



Massachusetts Medicaid
Policy Institute

Understanding MassHealth Members with Disabilities

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A Report from the Massachusetts Medicaid Policy Institute

In collaboration with:

The University of Massachusetts Medical School
Commonwealth Medicine
Center for Health Policy and Research

Boston University School of Public Health
Health and Disability Working Group

Foreword

The goal of this policy report is to promote a better and broader understanding of non-elderly MassHealth members with disabilities. This group of MassHealth members is exceptionally diverse and no report of this kind can possibly explain or explore all of its important nuances and subtleties. We have attempted to highlight major characteristics and trends in order to support a more informed public discussion of key policy issues that face the MassHealth program in financing care for members with disabilities.

The report focuses only on members under the age of 65 who qualify for MassHealth on the basis of a disability. It does not include elderly members with disabilities or non-elderly MassHealth members with disabilities who qualify for coverage on a basis other than disability, such as being a member of a low-income family.

We draw upon data and information from a number of sources. Most of the information comes from MassHealth claims and eligibility files. We have used data from other sources primarily to compare Massachusetts with other peer states and the nation. Although we have done our best to reconcile information from different sources, in a few cases there are inconsistencies that have been difficult to resolve, but that do not affect the overall analysis or conclusions.

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Executive Summary

More than 200,000 children and adults, or one in five members with MassHealth (the name of the Medicaid program in Massachusetts), qualify for MassHealth coverage because of disabilities. In Massachusetts and nationally, Medicaid is a vital source of health coverage for people under 65 with disabilities, and is the central mechanism for paying for essential services for the poor and near poor with chronic health conditions.

Medicaid members with disabilities are a diverse group but all have serious and chronic physical, developmental, and/or mental conditions. The most common types of disabilities among Medicaid members include major mental illnesses such as schizophrenia, bi-polar disorder, and major depression; physical or sensory disabilities such as paralysis, loss of limb, loss of sight or hearing; developmental disabilities such as mental retardation and autism; and significant chronic health conditions such as HIV/AIDS, cancer, and multiple sclerosis.

In Massachusetts, the number of non-elderly MassHealth members with disabilities is increasing, reflecting both deliberate state policy initiatives to extend Medicaid coverage to more people with disabilities, as well as the growing number of people living with chronic disease and disability. At the same time, rising medical costs are making it more expensive to provide care for those who have significant and chronic medical needs. As a result of these trends, 38% of Medicaid spending in Massachusetts goes to provide services to non-elderly members with disabilities. More than half of the increase in MassHealth spending during the past five years is attributable to services for these members.

Despite the large number of MassHealth members with disabilities and their importance in terms of overall program spending, this population is not well understood. The purpose of this policy report, therefore, is to promote a broader understanding of non-elderly MassHealth members with disabilities and a more informed public discussion of how to provide and finance essential services. The report provides an overview of the MassHealth population with disabilities, the criteria for enrollment, an analysis of enrollment and spending trends, a review of special programs for people with disabilities in Massachusetts and in other states, and a discussion of policy issues that must be addressed.

Key findings

The MassHealth program is a key health care safety net for children and adults with disabilities, and an especially important source of coverage for the poor and near poor.

As of June 30, 2003, there were 200,725 Massachusetts residents with disabilities aged 0–64 enrolled in various MassHealth programs. Of these members, 90% are adults; and 10% are younger than 18. Almost 60% are between the ages of 40 and 64. The vast majority of members with disabilities are very poor. More than 92% have family incomes below 133% of the federal poverty level (\$25,071 for a family of four in 2004). Only 3% of members with disabilities have incomes more than twice the poverty line. Almost all members with incomes above 133% of poverty are enrolled in CommonHealth (a MassHealth program to allow working people and children with disabilities to “buy-into” Medicaid) and contribute to their coverage based on a sliding scale.

People with disabilities enrolled in MassHealth are a heterogeneous group, with a mix of physical, mental, and developmental disabilities and a high prevalence of mental illness and chronic conditions. In 2002, 49% of the Supplemental Security Income recipients who had MassHealth were disabled as a result of mental illness, 31% had physical or sensory disabilities, and 13% were disabled due to mental retardation or developmental disabilities. Regardless of the primary cause of disability, MassHealth members with disabilities frequently have multiple chronic health conditions requiring complex, coordinated, and often expensive medical treatment. Nearly half of adults with disabilities have three or more chronic conditions. These figures for Massachusetts are consistent with national data, which show that over half of adults with disabilities covered by Medicaid report having two or more disabling conditions.

MassHealth members with disabilities are a relatively stable population. Consistent with the chronic nature of their conditions, MassHealth members with disabilities tend to be enrolled in the program longer than other MassHealth members under the age of 65. Eighty percent of members with disabilities have been enrolled for four years or more, compared to 51% of non-elderly non-disabled members. Only 10% of members with disabilities had been MassHealth members for less than two years, compared to 21% of non-disabled members. The stable nature of enrollment among MassHealth members with disabilities means that state investments in care coordination, service integration, and other new programs for this population are particularly worthwhile.

The number of MassHealth members with disabilities is growing, consistent with national trends. The total number of people receiving Medicaid benefits due to a disability in the U.S. has increased from 6.9 million in 1999 to 8.6 million in 2003, an increase of 25%. Expansion has been driven primarily by advances in medical technology and pharmaceuticals that have allowed many people with disabilities to live longer, decisions made by states to expand Medicaid eligibility to uninsured individuals with disabilities, the limited nature of insurance coverage in the commercial market, and the implementation of Medicaid buy-in programs to support individuals with disabilities who want to work. Since 1999, the number of MassHealth members with disabilities has grown by nearly 23,000, an increase of 13% (less than the national rate of growth during this period). All of the increase in the number of members with disabilities has occurred in the so-called ‘optional’ enrollment categories. Virtually all of the new members have been adults.

Spending on people with disabilities is increasing as a proportion of total MassHealth spending and now accounts for 38% of total spending. Overall spending on MassHealth members with disabilities increased from \$1.3 billion in FY99 to \$1.9 billion in FY03. This represents an increase of 45%, and an average annual growth rate of nearly 10% per year. The share of total MassHealth spending going to services for members with disabilities rose from 33% in FY99 to 38% in FY03.

Most of the increase in MassHealth spending for people with disabilities is coming from rising health care costs rather than growth in membership. Although there has been an increase in the number of MassHealth members with disabilities, 70% of the increase in spending for the members with disabilities has come from rising medical expenditures, with only 30% related to increase in enrollment.

Although the percentage of the state’s population with disabilities enrolled in MassHealth and the cost per enrollee are somewhat above the national average, they are close to levels in most peer states. When compared to other states, Massachusetts ranks 19th in spending per member, but has lower average spending than all but four peer

states (New England states and those states that receive the same percent of federal match for Medicaid). The percentage of people with disabilities in Massachusetts covered by MassHealth has been estimated to be 35% of non-elderly adults reporting significant disabilities on the 2000 US Census. This is slightly higher than the national average of 31%, but similar to the percentage of adults with disabilities who have Medicaid coverage in many peer states. MassHealth spending per member with disabilities was about \$11,900 in 2000, or approximately 20% higher than the national average.

Massachusetts has been an early leader and national model for the expansion of Medicaid for people with disabilities. The state pursued this strategy deliberately to achieve the following objectives: to reduce the number of uninsured in the Commonwealth; to support people with disabilities who are able to return to work and maximize their access to private health insurance; to address gaps in private coverage that create formidable financial barriers to living and working in the community and increase the need for institutional services; and to maximize federal reimbursement for eligible services.

Despite the severity of their disabilities and chronic conditions, the vast majority of members with disabilities are able to live in the community and the percentage that live in institutions has been declining. Almost all MassHealth members with disabilities live in the community and receive long-term care and support in their homes or other community settings. Only 3% of beneficiaries with disabilities live in institutional settings. The percentage of members in institutions has declined slightly over the past five years. The rate of institutionalization among children is even lower, with fewer than 1% of children with disabilities now living in institutional settings. MassHealth benefits play a critical role in enabling many members with disabilities to live in the community.

MassHealth plays a critical role in providing coverage to supplement other health coverage, particularly Medicare, which has profound implications for MassHealth spending. Forty-five percent of MassHealth members with disabilities also have some other type of health coverage (primarily Medicare). For these members, MassHealth provides benefits that are essential for people with disabilities but that are typically not provided in either private health plans or Medicare. For example, many private health plans have severe limits on mental health benefits and few, if any, provide coverage for any significant amount of durable medical equipment or personal care attendant services. Medicare has significant cost sharing for members, provides little coverage for community or institutional long-term care services, and has a very limited prescription drug benefit. Medicaid fills in these gaps for members who have other coverage. About 40% of total spending for MassHealth members with disabilities is for members who have other health coverage. If MassHealth were not available as a supplemental payment source, the out-of-pocket costs incurred by persons with disabilities for services needed, but not offered by other insurers, would likely lead to increased levels of impoverishment and institutional placement.

Spending for members with disabilities is heavily concentrated in services not covered by Medicare or most private insurers, with nearly two-thirds of expenditures devoted to prescription drugs, community supports, and institutional long-term care. Nearly 30% of expenditures for people with disabilities are for outpatient prescription drugs. One-third of drug spending goes for drugs used to treat mental health problems; another 15% is for drugs used to treat HIV. The second highest expenditure area (22%) is long-term care supports in the community, including personal care attendants, home health care, private duty nursing, day habilitation, mental health clinics, adult foster care, and a variety of other supportive medical services. Only 11% of spending is for institutional long-term care services,

primarily nursing homes. If MassHealth coverage were not available—or as widely available—as a gap coverage payment source, it is likely that this institutional spending percentage would be significantly higher.

Because spending on members with disabilities is concentrated in areas of high cost increases, the growth rate in spending per person for MassHealth members with disabilities is more than twice the growth in spending for non-disabled members.

From FY99 to FY03, the annual growth rate in spending per member with disabilities was 6.7%, compared to a 2.5% growth rate in spending per non-disabled member. The majority of the increased spending was for prescription drugs (41%) and community supports (24%), both of which reduce the need for institutional services.

Many actions have been taken and others are under way to moderate growth in spending and improve care for members with disabilities. The Massachusetts Medicaid program has taken a variety of actions over the past several years to maximize federal reimbursement and limit the growth of MassHealth spending, including instituting or improving prior approval processes in high growth areas, such as prescription drugs and personal care attendant services; increased “patient responsibility” through the use of increasing co-payments for pharmacy and other services; provider rate reductions; eliminating some benefits (e.g., eyeglasses, most adult dental care); and ensuring that payment by private health insurance is pursued whenever available. The state has also considered a number of actions to limit enrollment growth. Other new initiatives have been or are being developed to enhance and expand care coordination and case management.

Key policy questions remain to be answered in order to develop the next generation of programs and initiatives for MassHealth members with disabilities. These require broad discussion, including the involvement of MassHealth members and families.

The Executive Office of Health and Human Services recently articulated four themes as part of its overall strategy to manage spending and care for MassHealth members with disabilities: increased use of managed care; getting people to work; shared financial responsibility; and aligning Medicaid with other state programs. Movement from these general themes to successfully implemented programs requires the resolution of a number of policy and program design questions. Program planning and effectiveness can be strengthened by actively involving MassHealth members with disabilities and their families in setting goals, designing programs, evaluating progress and identifying unintended results, particularly because of the need to integrate medical, social, and family supports along with multiple funding sources.

Among the most important areas for action are the following:

- **Continue to pursue aggressive actions to contain prescription drug spending.** Since prescription drugs are the largest and fastest growing component of health care expenditures for people with disabilities, containing drug spending is essential. Further, to the extent that prescription drug costs can be reduced by price reductions rather than coverage restrictions, the impact on patient care can be minimized. To date, due to federal restrictions, the majority of drug cost containment initiatives have focused on prior authorization and generic drug substitution. Innovations in purchasing and price negotiation for drugs, including liberalization of federal rules that currently limit state options, are a potential source of significant savings and should be actively pursued.
- **Expand efforts to develop and promote new systems and models of care.** Improved care coordination and management of care hold perhaps the greatest potential for moderating

spending growth and improving quality of care for MassHealth members with disabilities, particularly given the chronic and persistent nature of their medical conditions and the high prevalence of co-morbidities. Despite their diversity, most members with disabilities have common needs for comprehensive primary and preventive care that is well coordinated with specialty care including behavioral health and community support services; care coordination and case management to reduce fragmentation of care; and support in navigating the health and social service systems

Most MassHealth members with disabilities (52%) are currently covered through the fee for service program, which provides no care coordination or care management. Forty percent of members with disabilities are covered by the Primary Care Clinician Plan (PCCP) and only 8% are enrolled in managed care organizations. Although MassHealth has a variety of specialized managed care programs for individuals with disabilities, most of these programs are small, and there is disagreement about whether some of these programs have produced cost savings or have demonstrated the ability to operate on a larger scale.

Given the diversity of members with disabilities, no one model or system of care will be appropriate for every member. A number of viable potential approaches can be identified, including increasing membership in the PCCP and/or MCOs, developing or expanding specialized programs for children and adults with disabilities, creating entirely new managed care approaches, and contracting with health plans or other entities to develop and provide care coordination and disease management programs. These approaches are not mutually exclusive. In some cases, pursuing these approaches will require advocacy efforts with the federal government in order to obtain approval for increased program flexibility and innovative financing. Massachusetts should examine the experiences of other states, where there may be lessons that can be applied.

