed the waiver for five years, renamed it the Medically Fragile waiver, and revised it to target consumers of any age who have an unstable condition requiring skilled services. The Ohio Home Care waiver, which began in July 1998 and is approved for a period of three years ending June 2001, combined the Disability and Medically Fragile waivers and added consumers with medical needs who may have indications of mental retardation or development disabilities. The Ohio Home Care waiver has reached capacity this fiscal year and last.

E. Current Challenges

As interest in community based care increases, the Department faces challenges on judicial, administrative, and legislative fronts. Many different points of view and concerns must be considered in the policy making process.

Appropriate targeting of services to people with disabilities. The Department must balance emerging issues implicit in the *Olmstead* decision including how to provide community alternatives with no openings currently available on the Home Care waiver. The Department is considering developing methods to more specifically target the population to be served in the Ohio Home Care waiver, and working with other Departments to better serve consumers with needs for specific services.

How to best accomplish service coordination. Currently, consumers receiving home care services through the Core Plus and Ohio Home Care waiver benefit packages receive service coordination through contracted agencies. The Department is evaluating whether this model is delivering sufficient quality of care and ensuring health and safety in the most consumer friendly and cost effective manner.

Enhanced quality monitoring and oversight. ODJFS is charged with assuring the health and safety of the consumers enrolled in the Home Care waiver. To better accomplish this, the Department has developed a comprehensive review to monitor quality of services, performance of contracted HSF agencies, and care coordination. The review includes face-to-face interviews with consumers and providers, as well as chart reviews of providers and HSF agencies. The analysis of this data will assist the Department in decision making related to contracting and will allow the Department to enhanced quality monitoring and oversight. The Department is also pursuing a centralized computer system to allow enhanced communication with the HSF agencies and monitoring capabilities of the Home Care program.

Role of providers. Consumers and direct care providers have an important role in quality monitoring. The Department, in response to requests for rule clarification, is pursuing the development of an operational manual for providers and is also considering the development of a user friendly consumer manual. Providing information in an understandable format will allow the consumer to better understand his rights and responsibilities related to Medicaid financed home care. A provider handbook will provide valuable information for the growing number of independent providers associated with the Home Care waiver. Independent providers must have

Services Offered for Specific Populations

a clear understanding of their responsibility to be actively engaged in the consumer's care coordination.

Provider shortages. The shortages of personnel in the home care service delivery field has resulted in concerns about consumers receiving all of the services they need in order to remain healthy and safe at home. Alternatives may include exploring the feasibility of employing assistive technology to replace human help in certain circumstances.

Enhanced support for a self directed care option. As the pool of independent providers grows, so do the concerns for the health and safety of the consumers choosing a self directed care option. What, if any, enhanced support systems are needed for consumers selecting the self-directed care option? What standards must be met by those wishing to join the provider community?

State infrastructure design issues. The Department also faces legislative action at both the state and federal levels. At the federal level, the "Ticket to Work and Work Incentives Improvement Act of 1999" is intended to enable persons with disabilities to work without losing their Medicaid coverage. It also offers states the opportunity to cover groups of persons with disabilities not previously covered, to apply for grant funds for outreach or infra-structure development, to impose premiums or cost-sharing charges on a sliding scale based on income, or to develop a demonstration project to cover the working disabled.

Department of Mental Health

A. Client Population

The publicly funded mental health system in Ohio serves a diverse population, whose needs vary significantly. The majority of the approximately 254,000 persons who received services in FY 1998 required only a single episode or brief intermittent treatment. A subset of this population, severely mentally disabled (SMD) adults and severely emotionally disturbed (SED) children, account for the majority of service utilization and expenditures. While the 74,348 SMD adults and SED children served in FY 1998 represent only 30% of people served in the system, they account for approximately \$470 million in expenditures, which is 60% of the total community expenditures.

It is important to note that many seriously mentally ill persons experience long term but episodic illness. This episodic nature of their illness is quite different from the disability experienced by people with mental retardation, and many frail elderly persons. The variable course of serious mental illness is relevant to level of care issues because most psychiatric hospital admissions tend to be short (less than a week). A small number of admissions for acute stabilization of psychosis last for weeks or even months because treatment proves elusive.

The publicly funded mental health system in Ohio functions as a safety net, providing acute mental health care services for indigent persons and virtually all long term care for persons with serious disorders, since private insurance often does not cover these services.

B. Services

Publicly funded mental health services consist of the following primary components:

Inpatient: State psychiatric facilities and psychiatric units of general hospitals paid directly by the state Medicaid agency.

Outpatient: Clinical services (e.g., diagnostic assessment, counseling, etc.) provided through community mental health agencies, and also private practitioners paid Medicaid directly by the state Medicaid agency.

Community Support: Range of rehabilitative/supportive interventions, provided primarily to SMD adults and SED children.

Crisis Intervention: Crisis intervention services provided by community mental health agencies in both facility settings and through mobile crisis teams.

Housing: This component includes residential treatment and support services and housing assistance programs.

Vocational/Daily Activity: This component includes services to support clients in employment training programs and programs which provide assistance in daily activities.

C. Community Structure

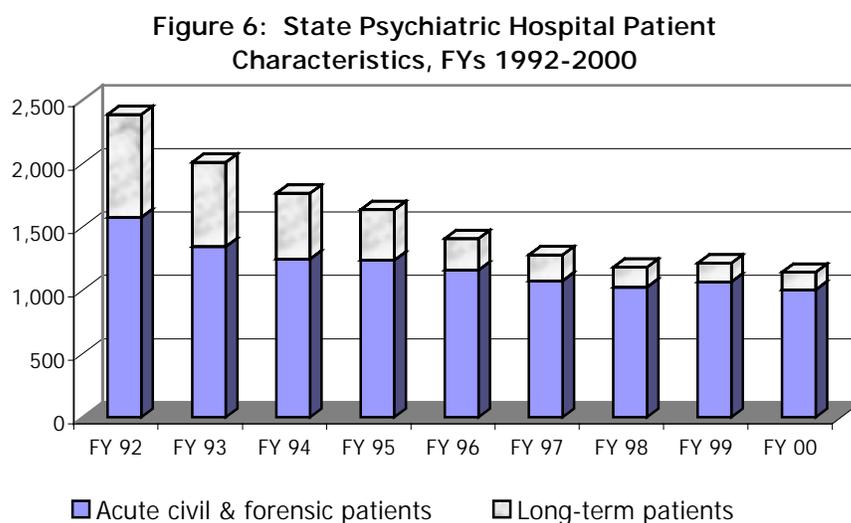
The hallmark of Ohio's publicly funded mental health system is local responsibility for mental health care. The 50 county-based Alcohol, Drug Addiction and Mental Health Services

Services Offered for Specific Populations

(ADAMH/CMH) Boards (serving Ohio's 88 counties) have responsibility for managing local systems of care. This responsibility includes the mandate to "provide a community support program" and the authority to manage essentially all public mental health funds, including Medicaid covered services provided by community mental health agencies. Boards have had instrumental Medicaid contracting responsibilities since 1982 and have had legal and financial responsibility for state hospital inpatient services since 1989 (this is discussed more extensively in the Chronology/Trends paragraph below). The boards do not provide services directly, but contract with more than 400 community mental health agencies to ensure that services are provided and coordinated effectively.

D. Chronology and Trends

Ohio has achieved dramatic results in reducing inappropriate, long term state hospitalization. From a state hospital census of over 25,000 people in the early 1950s (before the "first wave" of deinstitutionalization, and the transfer of many elderly mentally ill individuals to nursing facilities nationally following creation of the Medicaid and Medicare nursing facility benefits), Ohio public psychiatric hospital enrollment was reduced to about 4,000 persons in the early 1980s. However, many people still remained inappropriately hospitalized. Building on the concepts and values of the National Institute of Mental Health (NIMH) Community Support Program (CSP); using new Medicaid and Social Security benefits; and most critically via comprehensive state system reform, (Mental Health Act of 1988) state hospitalization levels in Ohio have been reduced to less than 1,200 individuals today. More critically, the number of non-forensic patients with a length of stay over one year has been reduced to a little less than 150 individuals (see Figure 6).



Preliminary reviews have been conducted to determine what services and supports for those persons who could be served outside an institutional setting or those persons critically underserved in community settings who are at continuous risk of institutional care (either public hospitals or jails). Preliminary findings of this review indicate that of the approximate 11,600 adults with the most severe and persistent forms of mental illness: 1) more than 100 severely mentally disabled adults remain hospitalized for long periods of time (i.e. greater than six months) who could more appropriately be served in community settings if intensive services and housing supports were made available; 2) approximately 300 severely mentally disabled adults residing in adult care facilities for long periods of time could be more appropriately served in a community based setting if intensive services and housing supports were made available (recent reforms regarding adult care facilities may also make these settings less available for mentally ill

Services Offered for Specific Populations

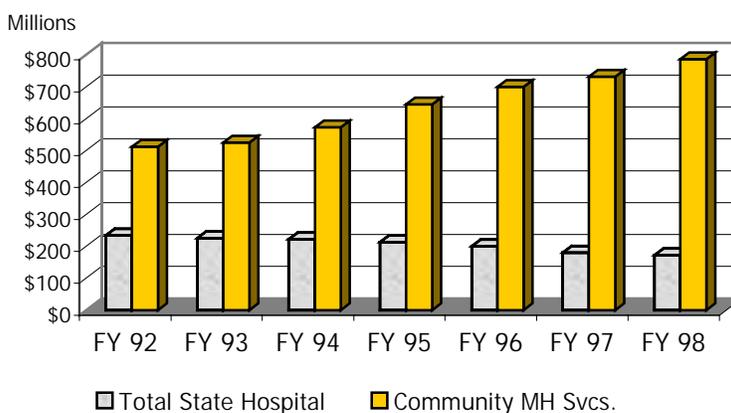
residents; and 3) of the remainder of the "most in need" population, we estimate approximately one-third, or 3,700 persons, are not adequately served in the current community mental health system. This estimate is based on analysis of state hospital data, ODJFS hospital data (Medicaid paid hospitalizations), and Multi-Agency Community Services Information System (MACSIS) data. The estimates rely on indicators related to frequency of psychiatric hospitalizations and crisis episodes in an annual period. Deficiencies exist in the community system in clinical and rehabilitative services as well as specialized housing supports needed by these persons.

There is considerable evidence that the combination of low institutional use, a flat mental health budget, and other forces are causing increased community problems for people with serious mental illness. Employment levels for SMD consumers are below 10%, so most rely on SSI, family or friends. Rental rates are rising faster than SSI payments, which are just over \$500 per month. There is a dramatic increase in the number of mentally ill persons in jails, prisons, and alternative housing programs such as Adult Care Facilities. [Additionally, there is considerable anecdotal evidence that deficiencies in community housing, treatment, and supervision for adults who are mentally ill are contributing factors to the substantial increase in mentally ill prison inmates in Ohio.] Currently, about 4,600 of Ohio's 45,000 plus prison inmates are severely mentally ill. Providing needed prison care has led to increased mental health expenditures by the Ohio Department of Rehabilitation and Correction.

The most important aspect of Ohio's mental health reform is not the state's success in reducing hospitalizations, but progress in expanding and transforming community care. The real success is in the renewed opportunities and enhanced living that many formerly hospitalized individuals have achieved. A broad range of community mental health services has been essential in this process. First, the amount of services has expanded greatly over the past decade, funded primarily through state hospital revenue transferred to boards to fund community services rather through increased state spending.

Federal matching funds for board contracted services covered by Medicaid have played a significant role in funding community service expansion as well. Community mental health expenditures for board contracted community mental health agencies more than doubled in the period from fiscal year 1990 to

Figure 7: Mental Health Community and State Hospital Expenditures, FYs 1992-1998



fiscal year 1998, increasing from approximately \$389 million to approximately \$786 million. Ohio's spending on state psychiatric hospitals is significantly lower than the national average. Ohio expenditures of \$17 per capita in 1998 for state psychiatric hospitals were 40% below the national average (\$28). Growth in community mental health funding in the common timeframe used for the graphs in this report was almost 60% (see Figure 7). Of special note is the growth in numbers of SMD adults and SED children served in the community mental health system over

Services Offered for Specific Populations

the period, an increase of approximately 88%. This increase in services was needed to meet the needs of discharged patients, to “catch up” with the effects of past deinstitutionalization, and to meet escalating community need. Now that state hospital downsizing is completed, resource reallocation is no longer possible. Tensions regarding the adequacy of community care are escalating. To compound the problem, the number of psychiatric treatment units in general hospitals has been declining. It is interesting to note that in the most recent national mental health funding study in 1997, Ohio’s per capita spending of \$51.76 is significantly lower than the national average of \$64.31, and places Ohio 29th among the 50 states in mental health spending.

Secondly, the mix of services has changed dramatically over the past decade. State and local funding partners now spend a great deal more to help a person with mental illness live in the community with strong supports, rather than to intervene only after a crisis. This change in mix reflects how essential a broad range of services is to establishing effective community treatment networks. Figure 8 shows the expenditure amounts for the primary components of the public mental health system (which includes inpatient and outpatient services paid directly by the state Medicaid agency and also described in B above) and the percentage of total expenditures each component represents.

Figure 8: Expenditures for Primary Components of the Public Mental Health System

	FY 90	% Total	FY 97	% Total
Inpatient	\$287 m	47%	\$255 m	25%
Outpatient	\$130 m	21%	\$239 m	24%
Community Support	\$50 m	8%	\$163 m	16%
Crisis Intervention	\$12 m	2%	\$34 m	3%
Housing	\$35 m	6%	\$96 m	10%
Vocational/Daily Activity	\$37 m	6%	\$82 m	8%
Other	\$63 m	10%	\$136 m	14%
TOTAL	\$614 m	100%	\$1,005 m	100%

E. Current Challenges

Ohio’s mental health system is at a different stage of development than the other human service systems profiled in this report. A comprehensive restructuring of the system occurred in the 1990s as the result of broad scope mental health reform legislation passed in the late 1980s. The legislation established a single fixed local point of responsibility (i.e. ADAMH/CMH Boards) for all publicly funded mental health services so that: a) placement of institutional resources, other state/federal/local funding streams, and client placement in state hospitals are under local control, so that there is no “back door access” to expensive institutional beds, and no financial incentive for long term institutionalization, which is the major budget-buster in all long term care/support systems; and b) access to community services can be locally planned and coordinated with the consumers and their families. The results of this restructuring include a substantial increase in the amount of mental health services provided in community settings, as well as changes in service mix, and a corresponding decrease in use of state institutions.

While the structural reform of Ohio’s mental health system has been successful in many respects, three broad problems have emerged as this process has run its course.

Progress is incomplete.

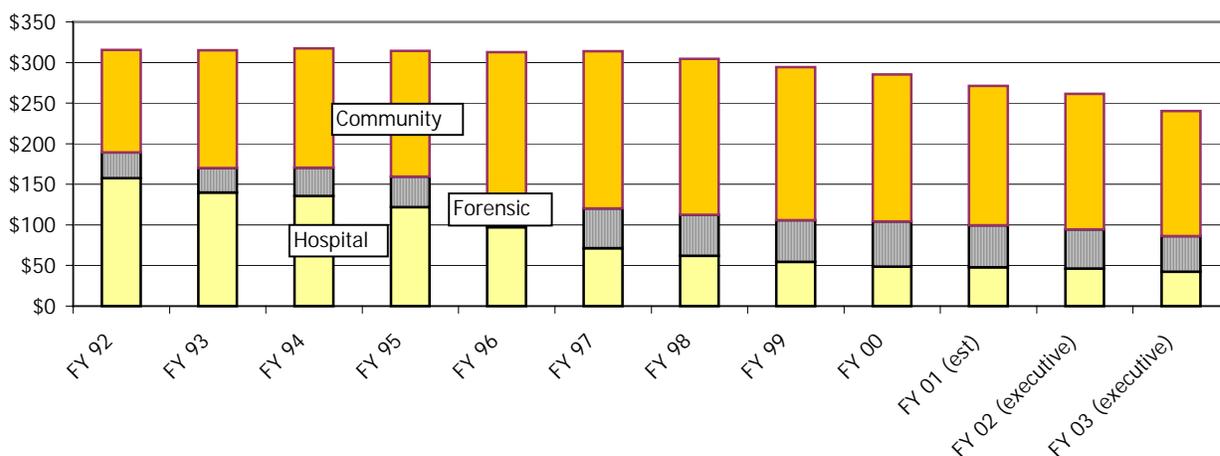
- Some individuals with a serious mental illness remain either inappropriately institutionalized or homeless and without access to services or housing.
- Many persons with a serious mental illness, though not subject to institutionalization, have only marginal levels of services and do not have true access to community life (employment, health care, school success for children).

The process of structural reform has improved service access, efficiency and appropriateness, but has not assured quality, accountability and cost control.

- No consistent system for assessing outcomes is yet in place.
- Research-validated (evidence-based) practices are used inconsistently.
- The Medicaid component of locally managed mental health care (Community Medicaid) is not subject to cost controls although all other aspects of local programs are limited to available state, federal and local funds. Therefore, Medicaid match requirements are beginning to “eat up” resources needed for services and individuals that are not Medicaid covered.

The mental health system has not been able to cope with an expansion of community needs and demands. Part of the problem is that General Revenue Fund (GRF) funding for ODMH has decreased relative to inflation in the past decade. Part of the problem is that reallocation of institutional resources toward community care has already been completed in mental health compared to other systems, so that, possibly unlike other systems with high levels of institutional care, resources from institutional realignment in mental health are not available to meet expanding community needs. Trends in GRF funding for ODMH community, hospital, and forensic costs are illustrated in Figure 9. It is important to note that local mental health levy trends have been virtually flat, as well.

**Figure 9: DMH GRF Budget Trends, FY 1992-2003
(1990 Dollars, in Millions)**



Services Offered for Specific Populations

In the face of no revenue growth, needs for mental health care are increasing. The demand for services to clients is expanding, and there is increased recognition of the impact of mental illness in other health, human services, law enforcement, and education systems:

- Disability: Recent reports from The World Health Organization find that mental disorders cause more disability world-wide than any other set of illnesses. Disability due to mental disorder is the fastest growing category in federal disability payments. In the business world, mental illness is the fastest growing cause of short term disability cost increases.
- Health care: Costs driven by mental illness are increasing within health care (e.g., formulary costs, and higher rates of death and disability due to depression in cardiac, cancer, and stroke patients).
- Welfare Reform: As welfare reform proceeds, a high proportion of the hardest-to-employ in national samples have depression and other mental disorders that are emerging as core problems in attaining independence.
- Employment Services: Mentally ill individuals are the largest category of persons entering the vocational rehabilitation system nationally, yet have worse outcomes than any other disability group. Compounding this problem in Ohio is the fact that the rehabilitation Services Commission has announced that it will terminate all specialty mental health rehabilitation programs within the next three years.
- Schools: The demand for mental health services for school children is increasing, partly in relation to “zero tolerance” policies that impact disproportionately on students with behavioral disorders, and partly due to an increased recognition that behavioral disorders cause serious obstacles to learning. Nationally, only 41% of students with identified emotional disabilities graduate from high school.
- Law enforcement, courts and corrections: The impact of mental illness in the adult and juvenile correctional systems is growing. Expenditures for mental health care in state prisons have increased by over \$50 million in the past few years. The Department of Justice, in a 1999 report, finds mental illness increasing as a problem in both prisons and jails. A majority of juveniles in DYS custody have significant mental disorders.
- Public Children Services: In the past several years, the demand for mental health treatment for children and adolescents served by Public Children Services Agencies has increased substantially. This increased demand is creating financial stress in a number of board areas.

All of these forces are aligning to increase the demand for mental health services, and create pressure on local mental health systems to respond, within essentially fixed budgets.

Pressure on the public mental health system from external forces is increasing.

- Unlike some areas of long-term care (e.g., MR/DD) but like care for the elderly, mental health needs are met through both private and public resources. A majority of individuals have access to some mental health care through their group health insurance. However, while market trends regarding elder long term care appear to be shifting away from nursing homes, there is an increased cost shift toward the public sector in mental health. Mental health expenditures, especially in the private sector, are declining as a percentage of health expenditures, largely due to managed care limitations, but also due to apparent “disenrollment” of mentally ill individuals from health plans. These pressures are compounded by the fact that Medicaid does not cover institutional long term care in mental health facilities (compared to ICFs/MR and nursing facilities).

Services Offered for Specific Populations

- For mentally ill individuals who are disabled, access to safe and affordable housing is the cornerstone of recovery. This access is being dramatically reduced. Tens of thousands of units of low income housing constructed with federal assistance years ago have reached the end of their subsidized contracts/obligations and are being converted to market rate housing. More of these low income housing contracts are expiring in Ohio than in any state. The federal government has phased back a number of housing programs that target the disabled and reduced the number of units of new of publicly subsidized housing. Additionally, the availability of federal Section 8 vouchers has slowed. The healthy economy has contributed to increasing rental rates, but not to production of very low income housing. The threat of homelessness is increasing for the seriously mentally ill. Additionally, an increased number of mentally ill individuals are being placed in subsidized but not-always-appropriate facilities (e.g., Adult Care Facilities). Statutory/regulatory requirements to address the appropriateness of these facilities increase the chance that these placements may be terminated or may not be available to mentally ill consumers in the future.
- The mandate to standardize and computerize health care transactions enacted in the Health Care Portability and Accountability of 1996 (HIPAA) will ripple throughout Ohio's mental health system. HIPAA's impact—far greater on health care than the impact of Y2K—will be throughout the state funded system, demanding substantial investments within the next few years.

Federal requirements in three key programs impede state and local reform efforts.

Medicaid

- Medicaid finances about 40% of mental health care in many states, but mental health is a minor consideration in Medicaid (3-5% of costs). Compared to basic health care or services for people with mental retardation, mental health fares poorly in Medicaid. Medicaid will not pay for free-standing psychiatric hospitals or mental health residential facilities under a long-standing federal "IMD exclusion" though comparable services for mentally retarded people are 100% covered. More critically, this means that flexible home- and community-based services waivers are not feasible in mental health. This discriminatory exclusion must be eliminated.
- Increased payment and services flexibility is urgently needed. Waivers that facilitate good mental health care are still too bureaucratic and hard to obtain.
- There is a need for more flexibility that recognizes the role of local models in mental health and facilitates integration of Medicaid with state/local funds.

Housing and Urban Development (HUD)

- Reduced HUD funding, cutbacks and a poor focus on disability housing, and increasing local housing authority control have greatly reduced housing access for many mentally ill consumers.
- HUD should reprioritize housing for the poorest disabled individuals through leadership, technical assistance, and a focus on this population.
- Disincentives to work (through increased rent contributions as soon as people obtain work) should be reduced, as Social Security has done.

Services Offered for Specific Populations

Vocational Rehabilitation

- Mentally ill individuals fare poorly under the "one size fits all" rehabilitation model, resulting in increased unemployment, disability and dependency.
- Vocational Rehabilitation's orientation to short term placements and case closures should be reexamined to allow flexible, low cost continued supports.
- National leadership for mental health rehabilitation is needed in vocational rehabilitation, since mentally ill individuals are the largest group using vocational rehabilitation services, and since they have worse employment outcomes than any disability group.

Department of Mental Retardation & Developmental Disabilities

A. Client Population

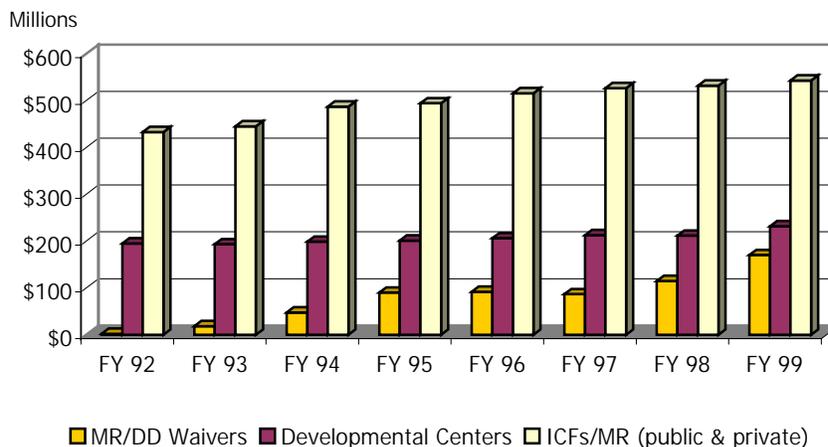
Numbers and Distribution. After World War II advances in medicine led to increased life spans for persons with mental retardation. While the majority of adults who receive services live with family members, by FY 1998 there were nearly 12,000 people receiving services in either institutional settings or through home and community based waivers. Four thousand of these individuals received waiver services, representing 100% growth in the number of persons served by the waiver between FY 1993 and FY 1996. An additional 3,000 people received state- and locally-funded supported living services in the community in FY 1999.

Severity of Condition. The MR/DD system that developed over the last several decades originally provided services for persons with mild, moderate, severe and profound mental retardation. In 1989 a functional definition of developmental disability extended services to individuals with other developmental disabilities such as cerebral palsy and epilepsy, when the individual's disability limits functioning in major life areas. Under the current definition, many individuals with mild mental retardation are not eligible for services, unless they were already receiving services at the time the definition was changed. Both people living in institutions and those receiving Medicaid waiver services must have an ICF/MR "level of care", indicating that the person requires institutional services or comparable community services. As the number of people living in state-operated developmental centers has declined over the past decade, the people remaining in those centers increasingly tend to be individuals with challenging behavior and/or with criminal justice involvement.

B. Services

Services Received. The MR/DD system provides a wide array of services, including early intervention, education, family support, habilitation, therapies, employment services for adults, and a variety of residential options. Eligible individuals typically require ongoing, intensive support with personal care such as bathing and toileting, daily living activities such as shopping and budgeting, and coordination with medical care and specialty services such as psychology, occupational therapy, and physical therapy.

Figure 10: Institutional & Waiver Expenditures, FYs 92-99



Services Offered for Specific Populations

Cost of Services. Investments in Medicaid home and community based waiver services have grown dramatically during the 1990s from \$2.3 million in FY 1992 to \$170 million in FY 1999. A large share of that growth came from the addition of the Residential Facility Waiver in FY 1998. The cost of waiver services must, on average, be lower than the cost of ICF/MR services.

Average Length of Time. Because developmental disabilities by definition begin during childhood and are expected to persist throughout life, services are generally lifelong, often beginning with early intervention for infants and toddlers and continuing through old age.

C. Community Structure

County boards of MR/DD, created in 1967 by HB 169, are an integral part of the community service system. In 1980, SB 160 redefined and expanded county board responsibilities, giving boards mandates to plan for local services and to monitor the quality of those services. At last count (October 1999), county boards were serving 54,400 Ohioans with MR/DD. In 1998 county boards across the state received local tax support totaling \$546 million. This amount offsets half of the cost of community residential services the boards provide and represents a significant increase from the \$292 million raised by local levies in 1990.

Residential services which encompass HCFA's waiver services and supported living are provided exclusively by private organizations that enter into contracts with county boards. The majority of ICF/MR services in Ohio are also provided by private agencies. Many supported employment and specialized therapy services are also provided by private organizations through contractual arrangements with county MR/DD boards.

Both county boards of MR/DD and private providers are regulated by ODMR/DD, which since 1980 has been a cabinet-level state department. ODMR/DD also operates developmental centers, which provide services for nearly 2,000 adults.

D. Key Chronology

The history of services for persons with MR/DD in Ohio demonstrates steady progress away from segregation of people with mental retardation in large institutions toward community integration. Nearly every service model used in the past twenty years continues to be present. While facility-based service approaches remain, new approaches have given some people the opportunity to make new choices and to find new roles.

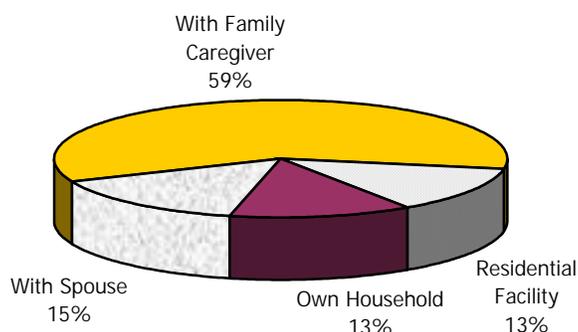
In 1963, there were 9,750 individuals in state MR/DD institutions. At that time, the President's Panel on Mental Retardation, formed in 1963, led to a greater public awareness of the plight of persons with mental retardation. The 1970s and the early 1980s was the era of deinstitutionalization in Ohio. In 1977, nearly 7,000 people with MR/DD lived in state institutions. By the end of the decade the number had dropped to 6,140. Public and private organizations used the new funding available through Purchase of Services, created in 1971 by SB 761, to develop group homes in communities throughout the state, and in 1977, SB 71 established a licensing system for residential facilities. In the 1980s, Orient Developmental Center closed as a result of continued downsizing of public institutions.

Services Offered for Specific Populations

During the late 1970s and early 1980s, Ohio's experiences with early intervention, family support, supported employment, inclusive education, and supported living prepared more people for the challenges of supporting people in integrated settings. In 1983, HB 291 established Family Resource Services, with the intent of preventing institutionalization. Families were able to receive financial assistance for respite, home modifications, adaptive equipment, special diets, training and counseling to help them keep a family member with MR/DD at home. Early experiments with supported living allowed some people to leave group homes for more individualized living arrangements in houses and apartments they owned or rented, with support from paid providers. In 1989 HB 257 established Supported Living Services in statute, and in 1990 the state capital budget included housing funds for persons with MR/DD. By 1984 the number of persons with MR/DD living in state institutions was under 3,500, and by 1985 Ohio's public spending for smaller community based residential services overtook spending for large congregate residential settings. During the 1980s heightened scrutiny of nursing home placements for persons with MR/DD led to evaluation of persons with MR/DD living in nursing facilities and the relocation of many to community residences. ODMR/DD closed Broadview Developmental Center in 1993.

The movement toward community based services gathered momentum in the late 1990s. Initiatives on person-centered planning and self-determination gave people new tools to convert from facility-centered to person-centered models. Support grew for the notion that people with MR/DD should be able to live, learn, work and play in their communities in ways that make sense to them, using public dollars in more effective ways. In the 1990s, limited state and local funding for community services increased pressure to bring in Medicaid dollars to create more living options for people with MR/DD. The Individual Options home and community based services waiver, established in 1991, made it possible for more people to live in their own homes, with paid support. Developmental center populations continued to decline, from 2,359 in FY 1992 to 2,004 in FY 1998. At the same time, waiver-funded support for people living in the community grew from 420 people in FY 1992 to 4,093 people in FY 1998, including in FY 1998 people living in group homes with financial support from the Medicaid-funded Residential Facility Waiver (RFW.) An additional 1,541 people were living in group homes with state funding.

Figure 11: Americans with Developmental Disabilities by Living Arrangement: 1998



Estimated Population: 3.24 million

Services Offered for Specific Populations

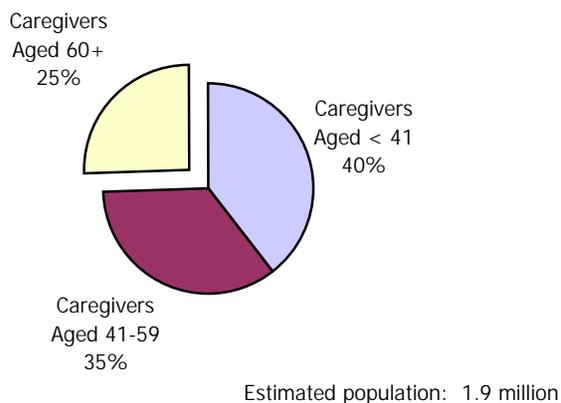
E. Current Challenges

In 1999, HCFA conducted a review of the RFW and issued a report finding a number of problems to be corrected. ODMR/DD and ODJFS, with participation of other key stakeholders, are currently addressing those problems, in preparation for extension of the RFW and eventual expansion of waiver capacity. A detailed discussion of current MR/DD Medicaid reform efforts is contained in Section VII, FY 2002-2003 Executive Budget.

The 1989 *Martin* case, a case which challenges the use of waiting lists, is still in process.

Determining the extent of the need for residential services for those who are waiting and addressing that unmet need is a pressing challenge. There are over 4,500 people with MR/DD living at home with aging caregivers in Ohio. As these family members age, many of the consumers will face crisis and will need emergency services. There are over 6,500 people currently on waiting lists who have indicated that they are in need of residential services and are not currently receiving them.

Figure 12: Americans with Developmental Disabilities Living with Family Caregivers: 1998



ODMR/DD is reassessing all personnel and service costs in the state-operated Developmental Centers to ensure that these services are delivered cost effectively and without compromising quality. This reassessment is part of the continuing effort to balance the state's investment in institutions and the state's investments to improve and expand community based care. The Department will also seek to improve access to available Medicaid reimbursement in both the Developmental Centers and the community.

Department of Aging

The Ohio Department of Aging is responsible for the management of many different programs that are designed to positively benefit and impact the lives of Ohio's elders (defined as those age 60 and over). While the Department's programs include many diverse activities, principal funding for home and community-based services is made up of four different funding streams:

- Medicaid (through PASSPORT).
- The Older Americans Act (federal funds for which the Department is the designated state agency).
- Residential State Supplement program (state supplemental funding to allow those age 18 and over to live in group settings such as residential care facilities, adult care facilities, and adult foster care homes).
- State GRF funding through the Senior Community Services Block Grant.

PASSPORT is Ohio's home and community-based services (HCBS) Medicaid waiver for Ohioans age 60 and over who would otherwise qualify for Medicaid-reimbursed nursing home placement. While PASSPORT began as a demonstration project in two areas of the state, the program was expanded statewide in 1990.

The goal of the PASSPORT program is to delay unnecessary and unwanted utilization of institutional long-term care services (e.g., nursing homes) by older Ohioans.

Unlike Ohio's other Medicaid waiver programs, PASSPORT has been continuously open for new client enrollment since 1994. Thus, no waiting list exists for prospective new clients. The PASSPORT waiver was renewed for an additional five years by the Health Care Financing Administration in 1998.