- **Develop a strategy to address the special issues related to the dually eligible population.** Thirty-eight percent of under-65 MassHealth members with disabilities is dually eligible for Medicare and Medicaid. Improved integration of funding and coordination of care could hold the potential for reducing overall spending, increasing efficiency, and improving quality of care. MassHealth has been a leader in developing innovative approaches for dually eligible elders, including the Program of All Inclusive Care for Elders (PACE) and the new Senior Care Organization (SCO) model. It is likely that these models can be successfully adapted for some non-elderly members with disabilities.

In addition, Massachusetts needs to continue to work with other state Medicaid programs and the state's Congressional delegation to support states in covering the significant benefit gaps for people with disabilities who are currently covered by Medicare. Dual eligibles are poorer and have lower health status than other Medicaid members with disabilities, so federal assistance through expanded Medicare benefits and coverage for people with disabilities or through other means is needed.

- **Continue to explore other promising approaches to moderating spending and improving care.** These potential approaches include using Medicaid and Medicare waivers (1115, 1915c, 222) as vehicles to provide additional supports to people most likely to use high cost services such as institutions; continuing to pursue consumer direction and flexible individual budgets that give members more control over the use of resources to meet their needs, and expanding initiatives to provide nursing home transition services to younger members with disabilities.

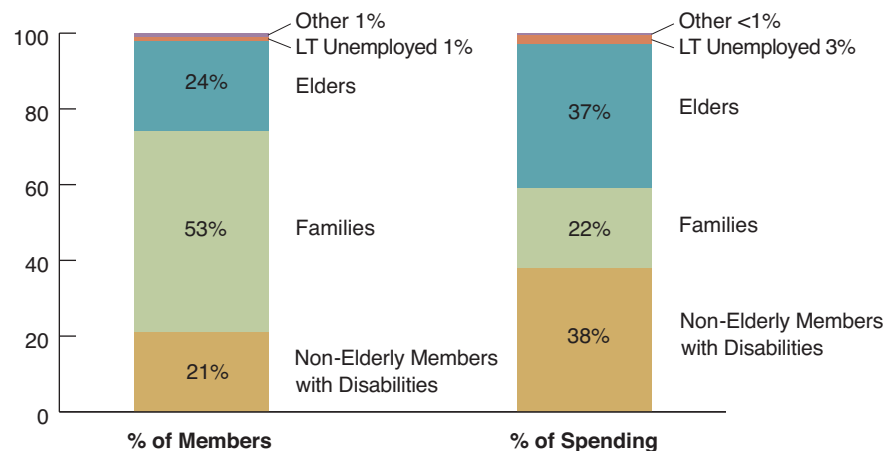
- **Evaluate the potential for moderating demand for services through co-payments and deductibles, but with very careful consideration of the significant limitations and potential consequences of this strategy.** The use of co-payments and deductibles is an increasingly common aspect of private health insurance. Studies have shown that for those with economic means, the use of co-payments does in fact decrease demand for both essential and non-essential services. There are special challenges in developing a cost-sharing strategy for MassHealth members with disabilities. Because this population is very poor and options regarding type and site of care may be limited, the potential for reducing spending through use of cost sharing is limited and the potential for negative unintended consequences is high.
- **Assess any potential changes to eligibility very carefully.** All of the recent growth in membership of MassHealth members with disabilities has been in “optional” eligibility categories and, therefore, is largely the result of state, rather than federal, policy decisions. It is important to consider whether current eligibility policies continue to be sound. However, the likely consequences of any eligibility changes must be carefully evaluated. Because the majority of MassHealth is financed by the federal government and MassHealth members with disabilities have long-term and complex medical needs, it is likely that reductions in eligibility will not save Massachusetts money overall because the costs will still be incurred, but will shift. The costs would likely shift to other MassHealth-funded service areas, particularly institutional settings; to fully state-funded public health and mental health hospitals; to other state-funded safety net programs in the community; to providers in the form of charity care costs; and to the uncompensated care pool, which is funded by insurers, hospitals, and the state. The potential consequences of proposed limits on asset accumulation for people with disabilities are of special concern and need to be evaluated carefully.
- **Continue to support and encourage participation in the community and workplace.** Buy-in programs like CommonHealth successfully address health care barriers faced by people with disabilities who are seeking employment. State policy should continue to encourage and support other MassHealth members with disabilities to participate in the workplace, and increase their income and independence without risking essential health care coverage.
- **Enhance the MassHealth administrative and information infrastructure to better support program development, implementation, monitoring and evaluation.** Although the recent reorganization of EOHHS holds some promise for enhancing close collaboration and coordination across multiple agencies, this will continue to be a major challenge. In particular, there is a substantial need for more, better integrated, and easily accessible information on MassHealth members with disabilities, including their medical, risk, and cost profiles, and the impact and outcome of the services they receive. Currently there is no comprehensive database that easily allows a review of the population by subset or as a whole. Development of a comprehensive strategy for MassHealth members with disabilities should include an information technology strategy that will facilitate better program design and evaluation. In addition, program development and evaluation require administrative resources, and expertise.

There are few more important investments that the Commonwealth could make than to increase the administrative and technical resources available to the MassHealth program.

Introduction

Nearly 38% of Medicaid spending in Massachusetts goes to provide services to non-elderly members who qualify for Medicaid by virtue of disability.¹ More than 200,000 children and adults, or one in five members with MassHealth (the name of the Medicaid program in Massachusetts), qualify for coverage because of disabilities.

Figure 1 Twenty-One Percent of MassHealth Members Are Eligible on the Basis of Disability; These Members Account for 38% of Total Spending



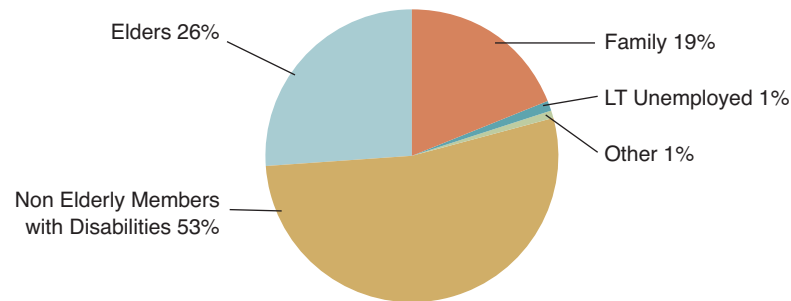
Source: UBER Eligibility Snapshot Data FY03 and TRAP claims data FY03
Note: Disabled Seniors are in Elder category. Other category includes Medicare Buy In, Refugees, and disabled categories not in our study population

In Massachusetts and nationally, Medicaid is the most important source of health coverage for people under 65 with disabilities, and is an especially important source of coverage for the poor and near poor who have chronic conditions. Nationally, 20% of non-elderly disabled individuals have health insurance coverage through Medicaid, but that number rises dramatically as income decreases. For working age adults with chronic disabilities, 41% of those with incomes under the poverty level who are insured get their health coverage from Medicaid, as do 15% of those with incomes between 100% and 200% of the poverty level.²

In particular, the Medicaid program plays a critical role in paying for services that are often not covered adequately by Medicare or typical commercial health insurance. The services covered by Medicaid for people with disabilities often allow them to live and work in the community instead of in institutional settings. In addition, people with disabilities often face barriers to obtaining private health insurance, particularly given the strong ties between group health insurance and employment, making Medicaid the insurance of last resort for many people with disabilities.

In Massachusetts, the number of non-elderly MassHealth members with disabilities is increasing, reflecting both deliberate state policy initiatives to extend Medicaid coverage to more people with disabilities, as well as the growing number of people living with chronic disease and disability. At the same time, rising medical costs are making it more expensive to provide medical care to those who have significant and chronic medical needs. As a result of these trends, nearly 54% of the increase in MassHealth spending during the past five years has been to provide services to non-elderly enrollees with disabilities.

Figure 2 Members with Disabilities Accounted for 53% of MassHealth Expenditure Growth Between FY1999 and FY2003



Source: TRAP claims data

Despite the large number of MassHealth members with disabilities and their importance in terms of overall program spending, this population of MassHealth members is not well understood either by most policymakers or much of the wider Massachusetts health care community. A broader understanding of MassHealth members with disabilities is critical, particularly as the Commonwealth confronts major challenges and opportunities in addressing the health needs of people with disabilities. Among these challenges are budgetary pressures as care for people with disabilities consumes an increasing percentage of the Medicaid budget, rapidly rising pharmaceutical costs, the need for specialized approaches to coordinating and managing care, the requirements under the *Olmstead* Supreme Court ruling to develop comprehensive approaches for providing more services to people with disabilities in the community rather than institutional settings,³ and opportunities to promote employment among people with disabilities consistent with the current administration themes of economic opportunity and personal responsibility.⁴

The purpose of this policy report is to promote a better and broader understanding of non-elderly MassHealth members with disabilities, with the goal of supporting a more informed public discussion of key policy issues that face the Commonwealth as it attempts to improve quality of care and life for MassHealth members with disabilities, while moderating spending growth in the MassHealth program.

Introduction Notes

¹ As noted in the Foreword, this report focuses only on members under the age of 65 who qualify for MassHealth by virtue of disability. It does not include elderly members with disabilities, or non-elderly MassHealth members with disabilities who qualify for coverage due to a factor other than their disability, such as being a member of a low-income family. For example, it is estimated nationally that 34–55% of Medicaid children with disabilities receive coverage through Transitional Assistance to Needy Families, or TANF. (Crown W. & Burwell B. Health Care Utilization and Expenditure Patterns of Children with Disabilities Under Private Insurance and Medicaid. DHHS Report, 1996, Washington, D.C.).

² Kaiser Commission on Medicaid and the Uninsured. Medicaid's Role For People With Disabilities, August 2003, p. 11.

³ In the *Olmstead* case, the U.S. Supreme Court held that unjustified segregation in institutions by the state constitutes discrimination under Title II of the Americans with Disabilities Act. It required states to take an “evenhanded” approach to institutional and community services. Depending upon the circumstances, this might require putting more resources into community placements, unless such use of resources constitutes a “fundamental alteration” of the state’s system for delivering services. 527 U.S. 581 (1999)

⁴ Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA) “was enacted to allow individuals with disabilities to work. Title I of the act provides access to employment training and placement services and Title II of the act provides health care supports for working individuals with disabilities.”

Profile: James

To see him today, you'd never know James had health problems. Tall and lanky, with close-cropped dark hair and deep brown eyes, he's a handsome 21-year-old with a quick wit and his whole life ahead of him.

But it didn't always look that way, at least not to James. At a time when most pregnant women with HIV—like James's mother—passed the disease on to their unborn babies, James escaped infection at birth. Unfortunately, he had other medical problems, and when he had to have his spleen removed as an infant, the blood he received during surgery was not “clean,” as it would be today. Little was known about the virus in those early years, except that it was a death sentence—and yet James is still around to tell his tale.

“I'm actually one of the few people in this area born in the early 1980s who got HIV and has lived so long,” he says. “I've been in a couple of studies.” But the Damocles sword he lived with all those years took its toll.

“As a kid,” he says, “I didn't really understand the disease. But I understood discrimination. They didn't want me in school, and people threw rocks at our house. Nobody wanted us around.”

His mother died when James was just eight years old, and he and his brother and sister—both of whom are HIV-negative—were split up. James went to live with an uncle, then with an older cousin. Though he had several episodes of severe illness, he wasn't very consistent about taking his medications, because he was only loosely supervised by his various guardians. “It was just, like, me,” he says of his childhood years. “I had to grow up pretty fast. And by the time I reached adolescence, I was just pissed off at the world. I had a chip on my shoulder the size of a TV.”

At age 16, when he learned he had non-Hodgkins lymphoma, “I said, ‘What the hell?’” he recalls. “What else can go wrong? It was like, ‘School? Whatever.’” He dropped out and

spent even more time rebelling, in “all sorts of different ways.”

James admits that he only recently came to terms with his illness. “Last year I got real sick and they almost lost me,” he says. He spent the whole summer in the hospital, including three weeks in intensive care. “But I jumped back again, and now the virus is undetectable. That made me realize I had to get with the program. Not too many people get second chances like that.”

Being away from the streets also gave James time for introspection. “When you're in the hospital there's nothing much to do,” he says. “You can't go out, can't even go to the playroom, because you could get real sick. So I started reading and writing, just to keep my mind occupied.” He had always kept a journal, but it was during those long hours alone that it became especially important to him. He also became interested in Eastern philosophies, saying they give him “a broader perspective, and a different way to think about the obstacles I've been through.”

He finished high school and will soon enter community college, where he hopes to embark on a career in filmmaking and begin writing a book about his experiences. Meantime, he's looking for work in retail or food service, both of which he has done in the past.

When asked how MassHealth has made a difference for him, James doesn't feel the need to elaborate, what with 60 or so pills a day and a lifetime of hospital visits. “Without it,” he says simply, “I'd be ice cold.”

Section I Who Are Non-Elderly People with Disabilities in Massachusetts?⁵

According to the U.S. Census, non-elderly people with disabilities comprise a significant proportion of the population in Massachusetts. Eighteen percent of the state's population between the ages of 21 and 64, or approximately 663,000 people, reported on the 2000 census that they had a significant disability that interfered with their activities of daily living.⁶ The rates of disability in Massachusetts are very similar to those nationally among people living in non-institutional settings and also similar to the rate of disability in other New England and peer states.^{7,8}

Figure 3 Distribution of Adults with Disabilities in Massachusetts is Similar to the National Pattern (Ages 21–64)

| Disability | MA | % of MA Population | % of U.S. Population |
|--------------------------|---------|--------------------|----------------------|
| Total Population 21–64 | 3.7 m | | 159.1 m |
| Any Disability | 663,354 | 18% | 19% |
| One Disability | 370,162 | 10% | 10% |
| Two or More Disabilities | 293,192 | 8% | 9% |
| Employment Disability | 453,721 | 12% | 12% |
| Physical | 200,947 | 5% | 7% |
| Mental | 133,209 | 4% | 4% |
| Sensory | 72,306 | 2% | 2% |
| Self-Care | 59,184 | 2% | 2% |

Source: 2000 U.S. Census

Eighty-five percent of the individuals with disabilities in Massachusetts are working-age adults between 21 and 64 years old; 15%, or about 116,000 are aged 5–20.⁹ (Figure 4) The prevalence of disability is higher among working age adults (19%) than among children (9%).

Figure 4 Distribution of People with Disabilities in Massachusetts by Age and Race

| Age Group | % of Total People with Disabilities in State 5–64 yrs |
|-----------|---|
| 5–15 | 7.5% |
| 16–20 | 7.4% |
| 21–64 | 85.1% |

| Race/Ethnicity | % of Total People with Disabilities in State 21–64 |
|--------------------------------|--|
| White | 81.0% |
| Black | 8.2% |
| Asian | 4.1% |
| Other | 6.3% |
| American Indian Alaskan Native | 0.5% |
| Hawaiian Pacific Islander | <0.5% |

Source: Census Summary File 3 for Race

The population with disabilities includes people with a wide variety of conditions, including physical, developmental, and mental disabilities. Among the most common physical disabilities are paralysis, loss of limb, congenital conditions, organ dysfunction, blindness, and deafness. HIV/AIDS, cancer, and multiple sclerosis are other examples of conditions that can be severe and

long-term. Developmental disabilities are severe, long-term impairments, such as mental retardation, cerebral palsy, or autism, and other conditions that begin at an early age and are expected to last a lifetime. Examples of mental disabilities include schizophrenia, bi-polar disorder, and major depression.

In comparison to non-disabled populations, people with disabilities tend to have greater health care needs, lower incomes, higher rates of poverty, higher unemployment, and less access to private health insurance.^{10, 11} In a recent national survey of people with permanent disabilities, the Kaiser Family Foundation found that:

- 54% worried that they might have difficulty paying for food or rent;
- 45% worried that they would become too much of a burden for their families;
- 36% thought that getting a job would mean losing their health insurance; and
- 23% were concerned that they might have to go into a nursing home or other facility.¹²

Many people with disabilities face challenges that make getting health care more difficult. For example, people with physical or developmental disabilities may have trouble accessing public transportation to get to medical appointments; and people with sensory disabilities often encounter problems communicating with health care providers.¹³

In addition, because many people with significant disabilities are unable to work, they often have limited or no access to health insurance in our employment-based health insurance system. Even for those who do work, health insurance may not be offered by their employers or may be unaffordable. If health insurance is available and affordable, typical private health insurance products usually exclude or limit many of the services needed by people with disabilities, such as durable medical equipment and community long-term care supports. MassHealth has a more comprehensive scope of benefits than private health insurance or Medicare and so helps fill in the gaps in these types of health coverage.

For all these reasons, the MassHealth program is a key health care safety net for children and adults with disabilities, and an especially important source of coverage for the poor and near poor.

Section 1 Notes

⁵ Definitions of disability vary depending on the type of survey or the eligibility criteria for federal programs. We present data from a number of sources.

⁶ The Census classifies individuals as having a disability if any of the following three conditions was true:

1. They were five years old and over and reported a long-lasting sensory, physical, mental- or self-care disability;
2. They were 16 years old and over and reported difficulty going outside the home because of a physical, mental, or emotional condition lasting six months or more; or
3. They were 16 to 64 years old and reported difficulty working at a job or business because of a physical, mental, or emotional condition lasting six months or more.

Census respondents can report more than one type of disability.

⁷ U.S. Census Bureau 2000 Summary File 3. Matrices P42, PCT26–33.

⁸ Using a different and stricter measure of self-reported disability, the U.S. Current Population Survey (CPS) suggests that the overall number of people with disabilities aged 21–64 has remained stable between 1981 and 2001 and that Massachusetts' prevalence rates are comparable to national estimates. "Disability Statistics in the United States". Houtenville, Andrew J. Ithaca, NY: Cornell University Rehabilitation Research and Training Center. 2004. www.disabilitystatistics.org. Posted May 15, 2003. Accessed March 30, 2004. Estimates from the CPS can be expected to be lower than the Census, as the CPS is based on a single question that asks specifically about work limitation, where the census uses several other definitions of disability.

⁹ The Census does not provide information on disability for children under the age of 5.

¹⁰ "Medicaid's Role for the Disabled Population Under Age 65," Kaiser Commission on Medicaid and the Uninsured. Medicaid Facts. April 2001. <http://www.kff.org/medicaid/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=13730>

¹¹ "Delivering on the Promise: Preliminary Report," U.S. Department of Health and Human Services, April 2002. <http://www.hhs.gov/newfreedom/prelim/employ.html>

¹² Hanson, K., Neuman, T. & Voris, M. Understanding the Health Care Needs and Experiences of People With Disabilities: Findings from a 2003 Survey. Kaiser Commission on Medicaid and the Uninsured, December, 2003. p. 22. <http://www.kff.org/medicaid/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=13730>

¹³ Maisels, L, et al. Access to Health Care for People with Disabilities in Massachusetts: Key Results of a Focus Group Study. June, 2000. <http://www.hdwg.org/reports/NIDRRRevisedFocusGroupThemes.pdf>.

Profile: Stephen and Timothy John

“I’m willing to pay my way,” Jude, the mother of Stephen and Timothy John, begins. “I feel very strongly that nobody owes me anything just because my children have disabilities. But my being able to get MassHealth benefits for my children helps keep my family intact, and keeps my children active and an integral part of the community.”



To say that her children have disabilities may sound to some like an understatement.

Stephen, 15, and Timothy John, 12, aren’t just slow learners or a little hyperactive.

Both have multiple, severe physical or cognitive issues that will require a lifetime of care.

Ironically, Jude met her husband when both were teaching in Taunton at the former Paul Dever State School, an institution for the care and training of mentally retarded children and adults. They fell in love when she was just 21 and married six years later. After struggling with infertility, the young couple was overjoyed when Jude conceived Stephen—but after a normal pregnancy, they were totally unprepared for what happened in the delivery room.

“There was no indication of any problem,” Jude says. “The baby just went into distress during labor. He was delivered by emergency C-section, and they whisked him out of the delivery room before we even knew if it was a boy or a girl. Later they brought me pictures of him because they didn’t think he’d survive.”

Stephen had persistent fetal circulation, a condition in which the lungs do not expand properly. At the time such infants rarely lived more than a few hours—but Stephen beat the odds. “After six days he just sort of kicked in,” Jude says. “We thought it was a miracle.”

Unfortunately, the resulting cerebral palsy left Stephen in a wheelchair and unable to speak. Jude’s other son, Timothy John, was born healthy and “the cutest damn baby in the world,” until at 15 months he began having

seizures caused by encephalitis—an illness totally unrelated to Stephen’s. Though he’s ambulatory, “T.J.” has no speech and is severely mentally retarded.

“It was just bad luck,” says Jude, “that we happened to have two really handsome kids who got whacked with different neurological issues.”

Though Stephen and T.J. have their primary health coverage through their parents’ insurance, the children are also covered by MassHealth’s CommonHealth program, through which people with disabilities pay premiums based on a sliding scale, and are covered for services not provided by private insurers. CommonHealth pays for medications, copayments, a wheelchair, and leg braces for Stephen, and other illness related incidentals. “Without MassHealth,” says Jude, “I don’t know how we’d pay for just the diapers alone. One package of adult diapers is \$12 to \$18, and we go through at least a package every two days.”

But it is the intangible benefits of CommonHealth that mean the most to Jude and her children. Without it, she points out, the boys would likely have to live in a residential treatment center. As it is, “Stephen knows just about everybody in the community. Neighbors take him for walks, he goes grocery shopping, he has friends over to the house.”

Stephen’s active social life aside, however, “I just want them to stay home,” Jude says. “They’re kids.”

Section 2 **How Do People with Disabilities Qualify for MassHealth?**

Nationally, the Medicaid program plays a vital role in covering the acute medical care, mental health care and long-term care needs for people with disabilities. Massachusetts has been an innovator in using its Medicaid program, MassHealth, to provide coverage to non-elderly low-income people with disabilities. These innovations have been driven by four major goals:

1. Reducing the number of people with disabilities who are uninsured in a manner that is fiscally and programmatically sound;
2. Maximizing the number of federal dollars, and, hence, minimizing the number of state dollars, that support state initiatives to provide medical care and services to people with disabilities;
3. Enabling people with disabilities to live in the community instead of institutions whenever possible;
4. Enabling people with disabilities to become employed without loss of vital health care benefits.

Qualifying for Medicaid on the basis of disability is a complex and challenging process. Eligibility is based on income level and specific categorical criteria. Federal law requires state Medicaid programs to cover certain groups of people with disabilities. It also allows states, at their option, to cover other groups of people with disabilities based upon income, medical need, institutionalization, and other criteria. In all cases, documented or proven disability according to federal criteria is the “front door” to MassHealth.

Appendix 2 provides a detailed description of the criteria and process used to determine eligibility for MassHealth on the basis of disability. This section provides a shorter summary of this information.

Qualifying for MassHealth Based on SSI Eligibility Rules for Adults and Children

The federal SSI definition of disability is based on the inability to work, and includes anyone who is statutorily blind or “has demonstrated an inability to engage in any gainful activity by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.”¹⁴ For children under age 18, who are not expected to work, the definition of disability is different: “[The] child has a medically determinable physical or mental disability, which results in marked and severe functional limitation, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of at least twelve months.”¹⁵

Massachusetts, and nearly all other states, use the federal SSI definition of disability to determine clinical eligibility for the state Medicaid program. However, having a serious health condition alone is not sufficient to qualify for SSI cash assistance. Many chronic illnesses, such as asthma, diabetes, cardiovascular disease, HIV, and multiple sclerosis, would not necessarily make an individual eligible for SSI and, therefore, Medicaid, unless the illness has been determined to be very severe or combined with multiple chronic conditions, resulting both in disabling impairment of work-related function and in high medical costs.

To be eligible for SSI benefits, and Medicaid, people with disabilities must also meet requirements for income, assets, residence, and citizenship. A person with a disability must have an

income below 87% of the federal poverty level and minimal assets (less than \$2,000 for an individual and \$3,000 for a couple) in order to receive SSI benefits. Anyone who meets both the clinical and financial criteria (as well as other legal and residential criteria) *automatically* receives Medicaid benefits in Massachusetts under federal law.

“Optional” Eligibility Groups

In addition to the mandatory eligibility groups receiving SSI, Massachusetts has chosen to extend MassHealth eligibility to other groups of people with disabilities. These optional categories of eligibility have been implemented over the years as part of deliberate strategies to accomplish a range of policy objectives, including:

- reducing the numbers of people without health insurance in the state;
- maximizing the use of private health insurance as a means of paying for medical care for people with disabilities;
- addressing benefit gaps in private health insurance that often discouraged people with disabilities from becoming employed, left them without adequate health care, or threatened to drive them into more expensive institutional settings; and,
- relieving undue burden for families trying to care for children and adults with disabilities in the community.

Some of the programs and populations Massachusetts has opted to include are:

- **“Medicaid Disabled.”** Low-income people with disabilities whose income is not low enough to qualify for SSI but up to 133% of the federal poverty level. These individuals must meet the same clinical definition of disability used by SSI.
- **MassHealth CommonHealth.** The CommonHealth program was created in 1988 and was initially entirely state funded to allow people with disabilities who wanted to work to “buy-into” Medicaid. The program is available to children and adults with disabilities who do not qualify for Medicaid as SSI recipients because they exceed the income limits. The CommonHealth program is currently jointly funded by Medicaid and by premiums paid by members on a sliding-fee scale based on income.¹⁶

Prior to the creation of CommonHealth, people with disabilities were reluctant or in some cases even unable to leave public benefits programs and become employed because private insurance does not generally pay for essential benefits, such as personal care attendant (PCA) services, durable medical equipment, and supplies. In addition, because many jobs do not offer health insurance, a move to employment might have left a person with disabilities without insurance. Barriers to receiving health care and PCAs were cited by people with disabilities as a major reason they were not employed. Until the creation of the CommonHealth Program, many people with disabilities could not afford to go to work because they could not afford the health care services they needed to be able to be employed.

- **Kaleigh Mulligan,** a program for children at risk of institutional placement whose families are otherwise over the income limits for Medicaid

Figure 5 provides basic information about the types of disabled coverage and eligibility criteria.