The Older Americans Act (federal) and the Senior Community Services Block Grant (state) provide substantial funding for community-based services, especially nutrition services, transportation, and in-home services. Funding is allocated by a population-based formula to each of Ohio's twelve area agencies on aging. Services are provided to older Ohioans without regard to their income (e.g., eligibility is not means tested). Because of this, service participants tend not to be eligible for services through PASSPORT, which is, like other Medicaid programs, means tested.

Funding through the Older Americans Act has been static (just under \$40 Million per year) for over a decade, yet the need for services has grown. This reality has led over half of Ohio's counties to propose and pass special property tax levies for senior services. The size of these county levy programs varies greatly, but in both Franklin and Hamilton counties, these levies generate \$15 million annually. Levy funds in those counties and others is used to fund a care-coordinated system of home and community-based services to those older persons who do not qualify for PASSPORT.

Services Offered for Specific Populations

The Residential State Supplement (RSS) program provides an income subsidy to very low income persons age 18 and older to allow these individuals to reside in less restrictive settings than a nursing facility – including residential care facilities, adult care facilities, and adult foster care homes (the distinction is largely one of size of the facility). In addition to the subsidy, RSS participants receive a Medicaid card to cover their health care needs and are assigned a case manager by the PASSPORT administrative agency.

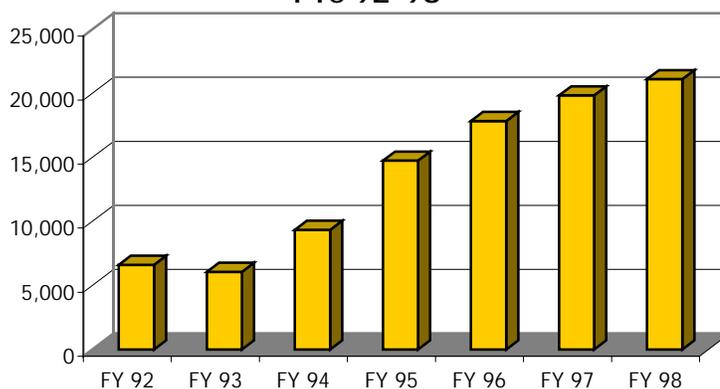
A. Client Population

PASSPORT. To be eligible for PASSPORT, prospective clients must:

- Be age 60 or over.
- Be Medicaid eligible. As part of the PASSPORT waiver, prospective clients must meet a “special income” test, meaning that the individual’s income may not exceed 300% of the Supplemental Security Income (SSI) standard of need. This amount is currently just over \$1500 per month. PASSPORT-eligible clients must have liquid assets of less than \$1500. Special assets and income rules that are applied to nursing home residents with spouses are also applied to PASSPORT clients. PASSPORT clients are subject to estate recovery provisions also.
- Be frail enough to require a nursing home level of care.
- Be able to remain safely at home with the consent of a physician.
- Have a care plan where the total cost does not exceed 50% of the cost of nursing home care over a twelve month period.

PASSPORT annual enrollment has grown from 6,594 in FY 1992 to 22,720 in FY 2000. The current daily census is 17,110. Each month, there are approximately 630 new PASSPORT enrollments, and about 3.15% of participants leave PASSPORT each month. Of those exiting PASSPORT, approximately 50% go to a nursing home, 29% die, and the remainder are disenrolled – either because they no longer need in-home services or because they no longer meet eligibility requirements.

Figure 13: People Served by PASSPORT, FYs 92-98



PASSPORT clients remain in the program an average of thirty months, but this statistic is deceiving. Mimicking a trend first observed in nursing homes, there are two very different groups of PASSPORT clients. One group is made up of those requiring short-term post-hospital care and another group is made up of those who are on the program for a much longer period of

Services Offered for Specific Populations

time. This is to be expected since PASSPORT eligibility is designed to mirror nursing home eligibility. The average age of PASSPORT clients is 77.6 years of age. Better than 80% of participants are female. Almost 30% are minorities.

PASSPORT clients, on average, need hands-on assistance with 3.2 activities of daily living (ADLs) such as bathing, dressing, transferring toileting, and eating. About 1/3 need assistance with four or more ADLs. Impairment levels of PASSPORT clients have increased over the last five years – again reflecting a trend that is also observable in the nursing home population.

On average PASSPORT clients need assistance with almost all of the Instrumental Activities of Daily Living (IADLs) such as shopping assistance, meal preparation, transportation, medication administration, and money management.

While the current “cost cap” for PASSPORT clients is set at 50% of the cost of nursing home care over a twelve month period, in practice, the average PASSPORT client receives a package of services costing \$690 per month in FY 2000.

Residential State Supplement (RSS.) To be eligible for RSS, prospective participants must:

- Be age 18 or over.
- Have incomes that are at or below \$850 per month.
- Reside in an “approved living arrangement” (residential care facilities, adult care facilities, or adult foster care homes).

The General Assembly has capped the number of RSS participants at 2,800 at any given time and the program has reached this level. New participants may be added when an existing participant leaves the RSS program. This has resulted in a “waiting list” for RSS of approximately 1,000 individuals statewide.

RSS participants may be younger than for either PASSPORT or Older Americans Act program participants. These clients present a very different picture than the Department's other clients. Currently 60% of all RSS clients are under age 60. Of this group, 70% have indications of chronic mental illness.

Eligibility for Older Americans Act (OAA) and Senior Community Services block grant-funded (SCSBG) programs is not means tested. Funding from these sources, as well as some county levy funds, are used to provide services to those who do not meet the more stringent eligibility requirements of PASSPORT. The intensity of service is also lower than for PASSPORT clients. Through Older Americans Act and Senior Community Services Block Grant funds, in 1998, 38,488 individuals received home-delivered meals. Approximately 19,200 received other in-home services equivalent to those provided by PASSPORT - homemaker, personal care, adult day service, or home repair services. Because these programs under Older Americans Act and Senior Community Services Block Grant are not entitlement programs, participation is limited to available funding. Therefore, waiting lists for some services such as home delivered meals and home repairs do exist. For services such as transportation, no waiting list is kept due to the episodic nature of the service.

Services Offered for Specific Populations

B. Services Provided

Each PASSPORT client has an individualized plan of care based on the needs and preferences of the individual client. Eligible services are personal care, homemaker, adult day services, home-delivered meals, minor home modifications, social work/counseling, emergency response systems, chore service, medical equipment, adaptive and assistive equipment, and medical transportation. A relatively recent addition to this package of services is independent living assistance, designed to assist PASSPORT clients with bill paying and other instrumental activities of daily living.

More than 89% of PASSPORT clients receive personal care, and 76.7% of all PASSPORT expenditures are for either personal care or homemaker services. In addition to the special package of services for which PASSPORT clients are eligible, PASSPORT clients also receive a Medicaid card entitling them to services under the traditional state Medicaid plan. The most-often used traditional benefit, not surprisingly, is the prescription drug benefit, though some PASSPORT clients also receive some skilled nursing assistance in the home in addition to personal care assistance with ADL needs.

RSS clients receive an income subsidy that is used for room, board, and some minimal level of personal care if required by the client. In addition, those on RSS receive case management services and a Medicaid card that can be used to provide other traditional state Medicaid plan services such as prescription drugs. Many RSS clients may also receive some mental health services through county boards.

The Older Americans Act and Senior Community Services Block Grant provide many of the same services provided by PASSPORT. Older Americans Act funds are also used to provide congregate meals, transportation, information and referral, legal, and ombudsman services to older Ohioans.

C. Community Structure

Administratively, the Ohio Department of Aging has contracted with the Ohio Department of Job and Family Services, to operationally manage PASSPORT and RSS. At the local level, PASSPORT and RSS enrollment and ongoing care management are the responsibility of thirteen PASSPORT Administrative Agencies (of these, twelve are Area Agencies on Aging with administrative responsibility for oversight of federal Older Americans Act programming and one is one of the original demonstration projects from 1984). The PAAs are also responsible for nursing home preadmission review as delegated by the state Medicaid agency. In turn, the PAAs contract with local service providers such as home health agencies, adult day care centers, senior centers, and others to actually provide the services. No PAA may provide a PASSPORT service directly.

The Department distributes Older Americans Act and Senior Community Services Block Grant funds to each of Ohio's twelve area agencies on aging. AAAs determine what services are needed in their area of the state, competitively select service providers (rarely, some services such as information and referral are provided directly by the AAA), and the level of annual funding available for each funded service. For some clients with a need for multiple services (usually those with more than \$1,500 in liquid assets which disqualifies them from PASSPORT), the AAA may provide case management services to coordinate the care and supports received by the participant.

D. Current Challenges

A clear challenge for PASSPORT and state long-term care policy is that 50% of all PASSPORT clients eventually go to a nursing home. While for some, this may be due to physical deterioration, more often, the move to nursing home care is precipitated by a breakdown in the informal care giving system of relatives, neighbors, and friends. For this reason, many states now cover assisted living facilities as a Medicaid waiver service (usually with a separate Medicaid waiver). While in the past Ohio has considered such an option, the state does not currently support publicly funded assisted living. Thus, consumers are forced to choose either nursing home care or home care, without an option somewhere “in between.” In that sense, truly free choice for Ohio’s elders is not achieved through PASSPORT.

A challenge faced by Ohio’s entire long-term care system is the shortage of staff (especially paraprofessionals) available to provide in-home care – a byproduct of a “full employment” economy. While seemingly unrelated to the pressure brought on the state by the *Olmstead* decision, current experiments toward self-directed care driven by worker shortages are completely consistent with the philosophy of that case.

Participation by new clients in RSS is limited by the fact that an existing client must leave the program before a new client can be added. This has resulted in a waiting list for the RSS program of approximately 1,000 individuals statewide.

Participation of older Ohioans in Older Americans Act and Senior Community Services Block Grant funded programs (as well as county levy funded programs) is limited now by the availability of funding.

The natural growth of the PASSPORT program will require that the current PASSPORT waiver be amended to add additional capacity to the waiver.

Services Offered for Specific Populations

Ohio Department of Health

The Ohio Department of Health (ODH) implements program activities with monies received through close to 150 different funding streams. These programs fall into one of two categories: (1) those that result in the reduced severity of a disease which might otherwise lead to institutionalization of affected individuals; and, (2) those that allow affected individuals to remain in a less restrictive environment by virtue of community-based support services

The Bureau for Children with Medical Handicaps

The Bureau for Children with Medical Handicaps (BCMh), established more than 80 years ago, provides health care and coordination services to eligible children with special health care needs (CSHCN) and their families. Since the late 1980s, BCMh has emphasized services for children which are family-centered community-based, coordinated and culturally competent. During FY 1999, the Bureau served 32,534 children, families and adults through its diagnostic, treatment and service coordination efforts at a total cost of \$21 million.

Children with special health needs served through the BCMh usually have chronic health conditions that require a variety of services. In some instances the complexity of the medical condition (quadriplegia, muscular dystrophy, spina bifida, cerebral palsy, etc) combined with the multiple systems that serve these children overwhelm the families and create situations that could result in the need for these children to be placed in institutional settings. Team service coordinators and public health nurses located in local health departments assist families in locating resources which allow them to care for their children in their home. Part of this work occurs through the Family Stability Fund of the Family and Children First Council to prevent out of home placement of children.

The coordination functions, delivered by local public health nurses and team service coordinators (master's prepared nurses and social workers), consist of the following:

- Assessment of the child's and family's needs
- In conjunction with the family, developing a plan to meet the needs, including a crisis plan
- Assuring that the family has the needed resources and supports to follow through with the plan
- Monitoring the child's and family's response to interventions in the plan, modifying the plan as necessary
- Communicating with others involved in serving the child and family to assure understanding and pursuance of common goals.

In the future, the availability of qualified public health nurses (PHNs) is likely to be a challenge. Additionally, both the public health nurses and team service coordinators will need updated information and skills.

AIDS Client Resources Title II Ryan White Programs

The AIDS Client Resources Section's Title II Ryan White Programs provide services to Ohioans living with HIV/AIDS. All five program components are focused on assisting these individuals in maintaining optimal health and the highest level of functioning possible. The HIV Case

Services Offered for Specific Populations

Management Community based program provides persons living with HIV/AIDS with a case manager to work with them to assess issues and provide community referrals. The HIV Case Managers work closely with their clients to ensure they are linked with health care providers and services such as nutrition, housing and additional financial assistance. HIV Case Management services can be linked to decreased emergency room visits by the HIV/AIDS population and increased follow-through with primary health care needs and adherence to medication regimes.

The Ohio Home Care Waiver, which began in 1998, combined the Disability and Medically Fragile Waivers and provided an additional 2,000 slots. HIV+ clients who are eligible for the Home Care Waiver continue to be referred to this program through the HIV Case Managers funded by the Ohio Department of Health. Approximately 4,500 individuals with HIV receive case management services.

The HIV Drug Program provides assistance with HIV medications to approximately 1,500 HIV+ Ohioans who are financially eligible. The HIV medications have proven to provide many individuals with a higher level of functioning and independence in the community. HIV/AIDS death rates have dropped dramatically since the introduction of protease inhibitors. The Emergency Financial Assistance Program assists those with HIV-related emergencies so that they may remain in the home. Approximately 3500 individuals utilize this program. The Health Insurance Premium Payment Program provides payment of insurance premiums for those who already have a policy. Approximately 150 people benefit from this program. The Home Health Program provides services to help people with HIV remain in their home or prevent hospitalization. Approximately 15 people utilize this program. The total expenditures for these five programs are \$17,306,342 per year.

Ohio Black Lung Clinics Program

For 22 years, ODH has funded The Ohio Black Lung Clinics Program through an annual grant of \$400,000 from the Department of Health and Human Services. This program funds four pulmonary rehabilitation clinics that assist coal miners and others living with chronic obstructive lung disease. The rehabilitation programs emphasize physical reconditioning with medical education, nutrition counseling and social support programs. In 1999, the Ohio Black Lung Clinics Program provided services to 2,257 medical users including 1,298 active and retired coal miners at a cost of \$390,000.

Newborn Metabolic Screening Program

Since the 1970s, the ODH has conducted screening of all newborn infants for a number of metabolic diseases. Two of these diseases, hypothyroidism and phenylketonuria (PKU), lead to profound mental retardation if not identified and treated within a few weeks of life. Sixty-three infants were diagnosed in 1999 with one of these two diseases. Individuals with PKU require a special formula, which is also provided through the ODH.

Early Intervention

Ohio's Early Intervention Program has been a national leader in identifying children with developmental delay. The Ohio Department of Health has the responsibility for children ages birth to three years of age. Networks of providers have been formed in every Ohio county to identify affected infants and children, and refer them for assessment and an individualized family treatment plan and follow-up services included in that plan. In FY 1999, 11,454 individuals were served at a cost of \$8.92 million.

Services Offered for Specific Populations

The success of the Early Intervention Program has resulted in the start-up of two additional programs aimed at preventing disabilities through timely intervention. Welcome Home provides an in-home nursing visit for first-time mothers and adolescent mothers. Between July 1 and December 31, 1999, 12,892 children were served at an allocation of \$100 per child. Early Start provides more intensive home visiting services for infants and toddlers who are at-risk for developmental delay and their families. In calendar year 1999, Early Start served 11,849 children. Counties are working to utilize Temporary Assistance for Needy Families (TANF) dollars earmarked for serving low-income families through the Early Start program. The Welcome Home and Early Start programs are administered locally through Family and Children First Councils.

The Department of Health oversees the quality of long term care facilities and residential facilities mentioned previously such as ICFs/MR, adult care facilities, and nursing homes. Professional staff, primarily registered nurses, visit 2,096 facilities and follow up on complaints to the state on care quality.

Department of Alcohol and Drug Addiction Services

The Ohio Department of Alcohol and Drug Addiction Services (ODADAS), ADAMHS/ADAS Boards, ODADAS-certified treatment and prevention programs, respective associations and constituent groups have worked to develop a seamless alcohol and other drug prevention and treatment services system on behalf of the citizens of Ohio.

A. Client Population

In FY 1998, 95,221 Ohioans received some form of publicly-funded alcohol and/or other drug treatment. Of that total 14,530 people, or 15%, were Medicaid eligible.

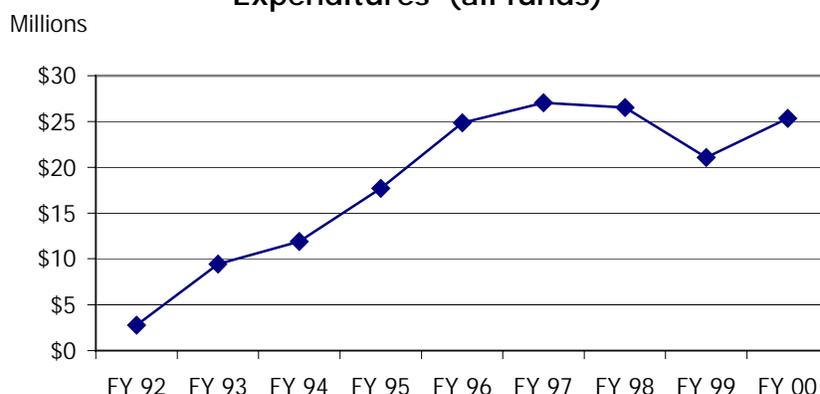
Clients receiving treatment and prevention services include men, women, and children who meet federal and state criteria for alcohol and other drug-related illnesses. The criminal justice system represents 46% of the referral base in Ohio's publicly funded treatment system. The alcohol and other drug treatment system provides prioritized services to low income pregnant women who are at high risk due to ongoing alcohol and other drug abuse or addiction and IV drug users. In addition, families and children within the child protection system are a priority population.