Figure 5 Overview of MassHealth Disabled Eligibility

| Eligibility Type | Eligibility Criteria | Other Factors |
|-------------------------|--|---|
| SSI Disabled | Eligible for SSI (meets SSI income limit, clinical criteria, and work rules) | Asset Limit - \$2000 Individual/ \$3000 Family |
| Medicaid Only | | |
| <i>Adults</i> | Income from 88–133% FPL | No Asset Limit |
| <i>Children</i> | Up to 150% FPL | No Asset Limit |
| <i>Kaleigh Mulligan</i> | Family Income > 150% FPL/Child's Own Income < \$60 /month | Requires Institutional Level of Care |
| CommonHealth | | |
| <i>Adults</i> | Income > 133% FPL | Sliding Scale Premiums/Non-workers Also Have One-time Deductible |
| <i>Children</i> | Income > 150% FPL | Sliding Scale Premiums |

The Federal Poverty Level, or 100% of FPL for 2004 is \$9,310 for a one-person family, \$15, 670 for a three-person family, and \$18,850 for a four-person family.

Section 2 Notes

¹⁴ 20 C.F.R.416.905(a)

¹⁵ 20 C.F.R. 416.906

¹⁶ Though everyone in this group receives SSI benefits, some may also receive SSDI, or Social Security Disability Income, cash benefits. In addition, SSDI recipients may be in any of the other categories as well.

Profile: Debbie

The first thing you notice about Deborah is her laugh. It is hearty, unreserved, infectious — and frequent. “She’s a pretty happy-go-lucky person,” says her mother, Carol. “She’s got the biggest heart you can imagine. She’s a hugger, and she’d do anything for anybody. You would not know there was something wrong with her unless you sat down and talked with her in depth.”



It wasn’t until the third or fourth grade that Debbie, now 44, was diagnosed as mildly retarded, a classification encompassing those with IQs in the 52 to 60 range. By age 16, she had developed epilepsy, as well—but she is accepting of and even stoic about her many hospitalizations for the disorder. “You forget,” she says, “and you get disoriented. You go to the hospital,

they watch you for 24 hours, then they let you go home.” Do what needs to get done: it’s the way she has approached many of the challenges in her life.

For instance, though schoolwork didn’t come easy for her—she attended special education classes in the Boston public school system and also went to a private school in Brookline for people with disabilities—she kept plugging away until at age 21 she graduated, a feat many with her condition never achieve. She qualifies for SSI, but has always worked as much as the rules allowed, at either food service or maintenance. And though she has never married—“that way you don’t get any headaches,” she points out—she has dated on and off since high school, and has a large roster of friends of all ages.

In her early 20s, Debbie moved out of her mother’s house into an apartment, and she’s lived on her own ever since. “It was such a traumatic experience for me when she left,” Carol says. “The first night I came home from work and she wasn’t there, I opened her bedroom door, and I cried my eyes out. But I’d been pushing her to do it, because if anything happens to me, she’s got to be able to take care of herself.”

Debbie takes care of herself just fine, thank you—with a little help from her advocates at Vinfen, the human services organization. “It’s a program for independent people with disabilities,” she says. “They help us pay our bills, or if there’s something we can’t deal with, they’ll go with us. They check in to make sure everything is all right, but I’m very independent.” She enjoys the ocean, the mountains, music, video games, and amusement parks, but her true love is also her biggest responsibility, outside of work. Blackie, a papillon-chihuahua mix, and Miss Tiger Lily, a cat, are “my buddies,” she says. “They keep me going.”

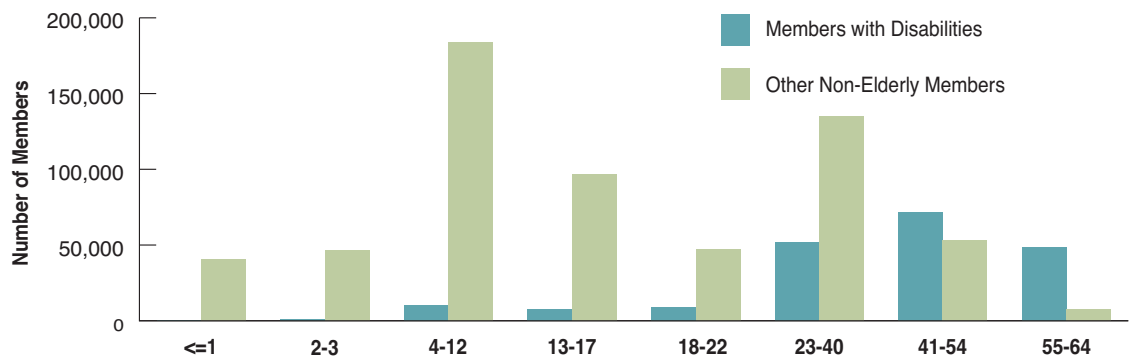
Also helping in that regard is the Medicaid coverage that pays for her anti-seizure medications and visits to the neurologist. “If I didn’t have these pills,” she says, “I would be in trouble. I would be in real big trouble, because the seizures would start all over again.” Her mother imagines an even grimmer scenario. “Without her MassHealth,” says Carol, who’s a pharmacy technician, “Debbie would be living with me, and I’d be struggling. I wouldn’t have any peace wondering what would happen to her after I’m gone.”

Section 3 Who Are MassHealth Members with Disabilities?

The MassHealth population with disabilities is made up primarily of adults but includes many children.

As of June 30, 2003, there were 200,725 Massachusetts residents with disabilities aged 0–64 enrolled in various MassHealth programs by virtue of disability. Of these members, 90% percent are adults, and 10% are younger than 18. Overall, MassHealth members who qualify for coverage by virtue of disability are significantly older than non-disabled members. This age distribution is not surprising because MassHealth eligibility rules permit children to qualify for MassHealth by virtue of income at much higher income levels, resulting in significantly fewer children in disabled categories of assistance. (Figure 6)

Figure 6 Distribution of Non-Elderly MassHealth Members By Age

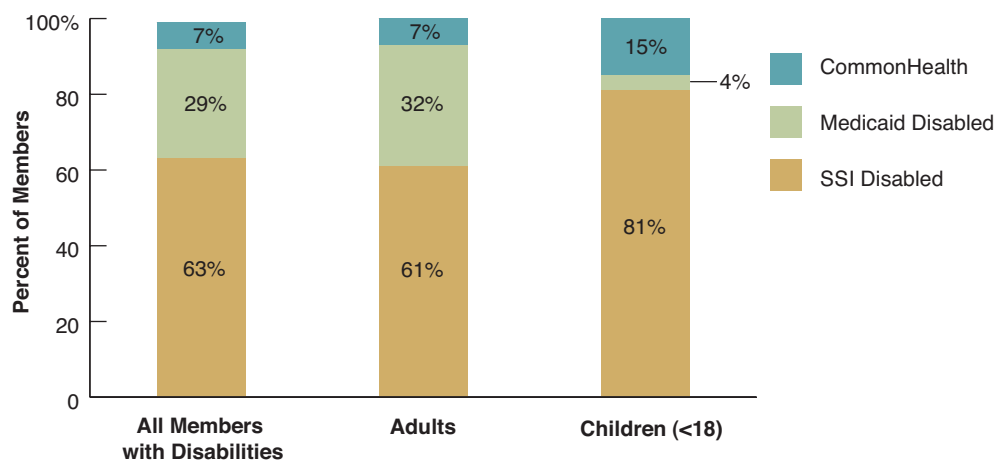


Source: UBER Eligibility Snapshot Data FY03

Most members with disabilities are eligible for MassHealth because they qualify for SSI.

More than 127,300 people, or 63% of MassHealth members with disabilities, were enrolled in the program as SSI Disabled on the basis of their eligibility for federal SSI payments.¹⁷ An additional 58,800 (29%) are enrolled as Medicaid Disabled using state-established criteria including income, medical need, and institutionalization. The remaining 14,604 enrollees (7%) are enrolled in the CommonHealth program. (Figure 7)

Figure 7 Nearly Two-Thirds of Adult Members with Disabilities and 80% of Children with Disabilities Qualify for MassHealth Based on SSI Eligibility



Source: UBER Eligibility Snapshot Data FY03

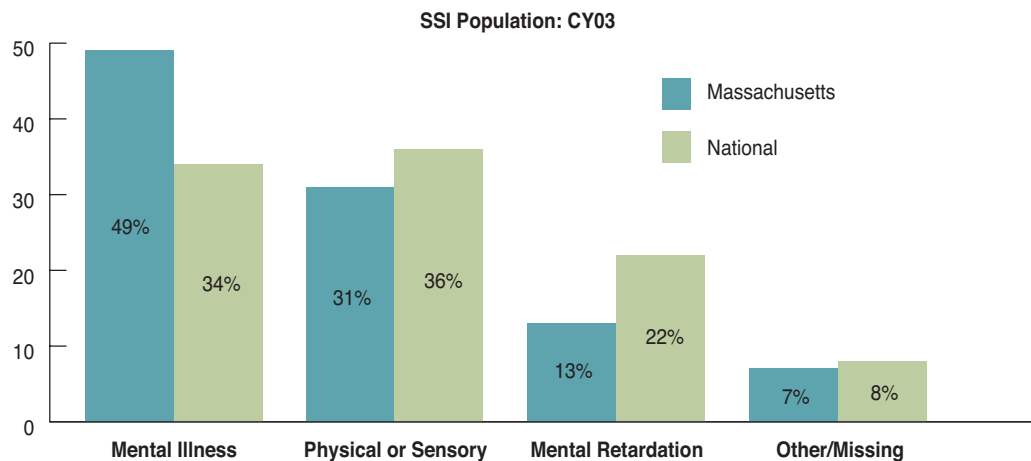
MassHealth members with disabilities have very low-incomes.

The vast majority of members with disabilities are very poor. More than 92% have family incomes below 133% of the federal poverty level. Only 3% of members with disabilities have incomes above 200% of poverty. Ninety percent of the members with disabilities who have incomes above 133% of poverty are enrolled in CommonHealth and contribute to their coverage based on a sliding scale. However, most CommonHealth members also have relatively modest incomes: 6% have incomes below 133% of poverty, 50% have incomes from 133–200% of poverty; 26% have incomes from 200–300% of poverty; and 9% have incomes between 301–400% of poverty.

People enrolled in MassHealth on the basis of disability are a heterogeneous group, with a mix of physical, mental, and developmental disabilities and a high prevalence of mental illness and multiple chronic conditions.

In 2002, 49% of the SSI recipients who had MassHealth were disabled as a result of mental illness, 31% had physical or sensory disabilities, and 13% were disabled due to mental retardation or developmental disabilities. (Figure 8) Data on disability type for a subset of the MassHealth population evaluated during FY2003 using SSI criteria found that 43% of the population met disability criteria based on a mental health disability, 55% on a physical or sensory disability, and 2% based on mental retardation or autism.¹⁸

Figure 8 MassHealth Members with Disabilities Are a Heterogenous Group, with A Mix of Physical, Mental, and Developmental Conditions



Source: SSI Work Incentive File and Revised Management Information Counts System (REMICS). Special data runs prepared for CMS by the Social Security Administration

Regardless of the primary cause of disability, MassHealth members with disabilities frequently have multiple chronic health conditions requiring complex, coordinated, and often expensive medical treatment. An analysis of claims data for members with disabilities, using a classification system developed as part of the Chronic Illness and Disability Payment System,¹⁹ found that, compared to other MassHealth members, members with disabilities have much higher rates of other conditions. For example, adult members with disabilities have 3 times the incidence of cardiovascular disease (34% compared to 10%), 4 times the incidence of diabetes (16% compared to 4%), and 4 times the incidence of cancer (8% vs. 2%). (Figure 9) Looked at on a percentage basis, approximately 45% of adults with disabilities and one-quarter of children have three or more chronic conditions. (Figure 10)

Figure 9 Members with Disabilities Have Much Higher Rates of Chronic Conditions Than Other Non-Elderly Members

| | # of Members in Analysis | Mental Disorder | Cardio-vascular | Diabetes | Cancer |
|--|--------------------------|-----------------|-----------------|----------|--------|
| Adults and Children with Disabilities | 108,880 | 54% | 30% | 14% | 5% |
| Adults and Children without Disabilities | 532,624 | 16% | 5% | 2% | 1% |
| Adults with Disabilities | 94,113 | 56% | 34% | 16% | 8% |
| Adults without Disabilities | 212,464 | 22% | 10% | 4% | 2% |
| Children with Disabilities | 14,767 | 45% | 8% | 2% | 1% |
| Children without Disabilities | 320,160 | 12% | 2% | <1% | <1% |

Note: Adults age >=18; Children age <18; No TPL during FY03

Source: UBER eligibility snapshot data FY03, FY03 Partnership claims data; FY03 encounter Data and FY03 TRAPs data using CDPS grouper

Figure 10 Members with Disabilities Are Much More Likely to Have Multiple Chronic Conditions Than Other Non-Elderly Members

| | # of Members in Analysis | <=1 Condition | 2 Conditions | 3 or More Conditions |
|--|--------------------------|---------------|--------------|----------------------|
| Adults and Children with Disabilities | 108,880 | 37% | 21% | 42% |
| Adults and Children without Disabilities | 532,624 | 80% | 12% | 8% |
| Adults with Disabilities | 94,113 | 34% | 21% | 45% |
| Adults without Disabilities | 212,464 | 69% | 16% | 15% |
| Children with Disabilities | 14,767 | 54% | 22% | 24% |
| Children without Disabilities | 320,160 | 88% | 8% | 4% |

Note: Adults age >=18; Children age <18; No TPL during FY03

Source: UBER eligibility snapshot data FY03, FY03 Partnership claims data; FY03 encounter Data and FY03 TRAPs data using CDPS grouper

These figures for Massachusetts are consistent with national data, which show that more than half of adults with disabilities report having two or more disabling conditions.²⁰ For example, over 75% of the people with cancer have another chronic illness, most often cardiovascular disease. Almost half of the people with serious mental illness also have a chronic medical condition such as diabetes or cardiovascular disease. Not surprisingly, older adults are more likely to report multiple chronic conditions than younger individuals.