B. Services Provided

Services Received. ODADAS' Medicaid services include the following: alcohol and drug screening analysis, assessment, case management, group counseling, individual counseling, crisis intervention, intensive outpatient treatment, medical/somatic, ambulatory detoxification, and methadone maintenance.

Cost of Services. As illustrated by Figure 14, investments in community Medicaid services have increased since FY 1992.

Figure 14: ODADAS Community Medicaid Expenditures (all funds)



C. Community Structure

ODADAS' Medicaid program was established in 1991 through an Interagency Agreement with the Ohio Department of Human Services (ODHS, now known as ODJFS). The Interagency Agreement authorizes the reimbursement of Federal Financial Participation from ODJFS to ODADAS for Medicaid services covered under the scope of the agreement.

Services Offered for Specific Populations

The department allocates most federal and state funds through local Alcohol and Drug Addiction Services and Alcohol, Drug Addiction and Mental Health Services (ADAS/ADAMHS) Boards to fund local programs for the delivery of community-based services. Although local Boards are subject to federal and state requirements, they do have some discretion on how funding is allocated.

D. Current Challenges

Over the past five years the alcohol and other drug addiction services system has increased service capacity and enhanced the quality and cost-effectiveness of those services with a concomitant emphasis on accountability. These approaches focused on managing Ohio's Medicaid cost for physical health care and for special health related services such as alcohol and other drug treatment services and mental health services.

Improvement included efforts such as OhioCare, Transfer Services and House Bill 215. While OhioCare and Transfer Services were not implemented for ODADAS and ODMH, these efforts were not in vain. The collaboration, education and deliberation during this period provided guidance to ODADAS to develop the alcohol and other drug treatment and prevention service system's direction for the next five years. Preserving the continued objective of providing greater access, quality, cost-effectiveness and accountable service delivery for all populations remains ODADAS' guiding principle.

Factors influencing ODADAS' strategic direction include:

- Welfare Reform: Efforts both nationally and in Ohio indicate that alcohol and other drug addiction remains one of the top barriers to self-sufficiency. This recognition has led to an increased number of Ohioans being referred to treatment. Alcohol and other drug treatment emphasizes the principles of self-sufficiency.
- Collaborative Partnerships: Because of the impact of alcohol and other drug addiction on other areas of a person's life, the alcohol and other drug services system has an opportunity as well as a challenge. The development of care coordination through collaborative partnerships with other state agencies such as the Ohio Departments of Aging, Youth Services, Job and Family Services, Health, Mental Health, Rehabilitation and Correction Services, Education, and others help provide clients with necessary life skills including educational training, housing, job readiness training, and aftercare programming, which are among the most essential elements for long term recovery.
- House Bill 484: H.B. 484, Ohio's legislative response to the federal Adoption and Safe Families Act, is distinctive from the federal law in that it emphasizes the impact of alcohol and other drug abuse on families in the child welfare system. As a result, H.B. 484 mandates that families that are a part of the child welfare system become a priority population for the ODADAS service system.
- IMD exclusion: Some federal regulations create barriers to accessing community based alcohol and other drug treatment. The IMD exclusion is an example of a federal Medicaid

Services Offered for Specific Populations

regulation that impedes efforts such as welfare reform by keeping people from the very community based treatment that can help promote self-sufficiency. ODADAS will be working with federal, state and local partners to repeal such regulations.

ODADAS is not in a position from a Medicaid eligibility standpoint to seek a Medicaid waiver at this time. Balancing the responsibilities of federal and state requirements for Medicaid and non-Medicaid populations can be achieved for the ODADAS service system by defining, developing, revising, and implementing current phases of work such as:

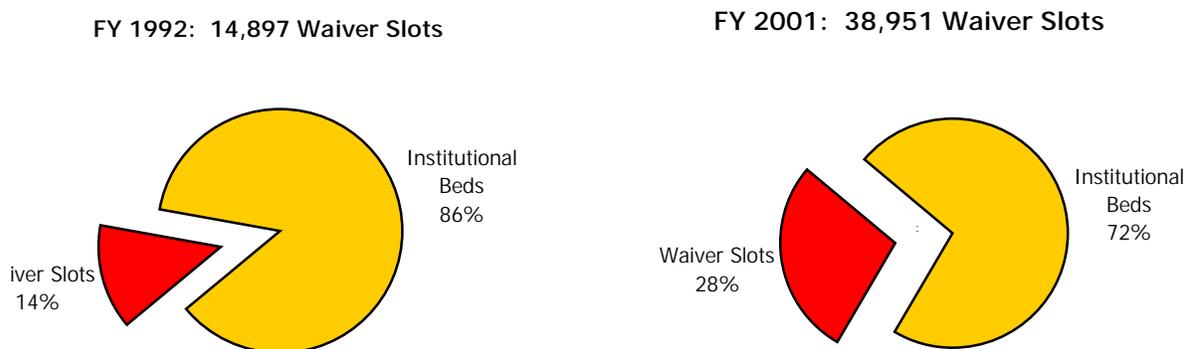
- Connecting the protocols for levels of care to ODADAS revised certification standards;
- Developing standards for prevention services as well Treatment Alternatives to Street Crime programs and Therapeutic Communities;
- Implementing a fixed fee schedule and statewide utilization review criteria for Medicaid and non-Medicaid services;
- Developing a provider procurement and dispute resolution process as well a client grievance and appeal process; and
- Establishing thresholds and triggers to indicate increases in ODADAS' community Medicaid that could require changes to comparability, free choice and state-wideness. Develop placeholder language for enabling legislation once thresholds have been reached.

Public Involvement in the Ohio Access Process

The Ohio Access Report would not be possible without the participation of consumers, their families, providers, and local government partners. Their willingness to share personal experiences and ideas for service delivery improvements is critical to effective system reform. State policy makers will use their feedback to develop changes and/or expansions to existing services that consumers desire. Appendix A contains Internet links to summaries of specific outreach events.

Consumer responses were generally positive regarding the state's home- and community-based waiver expansions over the past decade. Figure 16 illustrates the growth in home- and community-based waiver slots since FY 1992. Note that the pie charts below do not include psychiatric hospital beds because a home and community based services waiver alternative does not exist for the mental health delivery system due to Medicaid's federal IMD exclusion. Also, for the purposes of this analysis, the Department of MR/DD's Purchase of Service beds are included in the FY 1992 waiver slot number because these beds were later converted to RFW waiver slots.

Figure 16: Growth of HCBS Waiver Slots in Ohio, FYs 1992-2001



Despite significant advances in the number of HCBS waiver slots, consumers and their families indicated that even more resources should be directed to community care alternatives in the future in order to meet the overwhelming demand for community care. Other popular topics across all delivery systems were access, consumer choice of caregivers, and various challenges associated with the health care workforce shortage.

Department of MR/DD: Vision Committee

http://odmrdd.state.oh.us/What_s_New/Press_Releases/Press_Release_Info/visions_report.doc

The future of the Ohio Department of MR/DD should be driven by consumer choice. People with developmental disabilities and mental retardation want to choose where they live, who helps them, and how they participate in the communities in which they live.

The department began examining the service delivery system in 1997 when it recruited 17 people to define the department's mission for the future

The committee then gathered more people to look at issues, the system and finances. Their findings became the roadmap that focuses on serving more people, reforming and expanding systems and assuring quality and accountability. The report also addressed such roadblocks as funding inequities across counties, too few qualified workers and funding restrictions that limit choices. The result was the Vision Paper that was received by Governor Bob Taft in November.

Key ODMR/DD Vision Paper Recommendations:

- We envision a system of services for individuals with MR/DD that is "flexible" and allows individuals to make reasonable choices.
- We envision a system guided by quality and choice. A system in which ODMR/DD identifies and enforces quality standards for the delivery and optimum performance of services to individuals with MR/DD.
- We envision an Ohio system that promptly furnishes to all who desire and are eligible a residential setting of their choice and one which allows them maximum independence. We further recommend that sufficient funds be allocated for this purpose.
- We envision a state in which the incidence and prevalence of MR/DD is reduced through a proactive effort of educational and prevention activities. To that end, we recommend that the Department, in conjunction with other state agencies and private organizations, pursue aggressive prevention and education programs in an effort to minimize the biological and environmental influences that contribute to the development and increased occurrences of mental retardation and other developmental disabilities.
- We envision a state in which all citizens have access to appropriate health care. To this end, we recommend that the Department of MR/DD begin a process for improving access to appropriate health care for persons with MR/DD.
- We envision a state in which all persons with MR/DD can live, work and play in an atmosphere of safety and confidence. For this reason, the Department of MR/DD must provide protective services to all who may need and want them. Protective services should be provided without restraint or fear of retribution.

Public Involvement in the Ohio Access Process

- We recommend the Ohio Department of MR/DD and the county service delivery system continue to serve the existing population.
- We recommend that Ohio develop a means of collaborating with other departments that govern policy and services to people with MR/DD in order to lay the foundation for a more cohesive MR/DD system.
- We recommend that the structure, role and function of case management, the role of case managers, and the provision of service coordination be redefined, clarified, and standardized.
- We recommend that the Department of MR/DD direct immediate attention to the study of Long Term Care problems of older parents with older MR/DD offspring living at home.
- We recommend Ohio's MR/DD system expand its participation in the Medicaid program to maximize the amount of federal dollars available for services.
- We recommend the Ohio Department of MR/DD provide for a review of the current MR/DD reimbursement system.
- We recommend that funding mechanisms be flexible and responsive to consumer choice.
- We recommend developing a public policy by which families with resources may contribute some portion toward funding their family member's needs.
- We recommend an increased funding base for residential direct care workers to help stabilize the system.

Department of Mental Health: Commission on Mental Health

<http://www.mh.state.oh.us/initiatives/mhcommision/boft.html>

In November of 1999, ODMH Director Michael F. Hogan appointed a time-limited commission of interested parties in mental health to recommend changes in the vision, mission, values and priorities for mental health in Ohio. The Commission on Mental Health is the second stage in the Department's Building Our Future Together Initiative, which began with a series of nine public forums throughout the state in the fall of 1999. The Commission reviewed the feedback and discussions from the fall forums and consulted with independent experts to develop a report with findings and recommendations to the Director, which was completed in January 2001. The Commission recommends that this report be used as the basis for a strategic plan to meet the consumer and organizational objectives that are inherent in the statements on vision, mission and values.

The process leading to the development of the report was designed to maximize public input. The fall forums were widely publicized, and more than a thousand people from throughout the state showed up to lend their ideas on how to improve the quality of the public mental health system. The forums solicited input from the public regarding mission, vision, values, priorities and communication, as well as on a series of hot button issues in mental health today: best

Public Involvement in the Ohio Access Process

practices; children and adolescents; children and families; community support services; criminal justice; cultural competence; mental health and schools, housing, and employment.

The Commission's findings with respect to the service needs of disabled adults and children are in concurrence with and support the findings of the Ohio Access review. The Commission's report, which was published in January 2001, includes new statements of mission, vision, and values for mental health in Ohio, and recommends a strategy that focuses on four main strategic areas of attention in order to support those fundamental principles: 1) access; 2) effective treatment; 3) system design, function, and integration; and 4) financial support.

Key Commission findings and recommendations which are most relevant to Ohio Access include those findings and recommendations outlined below.

Access. The public mental health safety net is stretched too thin and has holes in some places. Statewide, the supply of mental health services does not meet current demand and will not meet increasing demand in the future.

Effective Treatment. The report contains similar findings regarding the need to improve the quality and effectiveness of community-based services for persons who remain institutionalized or who lead disrupted lives in the community due to the lack of effective treatment options. The Commission recommends the research validated PACT (Program for Assertive Community Treatment) model as a statewide initiative to help address this need.

System Design, Function, and Integration. The public mental health system in Ohio should become more efficient relative to design, function, and integration. Inefficiencies in these areas are barriers to providing access to quality services and achieving the system's mission and vision.

Financial Support. Ohio faces a mental health funding crisis that threatens the public mental health system's ability to meet basic access and quality demands.

Departments of Job and Family Services & Aging: Ohio Access Forums

<http://www.state.oh.us/odjfs/ohp/bcps/OhioAccessForums/>

The Departments of Job and Family Services and Aging joined efforts to hold a series of ten Ohio Access forums around the state to gather first hand information about the current delivery system and recommendations for the future. These forums were held between August 16 and October 25 in the following cities: Springfield/Dayton, Cleveland, Cincinnati, Mansfield, Toledo, Cambridge, Lima, Akron/Canton/Youngstown, Columbus, and Athens/Nelsonville. The Area Agencies on Aging (AAA) were instrumental in choosing the locations of the forums, accepting advance registrations by telephone, providing interpreters for the deaf and real time captioning, and providing staff at the sites to register participants and assist in other duties.

Audience turnout was impressive, ranging from a low of 65 people to a high of 250 people. Regional staff from the Health Care Financing Administration (HCFA) and the U.S. Department of Health and Human Services Office of Civil Rights attended one forum. The forums attracted a diverse group of people, including individuals with physical disabilities (including

developmental disabilities), individuals with mental health challenges, and elderly Ohioans. Attendees also represented not only those with disabilities but also their advocates, spouses, caregivers, agency staff, and county board members. Both Medicaid eligible and non-Medicaid eligible consumers attended, thereby reflecting a wide range of perspectives on access issues within Ohio's community long term care delivery systems.

All responses from each forum are posted on the web sites of the Departments of Aging and ODJFS. In addition, ODJFS gave stakeholders the opportunity to send e-mail or written comments to the department if they were unable to attend one of the forums or felt that they had more to say. There was broad consensus on specific themes.

Consumer choice and control – Participants identified these concepts as key components in the success of community services. Consumers want to receive services in the setting they prefer. Institutions should be the last resort for care, not the first. Additionally, consumers want more control over the types of services they receive and the provider who delivers the service, including the ability to hire and fire service workers. Additionally, consumers and their advocates stressed that funds used to provide services to a consumer in an institution should follow the consumer back to the community setting. One barrier often cited in the forums was the lack of housing alternatives should a consumer wish to leave the institution to return to a community setting. In rural areas especially, great concern was expressed about the lack of transportation services as well. These expressions of autonomy were also evident as forum attendees urged the state to adopt work incentives for persons with disabilities.

Improve access to information about available services – A second recurring theme expressed by those attending the forums was the feeling that there must be better access to information about available programs that already provide community services. Consumers expressed concern about the complexity of the current system and the reliability of the information currently available to them to assist in making informed choices about service options.

Increase the delivery capacity of the current system – The forums pointed out that the limited capacity of current waiver programs results in long waiting lists for potentially eligible consumers and in programs that are open for new enrollment for only a small portion of the year.

Address the shortage of home care workers – Closely related to the capacity issue of current programs is the reality expressed during the forums that even if programs exist to provide community services, their effectiveness and capacity is limited by the lack of workers to provide services in Ohio's low-employment economy. The worker shortage has also contributed to a feeling of dissatisfaction with current home care providers who can no longer promise to be an effective backup when workers call off or simply fail to show up at the scheduled time.

Place increased emphasis on the quality of community services – Community services are of limited benefit if they are of poor quality. Forum participants urged the state to take measures to improve the quality of in-home services.

Department of Aging: Summit on Health Care Workforce Shortage

<http://www.state.oh.us/age/releases/51press.html>

On July 27, 2000, Joan W. Lawrence, Director of the Ohio Department of Aging, hosted a meeting of state agencies to discuss the labor shortage in the health and long term care industry. Agency representatives agreed the labor shortage is a grave issue that needs to be addressed. Accordingly, the *Governor's Summit: Health Care Workforce Shortage* was scheduled for November 9, 2000, following a legislative reception on November 8 to call the issue to the attention of lawmakers.

The gathering was identified as the "Health Care Workforce Shortage" to focus on the health care industry and all professionals and paraprofessionals within it. The Planning Committee invited representatives from public and private sector, including all segments of the healthcare industry. Twenty-one agencies and organizations participated.

The Governor's Summit increased public awareness of the health care workforce shortage and identified best practices for recruiting and retaining workers, some of which are highlighted in Section VIII of this report. Participants recommended creating a structure for ongoing and collaborative efforts to reduce effects of the health care workforce shortage.

Federal Constraints

While community services in Ohio for persons with disabilities are funded through a wide variety of federal, state, and local funding sources, federal funds and programming are most heavily influenced by federal Medicaid policy.

Medicaid is a joint federal/state partnership. Each state establishes its own eligibility standards, benefits package, payment rates, and program administration under federal guidelines. These federal guidelines control such important aspects of state Medicaid policy as who is eligible, what services they receive, and who can provide Medicaid-funded services.