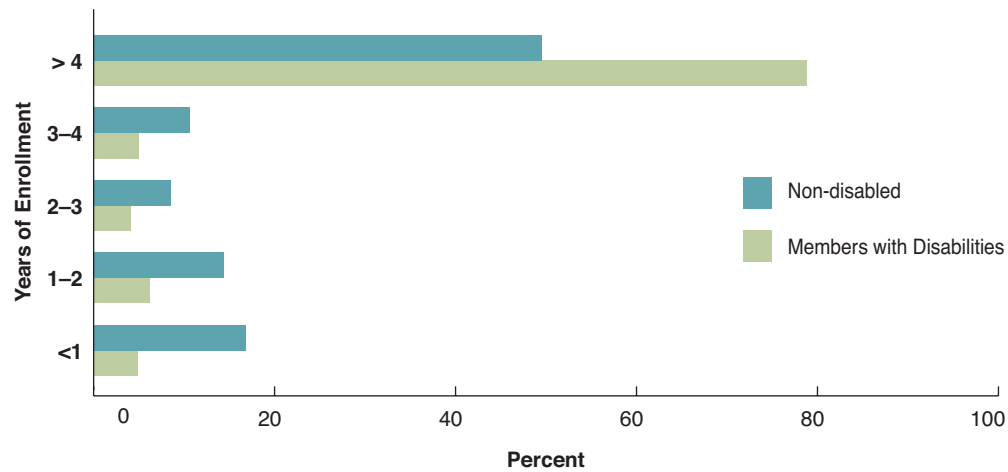
Despite the severity of their disabilities and chronic conditions, the vast majority of members with disabilities are able to live in the community, and the percentage that lives in institutional settings has been declining.

Almost all MassHealth members with disabilities live in the community and receive long-term care and supports in their homes or other community settings. Approximately 5,600 people, or 3% of beneficiaries with disabilities, live in institutional settings. The percentage of members in institutions has declined slightly over the past five years despite the growth in the total number of MassHealth members with disabilities. The rate of institutionalization among children is even lower, with fewer than 1% of children with disabilities now living in institutional settings, although capacity issues may well be a major factor in the small number of children in institutions.²¹ MassHealth coverage, and particularly benefits for community supports, plays a critical role in enabling many members with disabilities to live in the community.

MassHealth members with disabilities are a relatively stable population.

Consistent with the chronic nature of their conditions, MassHealth members with disabilities tend to be enrolled in the program longer than other MassHealth members under the age of 65. Eighty percent of members with disabilities have been enrolled for four years or more, compared to 51% of non-elderly non-disabled members. Only 10% of members with disabilities had been MassHealth members for less than two years, compared to 31% of non-disabled members. (Figure 11) The stable nature of enrollment among MassHealth members with disabilities means that state investments in care coordination, service integration, and other new programs for this population are particularly worthwhile for the MassHealth program.

Figure 11 MassHealth Members with Disabilities Are Likely to Have Longer Enrollment Than Non-disabled Members

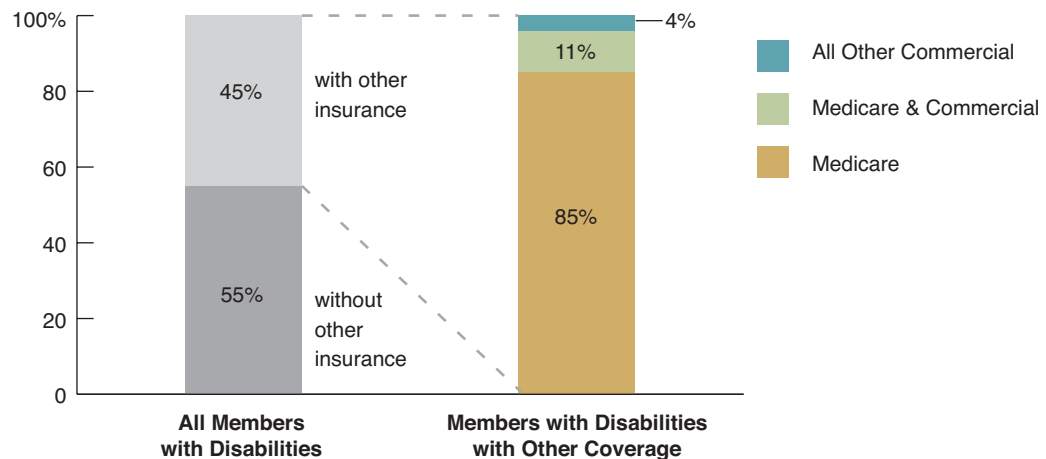


Source: 5-year study period UBER Eligibility Snapshot Data

MassHealth plays a critical role in providing coverage to supplement other health coverage, particularly medicare.

Forty-five percent of MassHealth members with disabilities have some other type of health coverage. The vast majority of these members, 85%, have Medicare as a primary insurer; the balance has some form of private health insurance. (Figure 12A) Overall, Medicare is the primary insurer for 38% of MassHealth members with disabilities. Nearly 30% of CommonHealth members and 14% of SSI disabled have commercial health insurance. (Figure 12B)

Figure 12A 45% of Members with Disabilities Have Other Insurance Coverage; 38% Have Medicare



Source: UBER eligibility snapshot data FY03

Note: Combination of LTC and Medicare variables were used to identify members with other insurance coverage.

Figure 12B Two-Thirds of Medicaid Disabled and CommonHealth Members Have Other Health Insurance Coverage, Compared to Only One-Third of SSI Disabled

| Other Insurance? | Total | SSI Disabled | Medicaid Disabled | CommonHealth |
|------------------|-------|--------------|-------------------|--------------|
| NO | 55% | 68% | 32% | 32% |
| YES | 45% | 32% | 68% | 68% |

| Percent of those with other insurance covered by: | | | | |
|---|-----|-----|-----|-----|
| Medicare | 85% | 82% | 93% | 66% |
| Medicare & Commercial | 4% | 3% | 4% | 5% |
| Commercial Only | 11% | 14% | 4% | 28% |

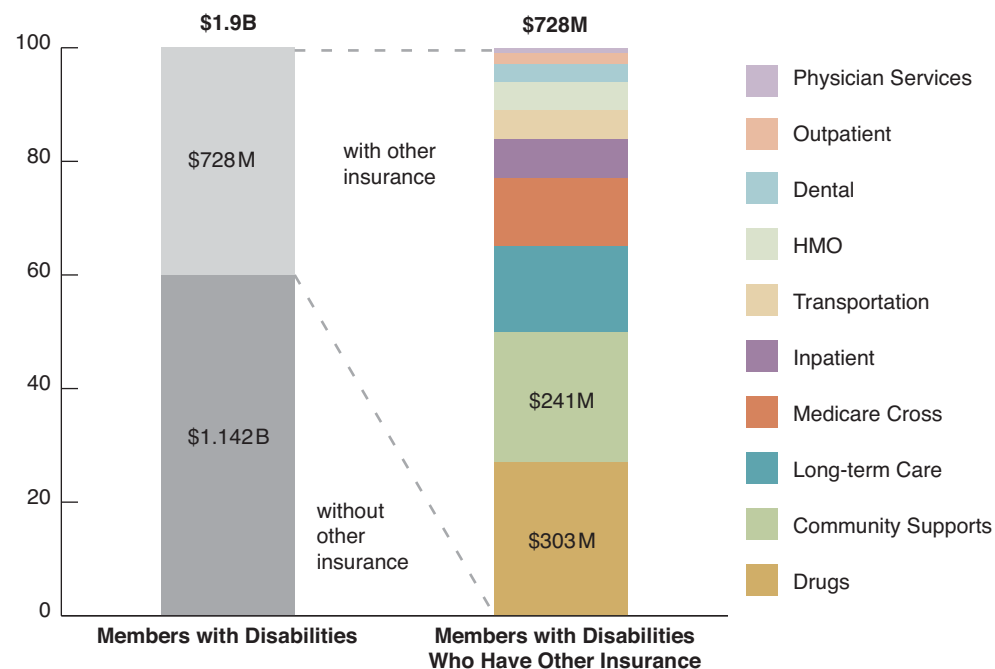
Source: UBER eligibility snapshot data FY03

The benefit gaps in Medicare and private insurance have a profound effect on Medicaid spending for people with disabilities.

Medicaid offers benefits that are essential for people with disabilities but that are typically not provided in private health plans or by the federal Medicare program. For example, many private health plans have severe limits on mental health benefits and few, if any, offer significant durable medical equipment, private duty nursing, or personal care attendant services, which are critically important for many people with chronic medical needs and disabilities. Medicare has significant cost sharing for members, provides little coverage for long-term care services, and has very limited prescription drug coverage. Medicaid fills in these gaps for Medicare members who are eligible for both programs (so-called “dual eligibles”).

The limited nature of the benefits offered by Medicare and private health insurers has a significant effect on Medicaid spending for people with disabilities, both in Massachusetts and across the country. In FY03, MassHealth spent \$728 million for members with disabilities who had other health coverage, or about 40% of total MassHealth spending for people with disabilities. (Figure 13)

Figure 13 MassHealth Spending on Those with Other Insurance is Primarily for Drugs, Community Supports and Long-Term Care



Source: TRAP claims data, FY03

The majority of this amount, approximately \$500 million, was for services provided to dual eligibles that are not generally covered by Medicare, including:

- \$300+ million on prescription drugs
- \$120 million on personal care attendant and home health services
- \$70+ million on Medicare co-payments and deductibles.

Because of other health coverage and state policy decisions, relatively few MassHealth members with disabilities get their care through contracted managed care organizations.

MassHealth members with disabilities obtain their care in one of three ways:

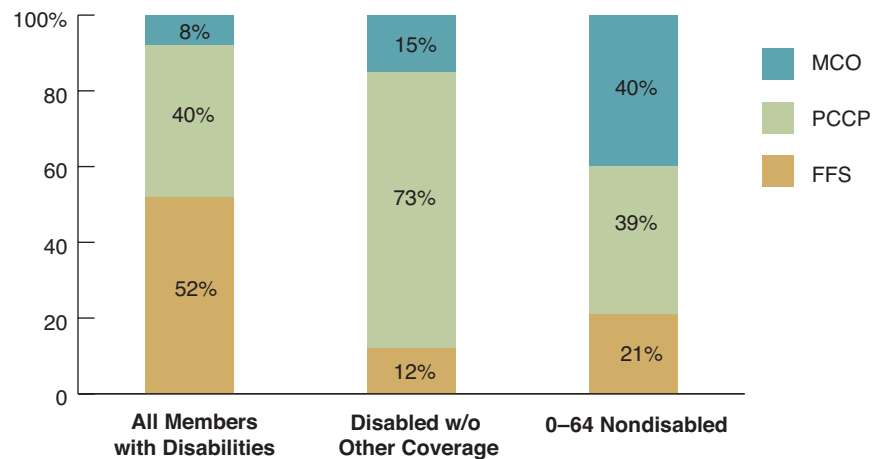
- *Primary Care Clinician Plan (PCCP)*, a managed care plan that is administered by the Commonwealth. Members in the PCCP choose a primary care clinician who provides most of their medical care and refers them as appropriate for/to other services. The PCCP pays providers on a fee-for-service basis, with a primary care enhancement paid for certain services. Members enrolled in the PCC Plan receive their behavioral health services through a behavioral health carve-out, currently contracted out to the Massachusetts Behavioral Health Partnership (MBHP), which is paid on a capitated basis. MBHP also provides some network management services for the PCCP.
- *Managed Care Organizations (MCOs)*, in which a member enrolls in one of four MCOs that contract with Medicaid, each of which requires members to select a primary care clinician and to receive most services from the plan's contracting network of providers. Three of the four MassHealth MCOs serve exclusively or primarily MassHealth members and only one, Fallon, is primarily a commercial health plan.
- *The fee-for-service program* is a non-managed care system in which members may obtain care directly from providers and Medicaid pays for that care on a fee-for-service basis.

Most members with disabilities who do not have other health coverage must enroll in the PCCP or an MCO. Members who do not affirmatively chose a plan within the allotted time frame are automatically enrolled into the PCCP.²² However, it is current MassHealth policy that members with other forms of health insurance—regardless of their disability status—must receive their care on a fee-for-service basis and may not enroll in either the PCCP or an MCO.²³ This policy is codified in the state's 1115 waiver, which has been negotiated with and approved by the federal government. The basis for this state policy decision is the difficulty of developing a capitated MassHealth payment rate that would accurately reflect the portion of health services that would be covered by the primary payer, and the difficulties in coordinating care that is being provided by more than one payer.

As a result of this policy decision, the vast majority of members with disabilities are covered through either the fee-for-service (52%) program or the PCCP (40%). Only 8% are enrolled in contracted MCOs. This contrasts sharply with the non-disabled under-65 population, where 40% are enrolled in MCOs, 39% are covered by the PCCP, and only 21% are in the fee for service program. (Figure 14)

As would be expected, given the differences in other insurance coverage across disabled eligibility groups, there is significant variation in managed care enrollment within the sub-groups of members with disabilities. The majority of CommonHealth and Medicaid members, most of whom have other health coverage, are in the fee-for-service program. In contrast, 62% of the SSI Disabled population, most of whom do not have other coverage, participates in one of the managed care programs, most in the PCCP.