While states do have flexibility in their administration of the Medicaid program, federal Medicaid policy has constrained this flexibility in principally four ways:

- The federal Medicaid program has a long-established institutional bias, which makes it more difficult to serve eligible individuals in the setting they prefer.
- Fragmentation in funding and policy exists between various different federal programs. This fragmentation impacts consumers directly who are trying to access community services and who do not know where to turn for comprehensive, complete, and accurate assistance – a concern often mentioned by participants at Ohio Access forums this fall.
- The federal Medicaid program has built-in inflexible requirements that make it difficult to provide effective community services to persons with disabilities.
- The federal Medicaid program is administratively cumbersome. The administration of the program itself often contributes to a perception that Medicaid programs are not responsive to the needs and desires of consumers.

The federal Medicaid program has a long-established institutional bias. The federal government mandates that certain services be covered in state Medicaid programs. Mandatory services under Medicaid include in-patient hospital care, out-patient hospital services, physician care, and nursing facility care. Of interest, services that are “optional” include personal care, medical transportation, hospice care, and rehabilitative services – in other words, the services most necessary for persons with disabilities who desire to remain in community settings. Consumer advocates often voice the concern that the structure of the Medicaid program is exactly backwards – instead of community services being “optional” or “waiver” services, these should be the norm and a “waiver” should be needed for institutional care.

By 1981, the federal government recognized the institutional bias of its own Medicaid program and created Medicaid “waiver” options for states to provide community services to populations who would otherwise be institutionalized. But even in creating the “waiver” option for states, vestiges of the institutional bias remained. For example, originally the size of state waiver programs, (i.e., the number of individuals that can be served during a given year,) was limited by the number of institutional beds that a state funded in its Medicaid program. The theory

Federal Constraints

was that if permission to operate the state waiver program was revoked by the federal government, the state should have enough institutional capacity to house all those receiving community services.

Another example of the federal bias toward institutional care is that the waiver itself is, in some cases, held to institutional standards and definitions. For example, it is very difficult to obtain home and community based service waivers for community mental health programs because federal rules prohibit federal funding for waiver services provided in lieu of state psychiatric hospital services for persons between the ages of 22 and 64 because such facilities are deemed by the Health Care Financing Administration to be an "institution for mental diseases" (or "IMD"), and are excluded from Medicaid coverage. The IMD exclusion is rooted in the well-intended decision to discourage in-patient psychiatric hospitalization by not funding this service. Yet federal policy, by treating Medicaid waivers as an institution, limits Medicaid funding for the very services needed by those with mental disabilities.

One troubling issue that is yet additional evidence of the continuing institutional bias in Medicaid is that housing costs are not covered by the Medicaid program unless the consumer is in an institution. A repeated concern with efforts to transition residents of institutions to community settings is "how will the cost of housing, including security deposits be paid." The answer is that Medicaid cannot be used to pay for housing outside of the institution. The Health Care Financing Administration has acknowledged this issue recently in response to the *Olmstead* decision by exploring greater cooperation with housing programs, such as the recent decision to set aside Section 8 housing vouchers for those desiring to leave an institution.

According to HCFA, total Medicaid expenditures for long-term care nationally were \$59.0 billion dollars in federal fiscal year 1998. (This amount includes spending for nursing facilities, ICF/MR services, home health services, personal care support services, and home & community based care services.) Of this amount, 70.1% was attributable to institutional care. The historic inequity in funding that exists between institutional and community services is exacerbated by even modest percentage growth increases in institutional spending. In other words, it is not easy for states to reverse the effects of the historic institutional bias.

Despite this historic inequity, Ohio is a major user of Medicaid waiver authority to provide community services, which is why Ohio policy is much more clearly linked to federal Medicaid waiver policy than the policy in other states relating to community services. Based on HCFA data, Ohio is more dependent on federal Medicaid waiver policy than other states. Ohio's ability to use or expand waivers in the future is in part contingent on its ability to control institutional expenditures and in part in gaining increased flexibility to operate its community services programs funded by Medicaid.

The budget is a zero-sum game because all state agencies are competing for the same pool of limited resources. It is important to note that in the MH system, where legal and financial responsibility for institutional and community resources have been consolidated in a fixed point of local responsibility, expenditures for institutional services have been reduced by almost two-thirds from 1991 levels. During this period community services have expanded significantly and overall growth (i.e., community and institutional services combined) is less than 50%; however, this has resulted indirectly in decreased investment in mental health services. The success of the Department of Mental Health suggests that further investments for community-based

Federal Constraints

services in other delivery systems should be made, at least in part, by a reduction in institutional spending, and, where possible, by considering integrated local responsibility under statewide direction and accountability. On the other hand, the ODMH experience suggests that more explicit commitments to sustain community care funding are also needed.

Ohio must give close consideration to developing strategies to fund community services in the future. This is particularly important in light of the tight budget and Governor Taft's principles for this initiative, which include expectations for increased community capacity, but within a framework of prioritized resources. Particular emphasis should be placed on strategies allowing for consumer choice followed by a reduction in institutional capacity.

Fragmentation in funding and policy exists between various different federal programs. There are a number of different programs and funding sources that are used to provide services to persons with disabilities. These include Medicare, Medicaid, Supplemental Security Income, Food Stamps, Social Services Block Grant, the Ryan White Care Act, Maternal and Child Health Block Grant, and the Older Americans Act. Consumers, during the Ohio Access forums conducted by ODJFS and ODA this fall, pointed out that it can be overwhelming for individuals to manage all the benefits for which they are eligible.

This same complexity also makes it very difficult for states to coordinate programs and funding streams – especially when program goals compete with rather than complement one another. For example, the same institutional bias that pervades Medicaid also pervades Medicare. The Medicare program contains incentives that lead to the sometimes unnecessary institutionalization of beneficiaries with the expectation that Medicaid funding for institutional placement will be available once Medicare coverage has been exhausted (a period of no greater than 100 days).

Fragmentation of programs also has created problems for states by creating a framework that allows costs for health-related services to be shifted to state Medicaid programs. There is little, if any, recognition that state-funded services such as prescription drug benefits, respite care, and other services actually save money for the federal Medicare program. This has led state governors to issue a call for budget neutrality across federal programs as opposed to a strategy that too often pits one program's objectives against another's.

The federal Medicaid program has built-in inflexible requirements. Despite changes made by the Balanced Budget Act of 1997 and recent attempts by the federal Health Care Financing Administration to create more flexibility in the Medicaid program as a result of the Supreme Court decision in the *Olmstead* case, the inflexibility of federal standards continues to inhibit the state's ability to respond to demands by consumers for greater choice. Several examples of this inflexibility have already been discussed above, such as the IMD exclusion as applied to home and community-based Medicaid waivers.

Another example of such an inflexible requirement is the Medicaid "Freedom of Choice" provision. Like many Medicaid regulations, the intent behind "Freedom of Choice" is well-meaning – to allow consumers to choose their own Medicaid provider from an array of options. However, as applied, the Freedom of Choice provision requires that states contract with any

Federal Constraints

provider who is willing to become a Medicaid provider. This federal requirement prohibits states from using market-driven concepts such as competitive bidding and direct negotiation to control service costs and ensure consumer access to higher quality services. All too often, obscure and ambiguous reimbursement rules govern provider rates for services and interfere with market driven rate setting processes.

In addition, experts believe that given the current environment of labor shortages for home care workers, the state could improve both quality of service and access to services if the state were able to selectively contract with fewer providers.

Yet another example are the federal requirements of “comparability of benefits” and “statewideness” that inhibit the flexibility of states to customize a package of optional benefits tailored to meet the needs of specific consumer groups. These requirements also inhibit the state’s ability to experiment with new programs that could provide a valuable alternative to costly institutional placement. States have shown that provision of a few, well-placed services such as respite care and minor home modifications significantly prolong the likelihood that the consumer can remain in the community for a longer period of time.

Federal requirements for free choice of provider, comparability of services, and statewideness impede the efforts of locally administered systems such as MR/DD, Mental Health, and Alcohol and Drug, where the integration of Medicaid with other local services and funding is critically important. Each of these local systems provide non-Medicaid services including housing, vocational, and other supportive services which are essential to the rehabilitation of consumers of these services, and must be well-coordinated with the Medicaid funded services.

The federal Medicaid program is administratively cumbersome. The National Governors Association has said that “placement in a nursing home should be the exception and require significant justification, rather than home and community-based placement being the exception and requiring a waiver.” This sentiment has certainly been echoed by consumers during the Ohio Access forums recently conducted by ODJFS and ODA. Particularly in regard to Medicaid waiver authority, states have been very concerned over the amount of staff time and the months and even years, in some cases, it takes to get approval from HCFA for a Medicaid waiver. This has prompted states to call for an end to the current system of Medicaid waivers in favor of increased flexibility in state plan amendments that can be used to create the same programmatic flexibility without the same bureaucratic limitations of the current system of waiver requests.

Every state now operates one or more Medicaid waiver programs. Yet even if Ohio wishes to implement the same type of waiver program that the Health Care Financing Administration has already approved for another state, Ohio is still required to go through the same cumbersome application and review process. States should be allowed to copy the design of any waiver approved for another state without going through a redundant process.

States are also concerned that often they are held to new programmatic changes before the Health Care Financing Administration has promulgated its rules and guidance. Too often HCFA has failed to meet statutory deadlines for new program requirements or has done so only after many years of delay. Yet states are financially penalized if their good faith attempts at program

Federal Constraints

implementation conflict with arbitrary federal rules that have been issued long after states have had to implement new programmatic requirements.

Policies inherent in other federal programs impede progress toward community integration. Federal programs such as Housing and Urban Development (HUD), Medicare, and Rehabilitation Services have historically provided essential support to persons with disabilities, and in each of these programs there are either operative policies, or an erosion of focus on disability issues, which work against disabled consumers in community settings. In HUD, reduced funding and a decreasing prioritization of housing for disabled consumers, have reduced access to safe and adequate housing.

Medicare pays fifty cents on the dollar for psychiatric services provided in community settings. No other service in the Medicare program is subject to this type of discounting, and this policy has significantly contributed to financial problems in the community mental health system.

Federal regulations which govern state vocational rehabilitation programs provide a focus which ignores the long term nature of most disabling conditions. These regulations support short term rehabilitation placements and reward "case closures" at the earliest possible time. This approach ignores the types of longer term supports needed by disabled consumers to retain jobs. Unemployment and job retention statistics for disabled persons, particularly for those with a mental impairment, argue for substantial change in federal rehabilitation policy.

The federal Medicaid program stifles innovation. Ohio is not alone in its effort to deal with federal Medicaid constraints. Most states are facing enormous budgetary pressures to control the growth of Medicaid, currently about 20% of the average state budget. Many states also share Ohio's interest in overcoming the institutional bias inherent in the current program and creating a long-term care system where consumer choice controls the setting in which services are received. These improvements are difficult to achieve in the context of the current program.

The National Governor's Association has identified Medicaid reform as its highest priority. The Governors contacted President-elect Bush in December 2000 to enlist the new Administration's help in making the program more customer focused, adaptable, flexible, cost effective, and accountable. The Governors' goals for Medicaid reform are to:

- Ensure that the program is operating efficiently and effectively, and thereby strengthen the program's fiscal integrity as well as improve the quality of services delivered to current beneficiaries; and
- Make further changes with regard to flexibility and financing to create incentives, such as an enhanced match, and options for states to expand coverage. If they so choose, states should have the flexibility to design expansions that fit the needs and circumstances of their citizens and their health care systems.

All Governors agree that added flexibility is crucial to safeguarding the continued provision of quality care through Medicaid. President George W. Bush and U.S. Health and Human Services

Federal Constraints

Director Tommy Thompson, both former Governors, are familiar with the inflexibility of the Medicaid program, and are expected to look to states for innovative ideas to reform the federal program.

Ohio is poised to be a leader in the Medicaid reform debate. Ohio Governor Bob Taft currently serves as Vice Chair of the National Governor's Association Human Resources Committee—the committee responsible for recommending changes to Medicaid policy and program design—and likely will become Chair of the committee in July 2001. As Chairman, Governor Taft will have a lead role in advocating Medicaid reform to the new Administration and in Congress.

Challenges to State Disability Policy

In issuing the three guiding principles for Ohio Access, Governor Taft indicated that publicly financed long term care delivery systems should be responsive to consumer demand for choice of services and supports and the need to develop additional capacity in community based services. This principle is embraced not only by health care-related agencies at all levels of government, but by consumers and provider groups as well. However, effective system-wide improvements do not occur overnight. As the State of Ohio works to implement initiatives aimed at making these improvements, a number of challenges to overall state policy for services to people with disabilities must be acknowledged. These challenges, discussed below, must be addressed collaboratively in order to grow the system in the most efficient, equitable, and federally compliant manner possible.

Resource Challenges

While Ohio's fiscal condition remains stable, the state faces a difficult budget environment characterized by lower than projected revenues in the current fiscal year, a slowing economy, increasing Medicaid costs, and school funding issues raised by the Ohio Supreme Court. Resources for expansion are limited in the FY 2002-2003 budget in light of these conditions.

A. Limited Resources

Even with stable revenue growth of state funds, resources for expansion are limited. This is particularly true in the FY 2002-2003 budget, where the Department of Education and Medicaid demand a high percentage of new revenues.

Funding for education is Governor Taft's number one budget priority for Fiscal Years 2002-2003. Policy makers must direct their attention to the timing and content of the response to the recent Supreme Court ruling that directs the state to make further modifications to the system of school funding. It is certain that school funding reform efforts will have a dramatic impact on the state's budget. The Governor has stated that it is his goal to fund school funding reforms with the revenues of a growing economy and without a tax increase. Given this fact, education will require the commitment of a substantial portion of expected available resources, thereby reducing resources available for other purposes.

Costs associated with Ohio's Medicaid program, including both acute care services and long term care, have increased significantly within the past year. This phenomena is occurring in a number of states and is attributed to a combination of variables: increasing costs, caseload, and utilization. The Department of Job and Family Services and other state agencies are working in concert with executive and legislative branch leadership to identify cost management tools which will enable consumers to continue receiving quality health care services at the most efficient and reasonable rates possible.

The challenge of limited resources affects Medicaid administration, as well. An accountable, strategic infrastructure is a critical component of the state's Medicaid direct care service delivery systems. Each state agency that operates and/or monitors the administration of Medicaid

Challenges to State Disability Policy

services must invest significant financial resources and staff time in order to assure that safe and quality services are afforded to all Medicaid consumers. When resources for expansion are limited, state policy makers are encouraged to spend as much of their modest annual increases as possible on the creation or expansion of direct care services; however, it must be noted that appropriate funding levels must be devoted to administration in order to sustain the viability of those direct care programs in the short and long term. State policy makers must address the challenge of limited administrative capacity by developing clear lines of communication and accountability between delivery systems.

B. Equitable Distribution of Limited Resources

State and local policy makers must endeavor to achieve an equitable distribution of limited resources among populations with diverse disabilities and service needs. Simply stated, how can the state use the next available dollar in the most efficient and unbiased manner? While from a purely mathematical perspective it may appear that most efficient option is to serve a large number of people with low service costs, it is clearly not an acceptable solution from the perspective of individuals with higher cost service needs. Similarly, while institutional service options may be more cost effective in certain circumstances, it is not acceptable to limit community based options as a result.

Decision making at a state level is further complicated by the fact that all publicly funded delivery systems are competing for the same pool of limited state resources. Is it preferable to make significant inroads in community expansion for one population if it means temporarily prohibiting growth in all other systems? Or is it better policy to allow all delivery systems to expand, albeit only slightly? What are the long-term ramifications of these decisions with respect to health and safety, waiting lists, and increased costs incurred in institutional settings due to a lack of community options? (Note: the question of whether to use local tax dollars as state match, discussed in Part E, adds another variable for consideration.)

C. Matching Capacity to Demand

Future predictions of the need for more institutional long-term care beds have been greatly overstated. Both the nursing home and assisted living industries appear to have excess unused capacity beyond that which is needed in the foreseeable future. This is supported by the facts and trends detailed below.

- Ohio's elder population aged 60 and over is currently declining and will continue to do so until 2005. This population will grow rapidly after 2010 as the "baby boomers" begin to reach age 65. This is due to the fact that from the beginning of the Great Depression to the end of World War II, fewer babies were born in the United States than either before or after this fifteen year period.
- This "baby dearth" means that between 2010 and 2020, the number of Ohioans aged 75-90 will actually decline as well – the population most in need of long term care in either nursing homes or residential care facilities. Because of increased longevity and declining disability, the number of Ohioans aged 85 and older will continue to grow without experiencing this fifteen year dip.

- One reason for this trend is that the rate of disability in the adult population has been declining consistently by 1.5% per year since the early 1980s, according to researchers at Duke University.

D. Residential Capacity Issues

The federal government pays approximately 59% of all direct care and residential service costs for Medicaid-eligible Ohioans residing in institutional settings. The federal government does not allow Medicaid to fund room and board outside of institutional settings. This reality introduces an additional financial challenge as Ohio examines options to accelerate the rate of community placements across various delivery systems.

Community residential costs are borne by either the consumer, a state or local government entity, a nonprofit, or some combination thereof. In many instances, people with disabilities live in their own homes and pay the rent with their monthly SSI check. It should be noted that as of January 2000, an SSI eligible individual receives \$512 per month, or \$769 per month if he or she has a spouse. Such a situation presents serious challenges, because these amounts typically are not sufficient to cover rent, utilities, and all other living essentials. In cases like these, government resources may be used as a last resort to provide the necessary housing supports for consumer independence if other funds are unavailable. These resources are most often secured via the state capital appropriations bill or local levies. If these revenues are not available, community based expansion may be hindered.

E. Local Match Challenges (Where Applicable)

If a person is deemed eligible for Medicaid long term care community placement, the state is responsible for approximately 41% of the costs associated with the individual's direct Medicaid services. Depending on the delivery system, this financial match responsibility may be shared with, or borne solely by, a county board entity. Such responsibilities are delineated in Ohio Revised Code and/or administrative rule.

Local match for community based Medicaid expansion, and Medicaid matching funds in all cases where local funding is used, needs to be explored more fully. Ultimately the provision of Medicaid matching funds is the responsibility of the state. However, in the case of the MR/DD and mental health systems, county boards use substantial funds, originating from both state allocations and local levies, to provide the state share of Medicaid match and thereby control long-term financial commitments. This causes a potential range of issues regarding the use of local dollars as match for Medicaid, and local board control of program delivery. Complicating factors include the differing fiscal capacities and program priorities that each local board introduces into a state wide Medicaid program. An increase in caseload, service intensity, costs, or provider contracts has already forced some county boards to supplant funds designated for non-Medicaid eligible populations for use as Medicaid match. Furthermore, failure of local levies or changes in board priorities could create serious equity issues that could be solved with additional state funding or by reducing the number of waiver slots to fit the funding available. The state might be left with no choice and no warning that state funding will be required to take over the support for long-term commitments that were planned to be county funded. It is for these reasons that strong state agreements with counties need to be signed.

F. Varying Expectations, Service Needs, and Costs Among Consumer Populations

As summarized in Section III, a number of cabinet-level agencies share responsibility for the provision of health care-related services to Ohioans with disabilities. These agencies' delivery systems have evolved over time with input from their respective consumer populations, provider organizations, and, where applicable, county board systems. Community based expansion by each agency has been influenced by the priorities of their respective stakeholder groups. This has resulted in a heterogeneous approach to statewide long term care: the priorities governing expansion in one system do not necessarily reflect the main concerns of all systems.

While all delivery systems strive to provide healthy and safe environments for their consumers, the range of services needed by specific populations may vary. An elderly person receiving PASSPORT services through the Department of Aging may be able to remain in his or her own home with minimal supports such as transportation, home delivered meals, and chore services. A person diagnosed with schizophrenia may require psychotropic medications, housing assistance, counseling, and a range of community support services. However, a person with medically fragile conditions may require more extensive home health care and homemaker services from the Department of Job and Family Services' Home Care Waiver in order to live independently.

Many consumers have expressed a desire to live in the most independent and consumer-directed setting possible. The unique home and community based service plans designed and funded by each state agency attempt to realize that goal for everyone. However, budgetary realities become evident when one begins to consider the effects of the varying expectations and service needs inherent in each delivery system. For example, the average cost of a PASSPORT waiver slot is approximately \$14,500 per year, and the average cost of an Individual Options (IO) waiver slot is more than \$47,800 per year. (These averages include acute care costs.) Cost disparities of this sort exist for a variety of reasons, including:

- the average acuity levels of recipients and their corresponding need for staff support are generally higher for some populations than others, thereby requiring the provision of more services per person;
- different payment structures and rate setting methodologies exist among delivery systems, which means that the cost of a particular service may vary depending on the system in which it is delivered; and
- values and priorities within each system vary in how appropriate services are defined.

The challenge for policy makers is to understand the complexities of individual delivery systems with regard to stakeholder expectations, service needs, and costs. A failure to examine the unique features of each system could preclude the opportunity to develop the most comprehensive and thorough improvements possible for each system.

G. Future Planning for Information Systems

As state agencies continue to enhance the provision of services to consumers, it is necessary to incorporate information technology into all planning processes. As evidenced by the following recent accomplishments, information technology enables the state to increase both efficiency and effectiveness.

- The Multi-Agency Community Services Information System (MACSIS), a collaborative effort of the Department of Mental Health, the Department of Alcohol and Drug Addiction Services, and their county board partners, was fully implemented last year. MACSIS standardizes and streamlines information between local boards, the two departments, and Ohio's Medicaid Management Information System (MMIS). Its functions include eligibility checking, enrollment, service assessment, billing functions.
- SB 171 was signed into law by Governor Taft in August 2000. This bill establishes the authority to create an abuser registry which enables tracking of persons involved in abuse or neglect and prohibits their employment in the field of MR/DD.
- Agencies are currently examining what effects the Health Insurance Portability and Accountability Act of 1996 (HIPAA) will have on current operations. Significant, collaborative planning will be necessary in order to standardize all health care transaction codes among provider organizations, as mandated in the act.

Future planning for information systems, both agency-specific and integrated, allows the state to maintain compliance with all federal guidelines.

Federal Constraints

While community services in Ohio for persons with disabilities are funded through a wide variety of federal, state, and local funding sources, federal funds and programming are most heavily influenced by federal Medicaid policy.

Despite changes made by the Balanced Budget Act of 1997 and recent attempts by the federal Health Care Financing Administration to create more flexibility in the Medicaid program as a result of the Supreme Court decision in the *Olmstead* case, the inflexibility of federal standards continues to inhibit the state's ability to respond to demands by consumers for greater choice.

- The federal Medicaid program has built-in inflexibility that makes it difficult to provide effective community services to persons with disabilities and is administratively cumbersome. The administration of the program itself often contributes to a perception that Medicaid programs are not responsive to the needs and desires of consumers.
- The federal Medicaid program has a long-established institutional bias, which makes it more difficult to serve eligible individuals in the integrated setting they prefer.

Challenges to State Disability Policy

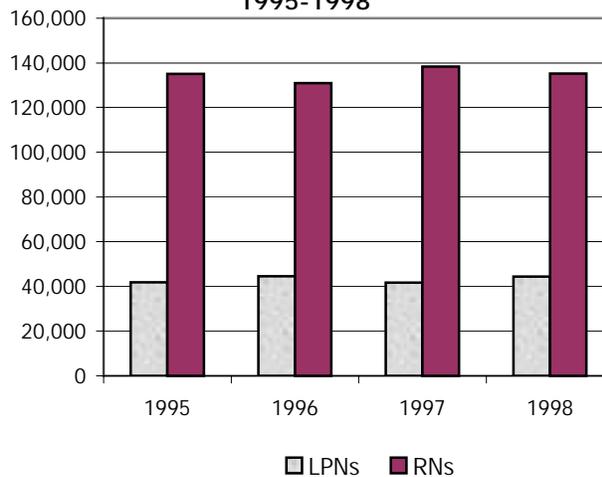
- The freedom of choice requirement has the nature of a provider participation entitlement and reduces states' ability to impact cost and quality through selective contracting. This principle has two components. First, any willing provider who wants to offer Medicaid services must be able to do so. Second, consumers must have the right to select any service provider from among those providing his or her necessary Medicaid services.
- Fragmentation in funding and policy exists between various different federal programs. This fragmentation impacts consumers directly who are trying to access community services and who do not know where to turn for comprehensive, complete, and accurate assistance – a concern often mentioned by participants at Ohio Access forums this past fall.
- The state control requirement creates tension between the HCFA designated single state agency (ODJFS in Ohio) when Medicaid responsibility has been delegated to other state agencies and county boards. Mental health and MR/DD service delivery systems in Ohio have a strong local presence due to legislative requirements and local levy funding. This tension creates additional administrative challenges.
- The requirement of comparability of services statewide is particularly challenging in a state like Ohio that relies on local systems and local levies. Unique local solutions are frustrated by this requirement.

Labor Shortage Issues

Finding a solution to the health care labor shortage will be a multi-faceted task. There can be no singular answer from one source for a problem that plays out not only in so many different settings, but that involves various types of workers and affects such a variety of consumers with individual needs. Furthermore, the solution must include a component that allows for a sufficient number of workers to be sustainable.

The diversity of settings includes home health, hospices, supported living settings for persons with MR/DD, mental health group homes, adult foster care, assisted living, nursing homes, homes for the aged and hospitals. Individual consumers wishing to hire their own workers and self-direct their care are also competing for the same types of workers. Figure 17 illustrates the number of nurses with active licenses in Ohio. This number has

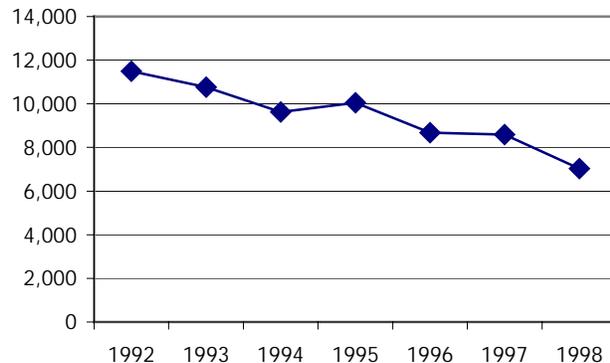
Figure 17: Active Licensed Practical Nurse and Registered Nurse Licenses in Ohio, 1995-1998



remained relatively stable in recent years; however, the increased demand for community care options is spreading the workforce thin. Currently, there is no easy and efficient way for any of these entities to hire and retain health care workers. The fact that this type of care is highly personal in nature and is necessary for many to live their lives with quality and respectability and often, to remain in their homes, serves to exacerbate the feeling of need and frustration.

The labor shortage of health care workers exists not only in Ohio, but can be seen throughout the United States. According to forecasts, this is expected to not only continue, but worsen, largely due to a number of demographic influences. It is important to note that long term care is needed by people in all age groups. In 1995, about 12 million people needed long term care. Of this total, about 57% are elderly while children and nonelderly adults make up the remaining 43%. It is essential to understand that people will have vastly different care needs at various points in their lives.

Figure 18: State Tested Nursing Assistants, 1992-1998



Aging is inevitable despite a healthy adulthood, and the process of aging increases the chance for disability. Despite medical advances and the corresponding delay in poor health, there are still higher rates of disability and long term care utilization by the 85-and-over population. Fourteen percent of Ohioans aged 65 to 74 were considered disabled in 1985. More than 58% of the people in that category were over the age of 85, an age group that is increasing at a significant rate.

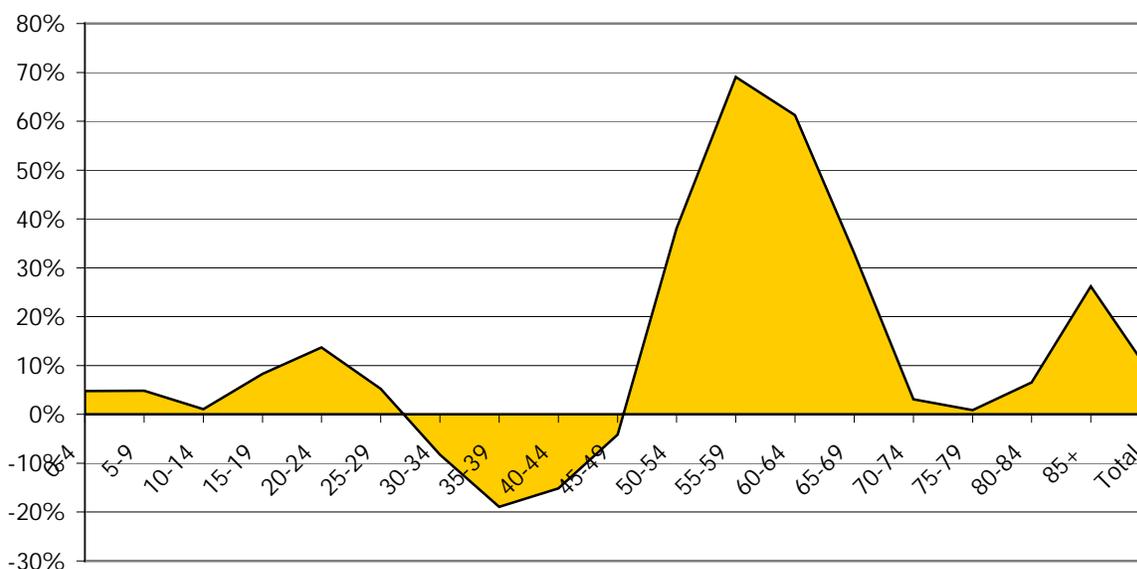
The U.S. Census Bureau has estimated that the rate of growth of persons aged 65 and older has far exceeded the growth rate of the population as a whole. The Bureau has also projected that the number of persons aged 65 and older will more than double by the year 2030 from 33 million in 1994 to 80 million. Comparatively, one in eight persons were over age 65 in 1994, with the ratio expected to jump to one in five by 2030. Even more remarkably, the number of persons aged 85 and older is growing at an even faster rate and is not projected to slow down. This group of the "oldest old" made up just over 1% of the total population in 1994 (about 3.5 million, which is 28 times larger than in 1900). However, from 1960 to 1994, this group increased an astounding 274%; those in the 65 and over bracket increased 100%; but the total population increased a "meager" 45%. This group of the "oldest old" will number about 19 million in 2050, comprising a distinctive 24% of the elderly and 5% of all Americans.

While the demographic projections in Figure 19 clearly illustrate the challenges to future workforce development and deployment, the future need for services by a growing elder population is less clear. Ohio's elder population is currently declining and will continue to do so until 2005. This is due to the fact that from the beginning of the Great Depression to the end

Challenges to State Disability Policy

of World War II, fewer babies were born in the United States than either before or after this fifteen year period. This "baby dearth" means that between 2010 and 2020, the number of Ohioans aged 75-90 will actually decline - that is, the population most in need of long-term care. The number of Ohioans aged 85 and older will continue to grow without experiencing a fifteen year dip due to increased longevity and declining rates of disability. The actual rate of disability in the United States has been declining by 1.5% per year since the early 1980s, according to researchers from Duke University. The effect of these demographic shifts is that Ohio's projected need for institutional long-term care capacity has been overstated in the past. It is not clear that as the first "baby boomers" reach age 75 in 2020, that there will be an increased need for institutional capacity at all.

**Figure 19: Ohio Population by Age Group
% Change 1995 - 2015**



This is significant since Ohio is typically ranked in the top ten of all states for the number of elderly persons. (California, Florida, New York, Pennsylvania, Illinois, Michigan, Texas and New Jersey are the other states with high elderly populations.) In 1990, the largest group of people in Ohio was aged 30 to 34. By the year 2000, the baby boomers were all over age 35, making the largest number of people in Ohio age 40 to 44 years. As technology improves, medical advances are made, and overall improvement in health from higher education levels and income continue to affect us, the labor shortage takes on an even greater importance and accelerated sense of urgency.

While wages are often the focus, numerous national studies indicate that the most important factors in job retention are job satisfaction and the ability to learn new skills.

There are a number of reasons for the shortage, including:

- Overall decreased interest in the health care field;
- Low wages/poor benefits for work that requires responsibility and reliability;
- Lack of respect for valuable work;
- Poor supervision;
- No career path;
- Lack of worker transportation (related to low wages);
- Irregular hours;
- Demanding and undesirable job requirements;
- Economic conditions: plentiful and more desirable jobs with similar if not better pay and benefits; expanded job opportunities for well-educated and experienced workers, especially nurses (drawn to academia, other health care settings, research, etc.);
- Retention is low (and replacement is costly);
- Federal constraints;
- Scope of practice and liability issues;
- Effect of managed care: cost cutting measures through staffing;
- Aging workforce, especially in nursing; and
- Lack of organized and effective recruitment efforts.

An approach to the problem should address the major issues: 1) increase the number of workers; 2) retain them; 3) employ them in areas where they are needed; and 4) enhance efforts to recruit new staff to work in direct care positions.

FY 02-03 Executive Budget

The Governor's Executive Budget document contains approximately \$145 million over the biennium for new initiatives and expansion of existing programs for Ohioans with disabilities. These recommendations are included in the budgets of various participating state agencies, as detailed in the following paragraphs.

Improve Access to Information Regarding Services

A wide variety of community long term care services are available to support Ohioans with disabilities; however, there is overall agreement among consumers, their families and providers that learning about and applying for services is elusive and cumbersome. Because different state agencies and local entities offer different services to different populations, it is often difficult for consumers to discern how to obtain useful information. To this end, an "Ohio Helps" web site is being developed by ODJFS to include information on all types of services available to people with disabilities. The site will contain links to other state agencies as well as telephone numbers for additional information on specific services. This is the first step in a longer-term plan to improve consumers' access to relevant information.

Expand Current Home & Community Based Waiver Programs

Home and community based waivers are designed to enable Medicaid consumers who are aged, blind, or disabled to receive care in their communities that was previously available only in an institutional setting. Ohio currently has four different waiver programs for target populations, including the elderly, people with physical disabilities, and people with developmental disabilities. These programs are vital to the consumers they serve and are a critical component of the state's long term care delivery system. The number of waiver slots available to consumers has grown significantly throughout the decade. Across all delivery systems, the number waiver slots approved by HCFA increased from 11,064 in FY 1992 to nearly 38,000 in FY 2000. This represents a 242% increase over FY 1992 levels.