Figure 14 MassHealth Members with Disabilities Are Much Less Likely To Be Enrolled in Managed Care Plans, Particularly in Managed Care Organizations



Source: UBER eligibility snapshot data FY03

Of the members with disabilities who enroll in an MCO, a little less than half are in the Boston Medical Center HealthNet Plan (BMCHP), and one-quarter are members of the Cambridge Network Health Plan. (Figure 15) Since 1999, the percent of members with disabilities enrolled in MCOs has been fairly steady, increasing slightly from 6% to the current 8%.

Figure 15 Number of Members with Disabilities Enrolled in Managed Care Organizations

| Managed Care Organizations (MCO) | Number of Members | % of Member with Disabilities Enrolled in MCOs |
|--------------------------------------|-------------------|--|
| Boston Medical Center HealthNet Plan | 9,160 | 55% |
| Cambridge Network Health Plan | 4,049 | 24% |
| Neighborhood Health Plan | 2,493 | 15% |
| Fallon Community Health Plan | 941 | 6% |
| Total | 16,698 | 100% |

Source: UBER eligibility snapshot data FY03

Section 3 Notes

¹⁷ Though everyone in this group receives SSI benefits, some may also receive SSDI, or Social Security Disability Income, cash benefits. In addition, SSDI recipients may be in any of the other categories as well.

¹⁸ MassHealth Adult Disability Determinations Approved based on SSI Impairment Listings Cases Received Between July 1, 2002–June 30, 2003, University of Massachusetts Medical School Disability Evaluation Services.

¹⁹ The Chronic Illness and Disability Payment System was designed to help Medicaid programs make risk-adjusted, health-based payments for Medicaid beneficiaries with disabilities. The system groups chronic conditions according to 18 categories. For this analysis, these 18 categories were further collapsed into only three, physical disabilities, mental disabilities, and MR/DD. See Kronick R., Gilmer T., Dreyfus T., and Lee L., Improving Health-Based Payment for Medicaid Beneficiaries: CDPS. *Health Care Financing Review* 21 (3):29-64, Spring 2000.

²⁰ Source: U.S. Census 2000, National Medical Expenditure Panel Survey 1996, Medical Expenditure Survey 1998.

²¹ The Medicaid criteria for pediatric nursing home placement are very stringent. In addition, the lack of long term institutional placement options for children with severe disabilities is a constraint on the number of children who can be cared for in institutional settings. As a result, many parents care for children at home but only with tremendous need for resources and supports. As these children and their parents age, the state will face a growing challenge of caring for young adults with significant medical problems.

²² Members may change their plan at any time and are not locked into a provider or plan assignment for any minimum period of time. However, very few members change plans.

²³ Some members with disabilities who have other health coverage are enrolled in managed care plans through their primary insurance plan

Profile: Sophia

The first time Sophia was hospitalized for depression was after her third suicide attempt—at age 12. Doctors had never before diagnosed her illness properly, apparently believing her earlier suicide attempts, beginning at age 9, to be the result of the difficult circumstances of a childhood no one should have to endure.

Sophia spent the first six years of her life in England, where she lived with an aunt before being sent to her mother in Boston. Her mother, diagnosed with schizophrenia in her 40s, was physically abusive, and the little girl was sexually abused by an uncle as well. By 13, Sophia was working — “I lied about my age and got a job at Kentucky Fried Chicken,” she says, “because you could eat there” — and had moved into the first of a series of foster and group homes she would live in until the age of 16 when she married her high school sweetheart “just to get out of the house.” By 22, Sophia was divorced and the single mother of two sons.

Sophia saw many of her struggling relatives and neighbors turning to drugs or alcohol, but says, “I could never understand why people don’t believe in seeking help but will seek a bottle or a narcotic.” And, unlike the majority of young single mothers—and many people with severe bipolar disorder, which was how doctors eventually diagnosed her disease—Sophia finished high school and went on to UMass Boston where she graduated with a degree in business management. Until the past few years, when another pregnancy triggered a devastating depressive episode, Sophia always worked, usually as an office manager or administrative secretary. “But I never stayed at one job long enough to work up the ladder,” she says. “I always got sick and started to feel like a hamster running on that little circle thing. I had to leave and go someplace else.”

Still, the health insurance she received from her employers helped keep her functioning and provided care for her two sons: Jonathan, who has asthma, and Brandon, who has ADHD and autism. But after her third son, Isaiah, was born, Sophia experienced severe postpartum depression, and could no longer work. On top of everything, at around the same time, her husband, a limousine driver, lost his job after hurting his back.

“SSI came after Isaiah was born,” she says, “and with my husband out of work, that’s our only income.” Sophia recently started a new prescription, Lamictal, to help with her bipolar disorder, and says it’s “doing wonders” and is the first drug that has ever really helped her. “But just to keep me steady,” she adds, “we’re down to bare-knuckle things—food and medicine. And at one point we were playing Russian roulette with the medicine; I’d get some stuff for Brandon, some stuff for Jonathan, and some stuff for me. No one was getting their full prescriptions, because we couldn’t afford the copays. You can’t yoyo someone on medication like that.”

Though she recently received notice that her copays were going to increase, being on MassHealth allows her to see her current primary care physician. “Even on days when I come in and I’m not myself,” Sophia says, “my doctor speaks to me with respect. She doesn’t talk down to me, doesn’t belittle me like some other doctors have done. She lets me hold onto my dignity.” And that, to Sophia, is worth its weight in gold.

Section 4 Recent Trends in Enrollment and Spending for MassHealth Members with Disabilities

Data Note: The spending numbers used in this section of the analysis do not currently include capitation payments made to Boston Medical Center HealthNet Plan or Cambridge Network Health Plan. Since approximately 8% of members with disabilities are enrolled in MCOs, the absence of these MCO capitation payments will lead to a slight underestimate of total spending, and limits our ability to evaluate the impact of managed care on program costs.

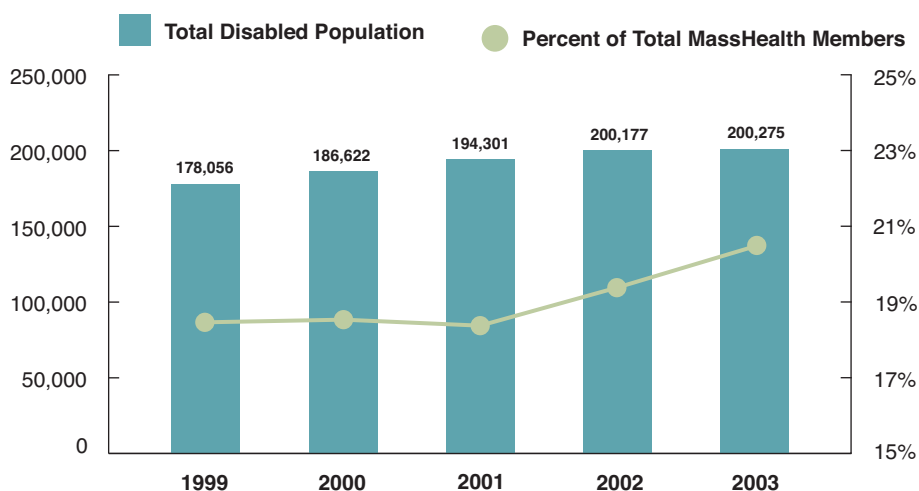
In addition, the spending figures include only direct MassHealth spending. Another source of state spending on MassHealth members with disabilities is for services that are provided by or through other state agencies and that are a “pass-through” for purposes of capturing federal reimbursement. While eligible for federal matching funds as a Medicaid expense, these services are separately accounted for and detailed claims data were not included in this analysis. In FY03, Massachusetts obtained \$880 million in federal matching funds for “pass-through” services for people with disabilities, which would represent an increase of 46% in total spending for members with disabilities. In contrast, pass-through services for non-disabled members in FY03 totaled \$280 million, or 18% of total spending. Over 50% of these funds supported residential, adult day services, home- and community-based waiver services and case management services provided by other state agencies, including the Massachusetts Department of Mental Health (DMH) and the Department of Mental Retardation (DMR). These pass-through dollars are not included in the spending numbers in this report.

All spending figures are nominal dollars and not adjusted for inflation

The number of MassHealth members with disabilities is growing, both in absolute terms and as a percent of total MassHealth enrollment.

Since 1999, the number of MassHealth members with disabilities has increased by nearly 23,000, an increase of 13%. (See Figure 16) As a result of this growth, combined with an overall decline in total MassHealth enrollment, the percent of MassHealth members who are eligible on the basis of disability has increased from 19% to 21%.

Figure 16 Number of MassHealth Members with Disabilities FY99–03



Source: UBER eligibility snapshot data

All of the increase in the number of members with disabilities has occurred in the so-called “optional” enrollment categories, with the vast majority of increased enrollment coming in the Medicaid Disabled category (+17,066 members, or 75% of the increase), although the largest

percentage increase has occurred in the CommonHealth program (+6,900 members, an increase of 88%). The SSI Disabled category has declined slightly. (Figure 17) Virtually all of the new members have been adults; the number of children with disabilities has grown by about 1,200, mainly in the SSI and CommonHealth eligibility categories.

Figure 17 The Number of MassHealth Members with Disabilities Has Grown by 13% Since 1999, Primarily in the Medicaid Disabled Category

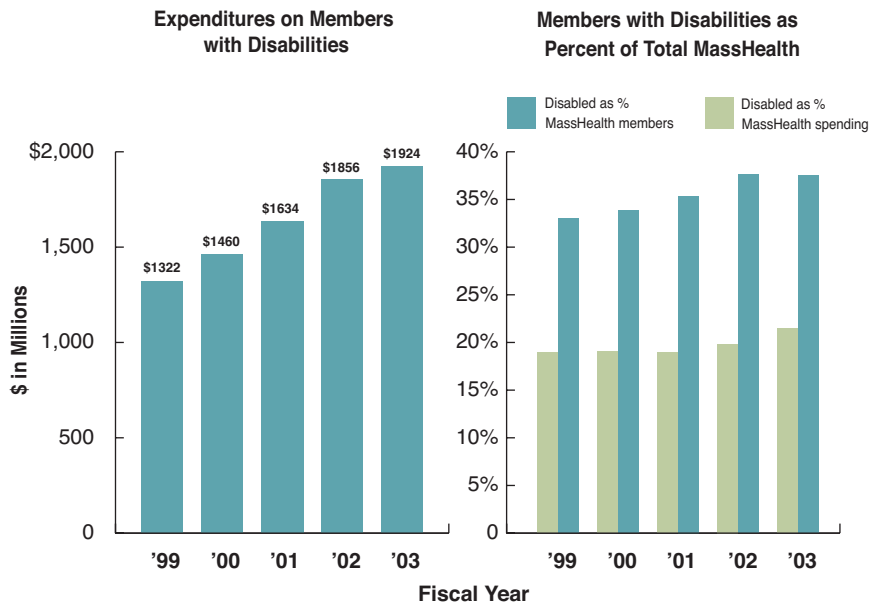
| | FY 99 | FY 03 | Increase | % Increase 99-03 |
|--------------------------|---------|---------|----------|------------------|
| Total | 178,056 | 200,725 | +22,669 | +13% |
| Adults | 159,439 | 180,883 | +21,444 | +13% |
| Children | 18,617 | 19,842 | +1,225 | +7% |
| SSI Disabled | 128,555 | 127,292 | -1,263 | -1% |
| Adults | 113,126 | 111,227 | -1,899 | -2% |
| Children | 15,429 | 16,065 | +636 | +4% |
| Medicaid Disabled | 41,763 | 58,829 | +17,066 | +41% |
| Adults | 40,777 | 57,932 | +17,155 | +42% |
| Children | 986 | 897 | -89 | -9% |
| CommonHealth | 7,738 | 14,604 | +6,866 | +88% |
| Adults | 5,536 | 11,724 | +6,188 | +112% |
| Children | 2,202 | 2,880 | +678 | +31% |

Source: UBER eligibility snapshot data FY03

Spending on members with disabilities is increasing as a proportion of total MassHealth spending, and now accounts for 38% of total spending.

Overall spending on MassHealth enrollees with disabilities increased from \$1.3 billion in FY99 to \$1.9 billion in FY03. This represents an overall increase of 45%, and an annual growth rate of nearly 10% per year. (Figure 18) The share of total MassHealth spending going to services for members with disabilities rose from 33% in FY99 to 38% in FY03.