Governor Taft is committed to the continued expansion of community-based alternatives. As a result, the FY 2002-03 budget recommendations include:

- Department of Aging – The PASSPORT waiver provides care to people over age 60 who are unable to function independently and would otherwise require nursing home-type services. As of FY 2001, the PASSPORT waiver includes more than 24,000 slots. Approximately 1,300 additional slots in FY 2002 and approximately 1,600 additional slots in FY 2003 are recommended for this program.
- Department of Job and Family Services – The Home Care waiver provides home and community based care in lieu of long term hospitalization or institutional placement to: 1) people under age 60 who require nursing or daily living services due to a physical disability or disease, or 2) people of any age with a chronic, unstable condition (such as ventilator dependency) who require nursing care. As of FY 2001, the Home Care waiver includes about 8,200 slots. Approximately 500 additional slots in both FY 2002 and FY 2003 are recommended.

FY 02-03 Executive Budget

- **Department of MR/DD** – The Individual Options (IO) waiver serves people who would otherwise require institutionalization in an intermediate care facility for the mentally retarded (ICF/MR.) The IO waiver serves approximately 3,300 consumers in FY 2001. The Department of MR/DD also administers the Residential Facilities Waiver, which serves about 2,900 consumers in FY 2001. The Executive Budget includes funding for approximately 500 additional IO slots in each year of the biennium.

Create New Opportunities for Independent Living

Because a transition from institutional care to community living epitomizes the Ohio Access initiative, it is recommended that the Department of Job and Family Services pilot a de-institutionalization project for individuals living in nursing homes during the next biennium.

The Ohio Access Success pilot would fund up to \$2,000 in transition costs for 75 individuals in FY 2002 and 125 individuals in FY 2003. The money would be used as seed money for the first month's rent, utility deposits, moving expenses, and other related costs. Eligibility for the project would be based on a consumer's desire to receive care in a community setting and his or her ability to be supported in a stable housing arrangement. (Federal requirements prohibit Medicaid from funding housing unless it is institutional in nature; however, state and county personnel will work with participants to explore all available housing options.)

Develop Cost Management Tools Which Promote Choice and Personal Responsibility

Due to the state's role as stewards of tax payer dollars and the realities of the current budget environment, it is imperative that costs be managed by state and local government agencies in the most efficient and equitable manner possible. Work has already begun in these systems to examine current practices and develop strategies to enhance state and/or county board roles as value purchasers. Any changes in funding arrangements should be designed to enhance service delivery and compliance with Medicaid standards such as consumer choice, health and safety, and quality.

Redesign the MR/DD Medicaid Delivery System

The Departments of MR/DD and Job and Family Services have been working collaboratively for the last year to design improvements to the Department of MR/DD's current Medicaid delivery system. This redesign initiative was prompted in part by HCFA's 1999 review of the Residential Facilities Waiver (RFW), in which the reviewers cited a number of programmatic and health & safety challenges.

In December 2000, Ohio responded to concerns of consumers' families, county boards, and HCFA about the need to redesign the delivery system to expand residential capacity, increase consumer choice, and improve management accountability. The plan filed with the federal government continues to be developed and does not rely on increased state or local funding. If successful, the redesigned system will provide matching funds for a higher level federal financing which would be used to expand residential services. The plan also calls for a reexamination and restructuring of activities and systems that support accountability and compliance. This process requires the participation of many stakeholders, including consumers, HCFA, county boards of MR/DD and other service providers. Due to the complexity inherent in many aspects of the redesign, the redesign process will not be complete for several years.

However, the state agencies are moving ahead with necessary data analysis and other tasks in order to successfully reform the system as soon as possible.

Transition Waivers. Re-design of the existing MR/DD Medicaid delivery system will center largely around re-design of the ICF-MR/DD based 1915c waivers and reconfiguration of the Medicaid State Plan Rehabilitation Option, known as the Community Alternative Funding System (CAFS) program in Ohio. As financing and design structures change, eventually culminating in expanded waiver options for individuals with mental retardation and other developmental disabilities, it may be necessary to develop and implement special transition waivers targeted to the particular needs of some people known to the delivery system. Both departments are currently working with HCFA to examine Ohio's options in this area.

The CAFS Program. CAFS is a set of services for people with mental retardation and other developmental disabilities that is structured under the rehabilitation option of the state plan. Ohio's coverage of the services using the state plan resulted from a lawsuit between Ohio and the federal government that originated in 1983. While Ohio was at the forefront of Medicaid financing of supports for people with mental retardation and other developmental disabilities it took a tack that in the long run was different from most Medicaid programs. Ohio's reliance on state plan services in lieu of habilitative waiver services for consumers is unique among the states.

Ohio's CAFS program has broad service definitions, lacks service limitations and is 100% cost reimbursed. The cost based nature of CAFS coupled with its wide open service definitions means that program expenditures are unpredictable and unmanageable. Service definitions need to be revised. The cost based CAFS program currently requires more administrative audit activity than the state can afford to provide. Moving to a fee schedule would eliminate the audit requirement.

In order to meet these challenges, Ohio will need an additional waiver with broad service definitions. The CAFS program has allowed the provision of waiver like services to a number of people. Ohio will seek to amend its service definitions in a way that enables the state to better manage the Medicaid state plan while transitioning people who are already dependent upon the "non waiver" service on to a waiver to allow them to continue to live in the community.

The rest of the CAFS program will move to a fee schedule in July 2001. It is important that Ohio develop a more consistent and federally compliant reimbursement methodology for services prior to implementing a system in July 2002 that is built upon consumer choice and self determination.

The Consumer Choice Waiver. Individuals served by the Individual Options (IO) and Residential Facility Waiver (RFW) waivers will be transitioned to a new waiver that is consumer choice driven, consistent with principles of self-determination, provides accountability for consumer health and welfare while maintaining compliance with applicable standards. At the same time, statewide reimbursement and contract standards are expected to be fully implemented for providers of all waiver services.

ODJFS and ODMR/DD have engaged key staff and are contracting with expert consultants to develop and execute this waiver. Key design elements of the waiver will be considered as part of Ohio's 2002-2003 biennial budget. Initial drafts of this waiver would be shared with HCFA in the Fall of 2001. By December 2001 the complete waiver package would be submitted to HCFA, and this waiver would be implemented July 2002.

Ohio must move to an MR/DD Medicaid service delivery system that offers more choice, provides more predictable costs, and is more accountable in understanding statewide what was purchased. The challenge to this effort is to do so without disenfranchising people from needed services.

Improve Cost Management Tools within the Community Mental Health System

Aggressive and coordinated steps are needed to preserve gains in mental health reform, prevent the "meltdown" of an increasingly stressed community system, and simultaneously improve the quality and accountability of services.

- Preserve the funding base – Given increased demand, Medicaid match requirements, and increased cost-shifting from private plans, investment levels must at least reach the inflation rate in the short term. This is critically important because any diminution in essential community services will likely result in an increased demand for services in state institutions. Such an eventuality would spark a vicious cycle that would quickly deplete essential community resources and negate the success of the past decade. In the long term, an increased commitment to mental health is required.
- Obtain a waiver of certain federal Medicaid requirements – This would afford the mental health system a limited set of managed care tools adaptive to Ohio's system and populations. This will require the state to revisit and continue the work done with shareholders on a range of cost and quality controls (both waiver and non-waiver) that will enable the state to control unnecessary cost increases, while preserving and enhancing access and quality. In order to prevent debilitating disruption in the community mental health system, the waiver program must be implemented by July 1, 2002.
- Take steps to promote the efficiency of provider agency operations – Necessary actions include increased automation and standardization as required by HIPAA, providing regulatory relief from paperwork requirements, and links to improved outcomes assessment.
- Clarify the funding responsibility for Medicaid mental health services to children placed in residential treatment facilities by Public Children Services Agencies – Lack of clarity with respect to match fund responsibilities is resulting in cost shifts to local mental health systems and is eroding financial resources for core support services for disabled persons.

Correct Inefficiencies in Current Long Term Care Facilities Reimbursement

Nursing homes fill an important niche in the array of long term care services. People who receive care in nursing homes may have higher acuity levels than those living in the community, or may require 24 hour care. However, it is apparent that many consumers do not want to live in nursing homes if they have other options. During the past decade, people with disabilities in

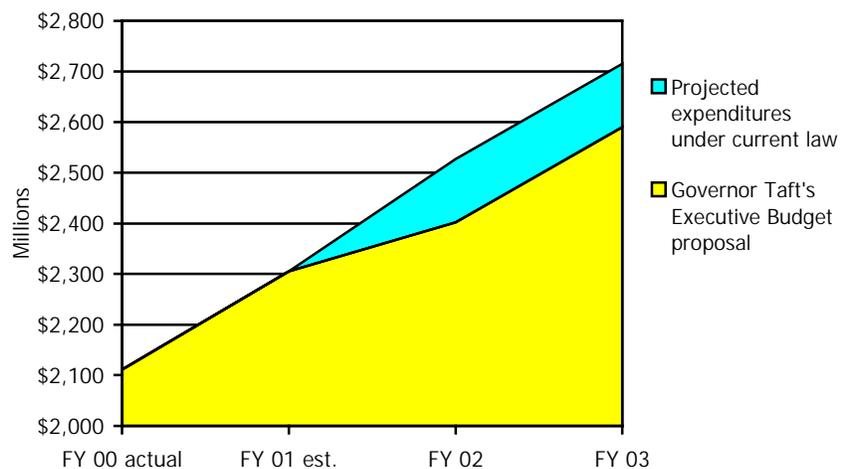
Ohio and across the country have indicated their growing desire for a choice of more community options as alternatives to institutional care. This sentiment was echoed at the Ohio Access forums, where many people talked about a system bias toward nursing homes. Other indicators reflect a shifting market preference for community-based options:

- Court decisions, most notably the recent Supreme Court decision in *Olmstead*, have begun to examine Americans with Disability Act compliance within publicly-financed programs, especially Medicaid. These court rulings challenge a perceived institutional bias.
- Occupancy in nursing facilities has been declining slightly for several years for both publicly and privately paid consumers, and now averages 87% statewide. The number of Medicaid eligible people as a percent of nursing facility occupancy has been stable. An increasing number of nursing facility admissions have been for Medicare post-acute, short-term stays. It is important to note that ICF/MR occupancy remains stable at 99%.
- Capital is reportedly harder to obtain in this market, a reflection of changing demand as well as the financial problems which are significant throughout the industry due to overly aggressive expansion and Medicare reimbursement changes.
- Three of Ohio's four Home and Community Based Services waivers are operating at capacity and have growing waiting lists.

Nursing homes serve a medically vulnerable population, and must be a viable alternative for those who require and/or desire those services provided in institutional settings. However, while the industry is a part of the private sector, 70% of its revenue comes from government. Therefore, it is incumbent on state government to make sound financial decisions regarding both nursing facilities and community services, particularly as consumer demand and legal precedent reshape the marketplace. State policy makers must take steps to achieve a balance between the two sectors that maximizes efficiency to offer a realistic choice for consumers.

The Executive Budget slows the rate of growth in nursing home spending. Under current law, nursing home spending will automatically increase 9.6% in FY 2002 and 7.5% in FY 2003. That's a \$222 million increase in FY 2002 and a \$188 million increase

Figure 20: Medicaid Spending for Nursing Facilities, Fiscal Years 2000-2003



FY 02-03 Executive Budget

in FY 2003. The Executive Budget proposes to increase nursing home spending 4.2% in FY 2002 and 7.9% in FY 2003 — that's a \$97 million increase in FY 2002 and a \$188 million increase in FY 2003. If these changes are not adopted, the General Assembly will have to find an additional \$125 million per year (\$51.5 million GRF per year) to cover the automatic increase.

Slowed cost growth will be achieved by eliminating outdated incentives that maintain excess bed capacity at a time when 13% of Ohio's nursing home beds are vacant.

- Use Medicaid funds to purchase services for Medicaid residents, not to subsidize the federal Medicare program. The state currently pays nursing homes for direct patient care based on the average disability ("acuity") of all nursing home patients. Since Medicare patients tend to be sicker and require more costly services, this policy inflates the amount Medicaid pays above the actual cost of Medicaid residents. This change avoids \$26.7 million per year in increased costs.
- Remove fiscal incentives that subsidize excess nursing home capacity. Since 1994, nursing home reimbursement levels have steadily increased while occupancy has declined. In an overly complicated formula, the state partially bases its rate on occupied beds. The recommended change would divide the rate across all the beds to ensure a truer per-bed cost for Medicaid. This change avoids \$89.7 million per year in potential costs.
- Remove the incentive to build more nursing home beds. The state currently pays a bonus to any for-profit operator whose bottom line shows more assets than debt. This policy originally was intended to encourage investment in nursing homes—and it worked—but it distorts today's market by subsidizing the actual value of assets. Making this change avoids \$9 million annually.
- Stop bailing out nursing homes that are in bankruptcy proceedings. The state currently pays a bonus to new purchasers of bankrupt facilities. This policy keeps facilities open that otherwise would close due to normal market forces.
- Make Medicaid payments only one time for the depreciation of property. When a facility that has been depreciated is sold for a profit, the state should have the option to either recapture some of the depreciation payments from the original owner or not have to pay depreciation a second time to the new owner.
- Close the loophole that discourages nursing home operators who owe the state money from giving notice when they sell their business. Current law requires operators to notify the state before transferring ownership and pay outstanding bills. Current penalties are very small for failing to provide notice. As a result, some owners may make a business decision to not give notice since the cost of providing notice, and facing possible paybacks, may be greater than the penalty.

- Protect the current reimbursement formula for patient care. Under current law, spending for direct care, like labor costs, is projected to increase 9.2% in FY 2002 and 9.3% in FY 2003. The Executive Budget preserves this increase.

These changes enhance Ohio's role as a value purchaser of health care services in a sector where consumer demands are changing. The Executive Budget takes a first step toward creating efficiencies in the existing reimbursement system for long term care facilities, and adapting the system to support consumer demand for alternatives to nursing facilities.

Recommendations

The analysis of current state supported programs, the examination of both historic and future trends, and the voices of literally thousands of consumers and their advocates lead Ohio to a new vision for the delivery of long-term care, services and supports. Thousands of Ohioans are faced with the challenges of advanced age or living with disabilities. Eighty percent of all long term care is provided by an informal network of care including family, friends, and neighbors. The value of services provided by the informal care giving network in Ohio has been estimated to be \$8 billion per year, which is more than the amount Ohio spends annually for all Medicaid services.

Continuing to live independently and avoiding institutional placement is of primary concern to elders and people with disabilities – and a diminished prospect without appropriate home and community-based care. Through public forums, elders, people with disabilities, and their family and friends who support them have overwhelmingly expressed a desire for independence and home and community care choices. Many of these individuals have family members who want them to remain at home if at all possible. These individuals want more control over their own care and decision making in order to prevent institutional placement to maximize the effectiveness of services.

The Medicaid program, which funds most of Ohio's long term care, has a strong institutional bias due to current federal requirements and historic state financing and program design. These constraints significantly limit coverage and the provision of services consumers desire and demand. In addition, the cost of institutional care is growing at an unsustainable rate and there is strong evidence supporting the cost effectiveness of home and community-based care. At the same time, institutional care is an important component of a complete array of services that must be available to consumers. Ohio Access does not substitute one needed service for another. It is driven by the need for Ohio to provide a full array of cost-effective choices for consumers.

The New Vision:

Ohio Access honors the commitment of families who provide care and supports them in their efforts. It is based on the premise that government programs should respect and integrate with the family's historic and primary role in care giving. Ohio Access supports this role by: 1) changing the way consumers are involved in their long-term care plan decision making and service delivery, and 2) shifting the focus of resource allocation to home and community based care aligned with consumer desire and demand.

The *cornerstone* of the Ohio Access vision is consumer self determination and a person centered planning approach with assistance from family, friends and caregivers. Consumers will be given more *control* over the funds available for their care and be integrally involved in the *choice* of services and caregivers comprising their individual service plan. A holistic approach to person centered planning and care will ensure consideration of each consumer's physical, mental, emotional and spiritual needs. Supported employment services programs will be

Recommendations

further developed and more widely available, and barriers to employment will be removed for consumers able to enhance their financial self-sufficiency.

Expected outcomes of this new vision include enhanced consumer: 1) independence, 2) personal dignity and responsibility, 3) access to community services and decreased reliance on institutional care settings, 4) quality of life, 5) health and safety, as well as 6) the most efficient use of limited funds. This approach will drive the development of home and community based care choices in support of health, wellness, and prevention of unnecessary, premature institutionalization. The future array of service alternatives will ensure options, including quality institutional care where it is clinically appropriate and cost-efficient, consistent with each consumer's need and desire. Community alternatives should be the norm rather than the exception.

Ohio's Goals for Elders and Persons with Disabilities. To achieve this new vision, it is recommended that Ohio adopt the following goals:

- Elders and persons with disabilities live with dignity in settings they prefer.
- Elders and persons with disabilities receive safe, high-quality long-term care, services, and supports wherever they live.
- Relatives, neighbors, and friends who care for and support elders and persons with disabilities receive the information and services they need to plan for the future and support their caregiver role.

Barriers to achieving a new vision for Ohio. In acting on these commitments and achieving the new vision where community services are the norm and institutional placement the exception, Ohio faces significant barriers:

- A need to realign Ohio's spending on institutional care to match capacity with consumer demand;
- Limited resources to expand and sustain community services;
- Federal policy constraints;
- A shortage of a trained workforce to support persons with disabilities; and
- Constraints on self-sufficiency and personal responsibility.