Figure 18 Expenditures for Members with Disabilities Are a Growing Share of Total MassHealth Spending

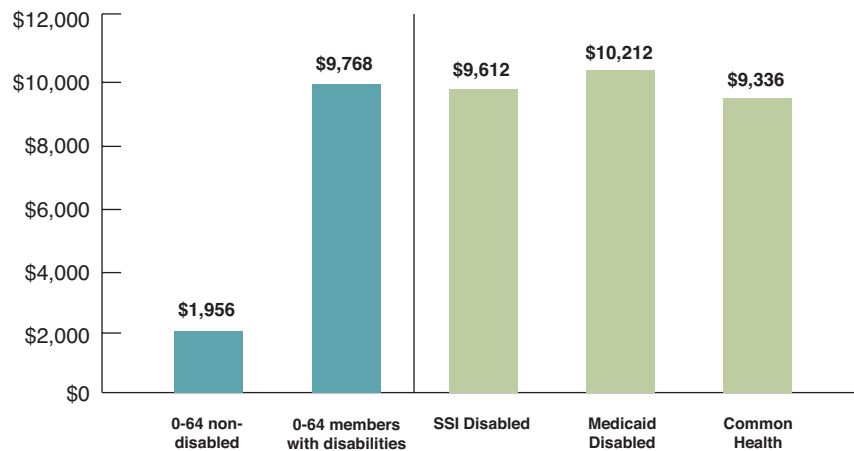


Source: UBER eligibility snapshot data TRAP claims data

The average per member spending for MassHealth members with disabilities is 5 times that for non-disabled non-elderly MassHealth members

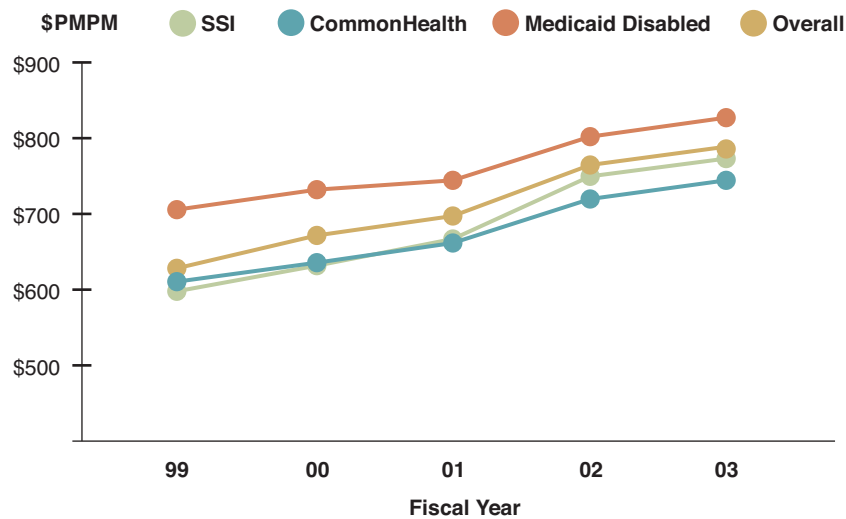
Because of their level of disability and the chronic nature of their medical needs, average per member spending for MassHealth members with disabilities is much higher than for other non-elderly MassHealth members. In FY 03, the average annual expenditure for in MassHealth members with disabilities was approximately \$9,800, compared to about \$2,000 for non-disabled enrollees. (Figure 19) Average spending per member was similar for the three major categories of enrollees with disabilities, and the rate of increase in spending is also similar. (Figure 20)

Figure 19 Average Annual Per Member Spending for MassHealth Members with Disabilities and Non-Disabled Members



Source: TRAP claims data FY03
Note: BMCHP and Network Health Capitations were not available for this analysis

Figure 20 Per Member Spending Trends are Similar Among All Categories of MassHealth Members with Disabilities



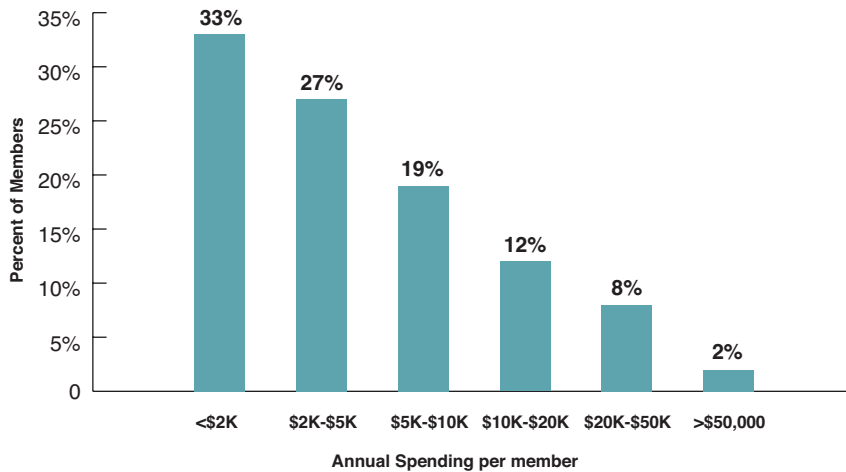
Source: TRAP claims data

Spending on members with disabilities is not evenly distributed across sub-populations.

Average spending varies according to several distinct parameters. As with all populations, a relatively small portion of the population accounts for a majority of the spending. In FY03, 10% of the under-65 population with disabilities accounted for 51% of total expenditures; 30% of the population accounted for 79% of total spending.

Average annual spending per member also varies widely: one-third of members have spending less than \$2,000, while 10% of members have spending greater than \$20,000. (Figure 21A)

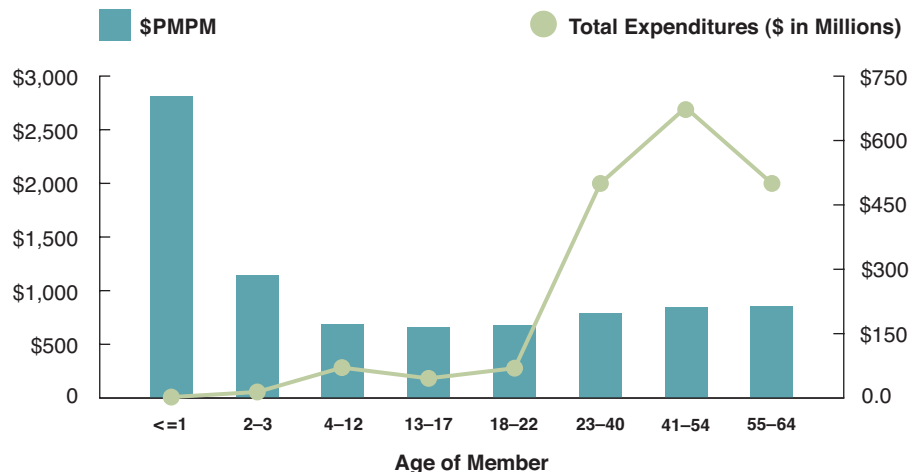
Figure 21A One-Third of Members Have Annual Spending Per Person Under \$2,000; Ten Percent of Members Have Annual Spending Per Person That Exceeds \$20,000



Source: TRAP claims data as of January 04

Within the population of people with disabilities, the most costly group on a per capita basis is very young children. Average annual spending on children less than one year old is nearly \$34,000; for children aged two to three years, average spending is nearly \$14,000. However, because most members with disabilities are older adults, total expenditures are the greatest for the age group from 41–64 (which accounts for nearly two-third of total costs), while children less than one year old represent less than 1% of total spending and members under age 18 less than 10 percent of spending. (Figure 21B)

Figure 21B While Spending Per Member is Highest for Children Under the Age of 4, the Majority of Total Spending Is for Adults with Disabilities

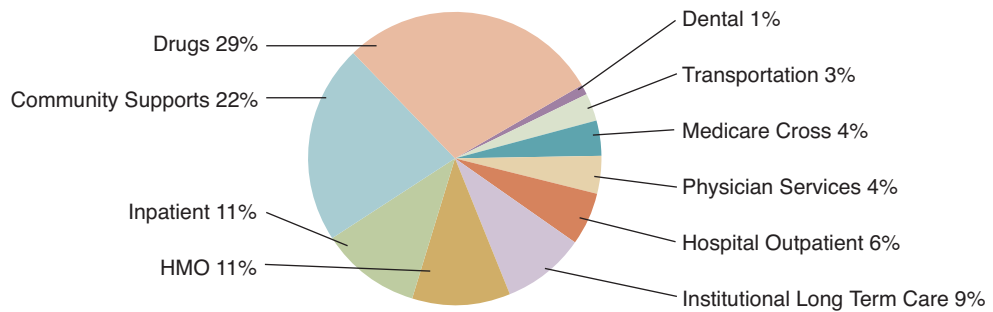


Source: UBER Eligibility Snapshot Data FY03. TRAP claims data FY03

Nearly two-thirds of total spending for MassHealth members with disabilities is devoted to prescription drugs, community supports, and institutional long-term care.

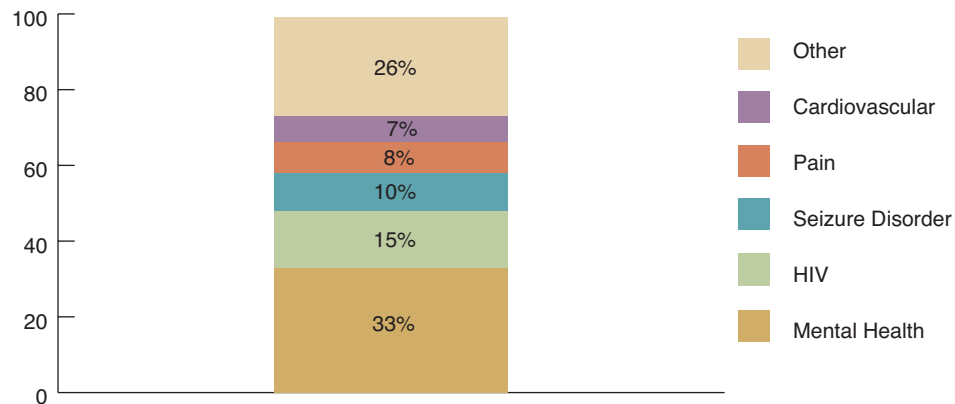
As shown in Figure 22, nearly 30% of expenditures for people with disabilities is for outpatient prescription drugs. One-third of drug spending goes for drugs used to treat mental health problems; another 15% of spending is for drugs used to treat HIV. (Figure 23)

Figure 22 The Majority of Spending for MassHealth Members with Disabilities Goes for Prescription Drugs and Community Supports



Source: TRAP claims data FY03

Figure 23 At Least Half Of Prescription Drug Spending for Members with Disabilities Is for Mental Health and HIV Drugs

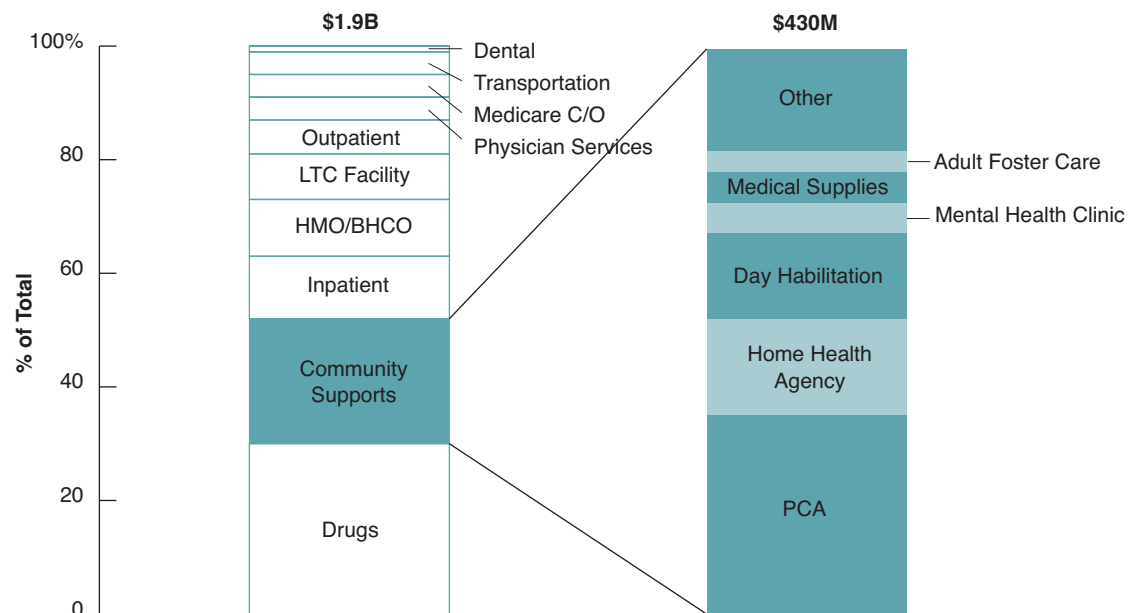


Source: UBER eligibility snapshot data FY03, FY03 Partnership claims data; FY03 encounter Data and FY03 TRAPs data

The second highest expenditure area (22%) is community supports, including personal care attendants, home health care (including private duty nursing), day habilitation, mental health clinics, adult foster care, and a variety of other supportive medical services. (Figure 24) Another 11% of spending is for institutional long-term care services, primarily nursing homes. (As noted above, the pass-through claims, which include home and community-based waivers and ICFs-MR, are not included in this analysis.)

Hospital services, both inpatient and outpatient, account for 17% of spending, while physician services account for only 4% of expenditures. MassHealth spending in these areas is relatively low because a significant portion of these services for people with MassHealth members with disabilities is paid by Medicare and private health insurers. In contrast, long-term care and community supports are not generally covered by Medicare program or by private health insurers, and Medicare has very limited coverage for outpatient prescription drugs.