Recommended Strategies for Overcoming Barriers to Achieving the Vision. The state agencies responsible for the provision of long-term care, services and supports recognize that the recommendations for overcoming the identified barriers are not achievable in the short-term. Budget constraints consistent with a slowing economy and the urgency of the need to address school funding coupled with the fact that these barriers have developed and existed for

many years and in some cases are beyond the state's control, necessitate a longer term strategy to be implemented over a six year period.

A. Match capacity with demand.

This report has highlighted the fact that there is an historic imbalance in public spending for institutional services in Medicaid and certain long-term care systems. This is certainly a byproduct of a system where institutional care was the norm and not the exception. While Ohio has dramatically increased its spending on community services for persons with disabilities over the last decade, the funding imbalance has been so great that 75% of the funding for Medicaid long-term care, services, and supports is still used for institutional care.

Put simply, expenditures for publicly funded care in Ohio are misaligned with the expectations and desires of Ohio's consumers. The statewide vacancy rate in nursing facilities is approximately 13% at a time when a significant waiting list exists for Ohio's home and community-based waiver for persons with physical disabilities. This misalignment has been created by federal and state reliance on institutional services over many years, including statutory reimbursement methodologies for institutional services, and the absence in most systems of a comprehensive state policy (such as Ohio Access) in favor of community-based services. Therefore, in most systems, it is not possible to correctly align public resources with consumer expectations in the short term. Yet, consumer expectations for community care can not feasibly be met without reduced institutional utilization and the closure and consolidation of institutions that are not needed and/or are too expensive. The recommendations below should be regarded as a start at addressing the imbalance rather than a total solution.

The budget is a zero-sum game because all state agencies are competing for the same pool of limited resources. It is important to note that in the MH system, where legal and financial responsibility for institutional and community resources have been consolidated in a fixed point of local responsibility, expenditures for institutional services have been reduced by almost two-thirds from 1991 levels. During this period community services have expanded significantly and overall growth (i.e., community and institutional services combined) is less than 50%. The success of the Department of Mental Health suggests that further investments for community-based services in other delivery systems should be made, at least in part, by a reduction in institutional spending.

The Governor's budget is an important first step in that it proposes adjustments to the current reimbursement system for institutional care that will slow the growth in the cost of these services, while at the same time investing an additional \$145 million dollars in the expansion of home and community-based services for persons with disabilities. Increased spending on home and community-based services will allow state agencies to serve an additional 5,000 consumers during the next biennium. Beyond the proposed budget, other complementary recommendations include:

- Ohio must realign its public resources in response to consumer demand.
- The state must work with existing private institutions and institutional providers to examine new ways to transition to new models of community-based care and in diversifying their businesses.

Recommendations

- Implement a small transition pilot program that allows those living in nursing homes to successfully transition to community living if they desire.
- Implement self-determination strategies in the twelve developmental centers operated by ODMRDD to allow individuals who choose to leave the centers to have the needed funding for community services. As individuals choose to leave, the capacity of the developmental center will be reduced.

B. Generate and sustain the necessary resources to expand community services. Beyond recommendations that realign institutional spending, over time the state must generate and sustain the necessary resources to support consumer desires to live in community settings whenever possible.

A review of successful system realignment efforts here in Ohio, as exemplified by the Mental Health Act of 1988, and in other states makes evident how essential comprehensive structural reform is in achieving a balanced and sustainable delivery system. Isolated program initiatives alone will not be effective. Financing, statutes, regulations, local infrastructure, and the support of affiliated public agencies must be strategically aligned to achieve the intended results. A sustained reduction of institutional capacity and funding will not occur without a comprehensive, strategic focus. Without a shift of some funding to community settings, alternative community services will not grow and be sustained.

It is also important to underscore strategies to sustain community-based delivery systems as we match capacity with demand. The budget challenges which exist in Ohio's community mental health system, for example, presents the very real possibility of a destabilized community system resulting in an increased demand for institutional capacity that no longer exists.

- Consistent with the Governor's proposed budget, redesign the current home and community-based waiver programs operated by ODMR/DD and ODJFS, consistent with the principles of consumer choice and control and high quality.
- To help sustain community-based delivery systems, obtain a waiver of Medicaid requirements in order to establish a range of cost and quality controls which will permit the state systems to manage a program of Medicaid funded services within available resources that maximizes the effectiveness of state and local resources.
- Successful transition to a community-based system requires that the state explore consumer demand for alternatives such as assisted living.
- Study ways to better link all programs that provide community services to persons with disabilities to end the fragmentation that currently exists. Better linkages are needed at the federal, state, and local level.
- Take steps to promote the efficiency of provider agency operations. Necessary actions include increased automation and standardization as required by the Health

Insurance Portability and Accountability Act (HIPAA), providing regulatory relief from unnecessary paperwork requirements (while maintaining the focus on accountability) and a better focus on program outcomes that benefit consumers.

- Clarify the role, responsibilities, and strengthen accountability for local and regional entities responsible for assisting consumers and their families in accessing and coordinating services.
- Increase the participation of consumers and family members in assessing the quality and effectiveness of services.

C. Overcome federal policy constraints.

Section V of this report highlights the significant federal constraints faced by Ohio in achieving a new vision where consumer choice controls the setting in which services are received. With a new administration on the federal level comes a new opportunity for Ohio to realign its public support for services for elders and persons with disabilities. The following recommendations are offered by the state agencies responsible for the provision of publicly funded long-term care, supports, and services:

- Working with the National Governors Association, advocate for additional flexibility in the provision of long-term care, services and supports with the Health Care Financing Administration leadership, including the ability for Ohio to provide targeted, affordable home and community-based services without a federal Medicaid waiver to eliminate bureaucracy and time delays in program implementation.
- Continue to be responsive to the Health Care Financing Administration and the federal Office of Civil Rights to assure Ohio's compliance with the mandates of the Americans with Disabilities Act (ADA), allowing consumers to choose the most integrated settings for services.
- Seek federal approval for additional state flexibility in adopting market-based and value purchasing-driven strategies for working with service providers, such as competitive rate-setting processes and selective contracting with providers of services.
- Seek additional federal flexibility in the type of community services and work with the new federal administration to better address the housing needs of low-income persons with disabilities, including those wishing to relocate from institutions.

D. Address the health care workforce shortage.

The labor shortage of health care and related community services workers in Ohio and throughout the United States has persisted for a number of years. According to forecasts, this is expected to not only continue but worsen – despite the evident slowing of the economy. There are a number of reasons for the shortage. Census projections indicated that fewer people will enter the labor market. This demographic reality means that health care and community services providers will be competing with other employers for a limited group of workers. There is a public perception that these positions are poorly compensated, considering the difficulty of the work and the responsibility and reliability required. Lack of worker

Recommendations

recognition and satisfaction contributes to low worker retention. Specific barriers exist in the areas of worker transportation and training. Ohio must develop and test new strategies that enable health care and related professions to compete with other expanding job opportunities for a limited number of workers.

In November, a consortium of public and private agencies under the leadership of Ohio Department of Aging hosted a Governor's summit dealing with the critical issue of the need for workers to provide health care and related community services and supports in both community and institutional settings. In the longer term, the administration should build on the impetus provided by the summit to develop innovative ways to deal with worker shortages. Of special interest is that many of the recommendations below contribute not only to alleviating the worker shortage, but at the same time are responsive to the desire of consumers for greater control over service provision. The agencies propose the following recommendations:

Enhance workforce development initiatives. Ohio must encourage public and private efforts to reengineer the direct care workforce and improve efficiency. Good management techniques and the adoption of best practices can create a work environment in which people are treated fairly and professionally. Job satisfaction is more than just wages and benefits. More emphasis should be placed on training and supporting supervisors who make the transition from direct care.

The state should encourage the creation of demonstration projects to increase workforce efficiency. These include centralized recruitment and retention programs such as the program operated by the Council on Aging of Southwestern Ohio, creation of "career ladders" within the profession, provision of additional scholarship opportunities, and sponsorship of recognition events. Examine the use of payments to family members and other informal caregivers on a controlled basis for some services. Ohio should also study the use of worker owned cooperatives that offer higher wages and more benefits, such as the Paraprofessional Healthcare Institute.

- Build on the success of the Governor's Summit on the Health Care Worker Shortage by exploring the creation of a public-private work group under the auspice of the Governor to link workforce development activities with strategies to address the particular shortage of health care workers.
- Conduct a labor market analysis for each group of health care professional and each type of setting. Non-medical providers, such as those who provide homemaker services should also be included in this analysis.
- Study wage and rate issues to improve consistency across state-funded programs.
- Better align the need for health care and community services workers with Ohio's technical and vocational preparation programs, slated for expansion in the Governor's budget.
- Work with Ohio's nursing programs to increase student enrollment and retention.

- Work more closely with Ohio's jobs programs for persons leaving welfare. Also, the state agencies should work more closely with the Rehabilitation Services Commission and its initiatives.

Examine alternatives to the traditional provision of long term care. In addition to increasing its workforce development efforts, the state must create strategies to examine innovative responses to the direct care workforce shortage. These initiatives may be aligned with the principles detailed in President Bush's New Freedom Initiative, which he proposed to Congress on February 1, 2001.

- Examine "scope of practice" issues, including delegated nursing and responsible alternatives to delegated nursing.
- Explore the use of available technology which can allow individuals to stay home and decrease the need for human help to reduce reliance on an overburdened labor force. Increase utilization of existing technological advances, including the expanded use of telemedicine.
- Explore the increased use of independent service providers. The use of independent workers by consumers gives them more control and allows for greater self-determination.

E. Overcome policy constraints on self-sufficiency and personal and family responsibility.

A consistent theme throughout the public process that surrounds the development of the Ohio Access report, was that there are currently far too many policy barriers that inhibit persons with disabilities from achieving self-sufficiency. To the extent that such barriers exist, the state has an important role in developing mechanisms to remove those barriers.

Also, while the state plays an important role in financing and organizing long-term care services, the fact remains that the vast majority of long-term care, services, and supports is provided informally by relatives, neighbors, and friends. Thus, the state also has an important role in supporting this informal network. While none of the listed recommendations below guarantee that the existing barriers to self-sufficiency and personal responsibility will be removed, each of the recommendations should be evaluated.

- Provide better information and assistance for consumers and their caregivers. Recognizing that people access services and information in many different ways, the agencies recommend movement toward the concept of "no wrong door" where Ohioans are given consistent, accurate, and timely information regardless of how they choose to enter the system. In the short term, mechanisms toward this approach include Ohio Helps and the Long-Term Care Consumer Guide – both Internet-based approaches – and the statewide toll free number that will be implemented this winter by Ohio Department of Aging.

Recommendations

- Explore options that create opportunities for people with disabilities to work while still receiving health care coverage, especially the federally created “ticket to work” initiative.
- Explore the potential of the expanded opportunities states have been offered under Section 1902r of the Social Security Act that could remove barriers that exist in Medicaid eligibility requirements.
- Examine successful programs, such as the LEAP program in Cleveland that trains persons with disabilities to become care workers themselves.
- Develop a public policy by which those with resources may contribute some portion toward funding needed community services without jeopardizing their eligibility for those services. This overcomes Medicaid’s “all or nothing” approach, whereby either 1) the individual is economically eligible for the program and receives an extensive entitlement to a wider array of services than is available under any private insurance plan, or 2) the individual qualifies for no benefits at all.
- Encourage Ohioans to plan for their future needs for long-term care, services, and supports. Few Ohioans consider that they may need such supports in the future and even fewer consider the purchase of long-term care insurance. In part, this is because these policies, like Medicaid itself, emphasize institutional placement over community placement. However, newer policies may provide consumers with more choices and controls while still preserving private resources and assets. The state can play an important role as new insurance products develop as well as an important role in ensuring that the insurance products offered in Ohio are of high quality. The Department of Aging currently offers a free, in-home assessment to any Ohioan concerned with the future need for long-term care and services to encourage Ohioans to plan in advance of the actual need for services.

Conclusion

The Ohio Access report is a blueprint for Ohio’s future. In order to achieve the new vision for elders and persons with disabilities, the state must work with consumers and their families, local funding partners, and providers to overcome the barriers and constraints identified in this report. The implementation of the strategies outlined in Section VIII will require the commitment of all of these stakeholder groups, as well as the realignment of limited resources to purposefully and efficiently match capacity to demand.

The agencies recognize that the new vision cannot be achieved quickly. Ohio’s current system of long-term care and services has evolved over many years and the issues highlighted in this report will not be resolved in the near term. However, Ohio Access marks a beginning, not an end point, and with the concerted efforts of all affected Ohioans, a vision based on self-determination and person-centered planning will be realized for our futures.

Web Sites Containing Related Information

Ohio Access Forums:

<http://www.state.oh.us/odjfs/ohp/bcps/OhioAccessForums/>

<http://www.state.oh.us/age/accessforums.html>

Report of Ohio's Mental Health Commission:

<http://www.mh.state.oh.us/initiatives/mhcommision/boft.html>

MR/DD Vision Paper:

http://odmrdd.state.oh.us/What_s_New/Press_Releases/Press_Release_Info/visions_report.doc

Department of Aging: Summit on Health Care Workforce Shortage:

<http://www.state.oh.us/age/releases/51press.html>

Figures Contained in the Ohio Access Report

Figure	Title	Page
1	Average Annual Cost by Setting, FY 1999	7
2	HCFA-Approved Home and Community Based Waiver Slots, FYs 1992-2001	7
3	Home and Community Based Waiver Expenditures, FYs 1992-2000	8
4	Percentage of Home Care Waiver Consumers Receiving Services, FY 1999	11
5	Home Care Waiver Cost Levels (7,343 consumers as of 2/21/01)	12
6	State Psychiatric Hospital Patient Characteristics, FYs 1992-2000	16
7	Mental Health Community and State Hospital Expenditures, FYs 1992-1998	17
8	Expenditures for Primary Components of the Public Mental Health System	18
9	DMH GRF Budget Trends, FYs 1992-2003 (1990 Dollars, in Millions)	19
10	MR/DD Institutional & Waiver Expenditures, FYs 1992-1999	23
11	Americans with Developmental Disabilities by Living Arrangement: 1998	25
12	Americans with Developmental Disabilities Living with Family Caregivers: 1998	26
13	People Served by PASSPORT, FYs 1992-1998	28
14	ODADAS Community Medicaid Expenditures (All Funds)	35
15	Growth of HCBS Waiver Slots in Ohio, FYs 1992-2001	39
16	Active Licensed Practical Nurse and Registered Nurse Licenses in Ohio, 95-98	56
17	State Tested Nursing Assistants, 1992-1998	57
18	Ohio Population by Age Group, Percentage Change 1995-2015	58
19	Medicaid Spending for Nursing Facilities, Fiscal Years 2000-2003	65

Acronyms Contained in the Ohio Access Report

AAA	Area Agency on Aging
ACF	Adult Care Facilities
ADA	Americans with Disabilities Act
ADAS	Alcohol and Drug Addiction Services
ADAMH/CMH	Alcohol, Drug Addiction, and Mental Health/ Community Mental Health Boards
ADAMHS	Alcohol, Drug Addiction, and Mental Health Services
ADLs	Activities of Daily Living
BCMH	Bureau for Children with Medical Handicaps
CAFS	Community Alternative Funding System
CSHCN	Children with Special Health Care Needs
CSP	Community Support Program
DLS	Daily Living Assistance
EPSDT	Early Periodic Screening and Diagnostic Treatment
ERS	Emergency Response Systems
FY	Fiscal Year
GRF	General Revenue Fund
HCBS	Home and Community-Based Services
HCFA	Health Care Financing Administration
HIPAA	Health Care Portability and Accountability Act of 1996
HSF	Home Services Facilitation
HUD	U.S. Department of Housing and Urban Development
IADLs	Instrumental Activities of Daily Living
ICF/MR	Intermediate Care Facility for the Mentally Retarded
IMD	Institution for Mental Diseases
IO	Individual Options waiver
LPN	Licensed Practical Nurse
MACSIS	Multi-Agency Community Services Information System
MMIS	Medicaid Management Information System
MR/DD	Mental Retardation/Developmental Disabilities
NIMH	National Institute of Mental Health

Acronyms Contained in the Ohio Access Report

OAA	Older Americans Act
ODADAS	Ohio Department of Alcohol and Drug Addiction Services
ODH	Ohio Department of Health
ODHS	Ohio Department of Human Services
ODMH	Ohio Department of Mental Health
ODMR/DD	Ohio Department of Mental Retardation/Developmental Disabilities
ODJFS	Ohio Department of Job and Family Services
OHC	Ohio Home Care waiver
PAA	PASSPORT Administrative Agency
PACT	Program for Assertive Community Treatment
PHN	Public Health Nurse
PKU	Phenylketonuria
RFW	Residential Facilities Waiver
RN	Registered Nurse
RSS	Residential State Supplement program
SCSBG	Senior Community Services Block Grant
SED	Severely Emotionally Disabled
SMD	Severely Mentally Disabled
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
SFY	State Fiscal Year
TANF	Temporary Aid to Needy Families