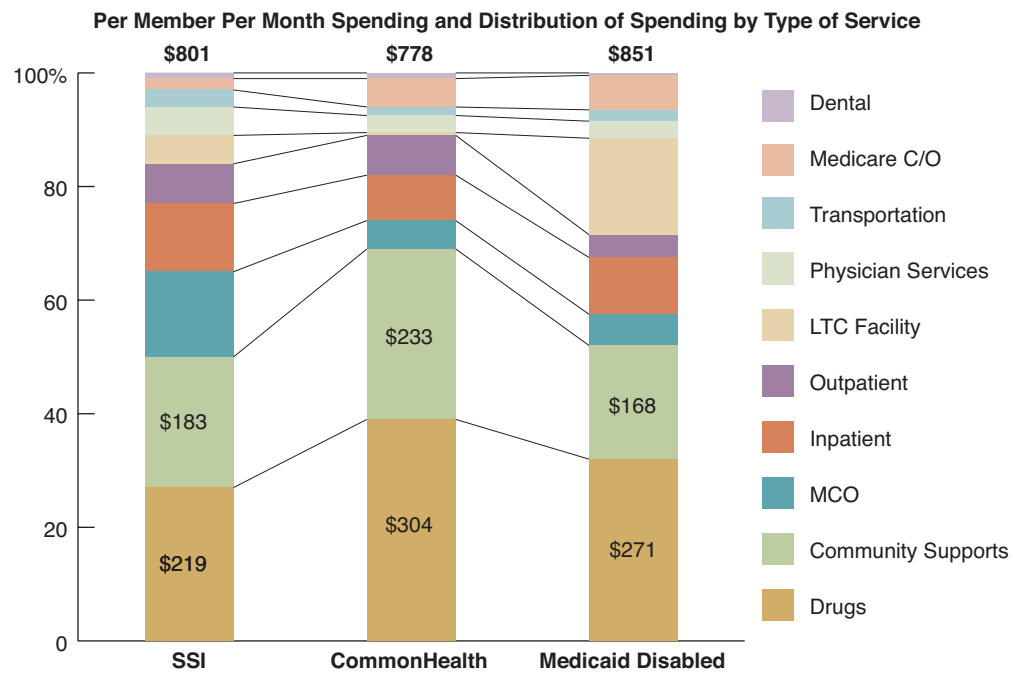
Figure 24 Community Supports (PCA, Home Health, and Day Treatment Programs) Account for Nearly One-Quarter of Total Spending



Source: TRAP claims data FY03

The distribution of expenditures across service categories is relatively similar among different eligibility categories. (Figure 25) Prescription drug spending is the most significant type of spending across all categories of member with disabilities. The CommonHealth population uses relatively more prescription drugs and community support services, while the Medicaid Disabled population uses relatively more long-term facility care.

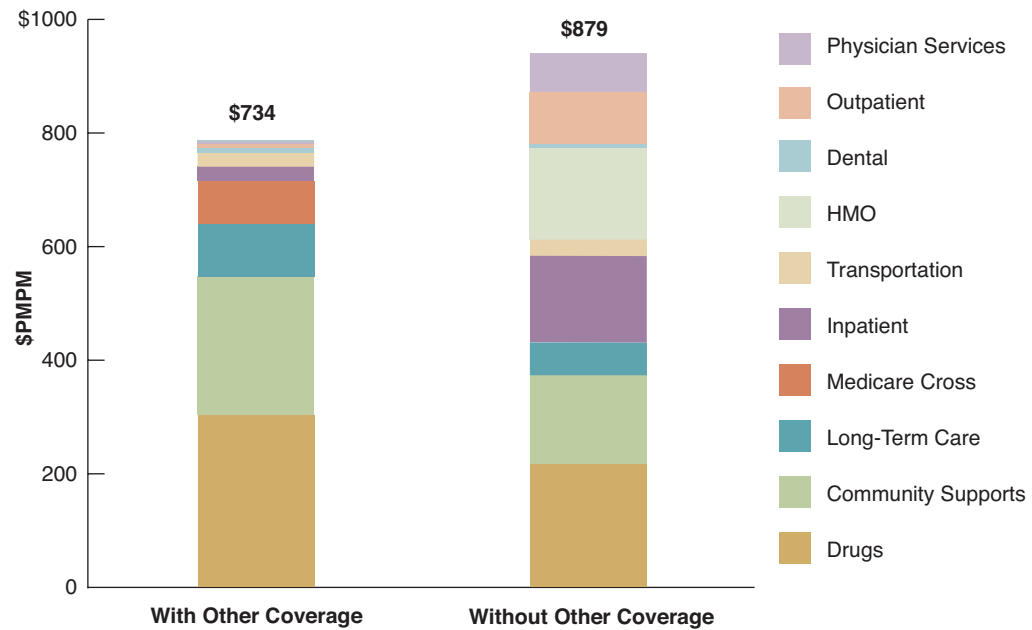
Figure 25 Drug Spending and Community Supports Represent the Most Significant Portion of Expenditures Across All Disabled Eligibility Categories



The pattern of spending varies significantly for members who have other insurance coverage and those who do not.

There are significantly different MassHealth spending patterns between enrollees with and without other forms of coverage.²⁴ MassHealth spending is lower for members who have other insurance, but these members rely on MassHealth to provide coverage for essential services that are generally not provided by Medicare or commercial health insurance. Over half of the MassHealth spending for members with disabilities who have other health insurance is for prescription drugs and other community supports, such as personal care attendants, that are not covered by Medicare. (Figure 26)

Figure 26 MassHealth Spending per Member per Month Is Higher for Those Without Other Coverage, and Pays for a Different Mix of Services

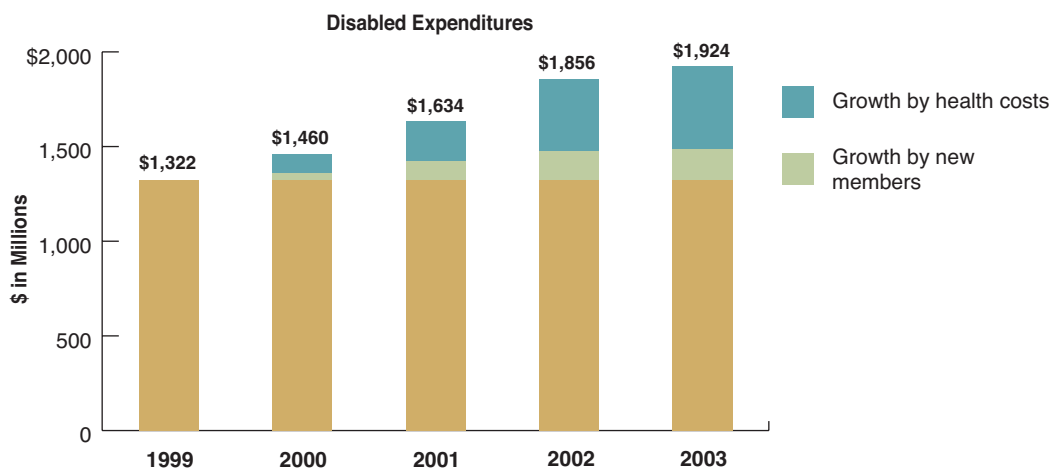


Source: TRAP claims data FY03

Most of the increase in MassHealth spending for people with disabilities is coming from rising health care costs rather than growth in membership.

Although there has been an increase in the number of MassHealth members with disabilities, 70% of the increase in spending for members with disabilities has come from rising medical costs, with only 30% related to increase in enrollment. (Figure 27)

Figure 27 More Than 70% of Spending Growth for Members with Disabilities Has Come from Rising Health Care Costs and Use, Rather than Enrollment Growth

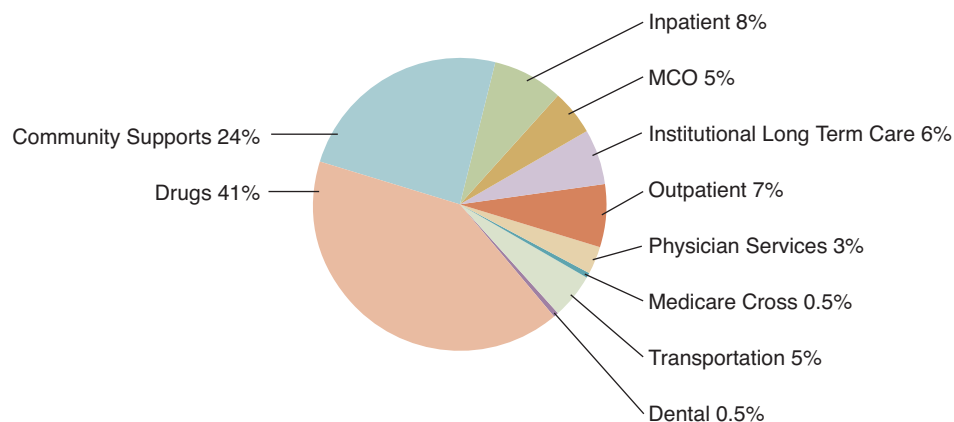


Source: UBER eligibility snapshot data. TRAP claims data.

Much of the growth in per member spending for people with disabilities is being driven by prescription drugs and community supports, particularly PCA services.

Over the past four years, 41% of the total increase in spending for MassHealth members with disabilities has been devoted to prescription drugs, and another 24% to community supports. (Figure 28)

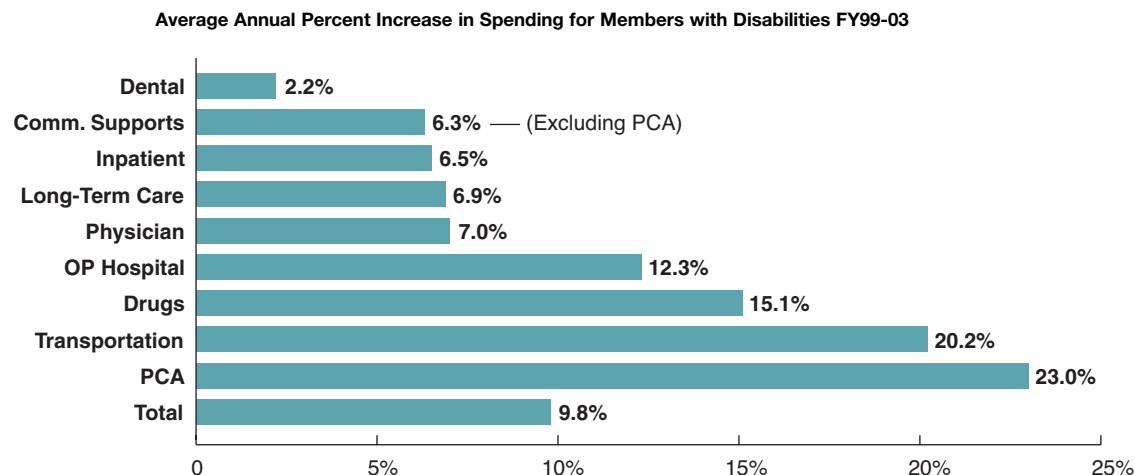
Figure 28 The Growth In Disabled Spending Has Been Driven Primarily by Prescription Drugs and Community Supports



Source: TRAP claims data

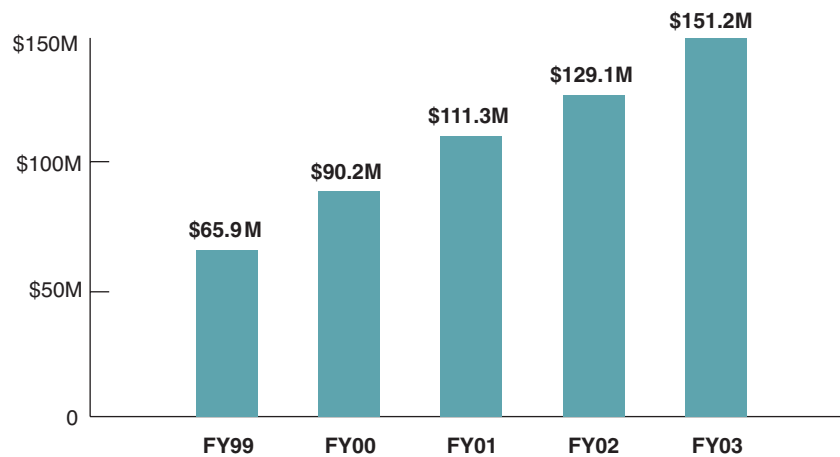
The annual rate of increase in spending by service type was greatest for PCA services (23% per year) and transportation (20%), followed by outpatient drugs (15%), outpatient hospital (12%), and community supports (11%). (Figure 29 and 30) The rate of increase in PCA spending is due to an increase in the number of members who are using these services, the amount of services used per member, and increases in provider payment rates.

Figure 29 PCA, Transportation, Drugs and Outpatient Hospital Are Growing Much Faster Than Other Services.



Source: TRAP claims data

Figure 30 Spending on PCA Services Has More Than Doubled in the Past Four Years and Now Accounts for 8% of Total Spending for MassHealth Members with Disabilities



Source: TRAP claims data

Because spending on members with disabilities is concentrated in areas of high cost increases, growth in spending per person for MassHealth members with disabilities is more than twice the growth in spending for members without disabilities.

From FY99 to FY03, the compound annual growth rate for in spending per member with disabilities was 6.7%, compared to a 2.5% growth rate in spending per non-disabled member. (Figure 31) The difference in the rate of growth of per member spending had the most significant impact on total spending for hospital services, pharmacy, and community supports.

Figure 31 The Rate of Growth in Spending per Person for Members with Disabilities Is More Than Twice the Growth for Non-Disabled Members

| | Members with Disabilities | | | Non-Disabled Non-Elderly Members | | |
|---------------------|---------------------------|--------------|-----------------------------------|----------------------------------|--------------|------------------------------------|
| | FY99 PMPM | FY03 PMPM | FY99 – FY03 Annual Growth Rate | FY99 PMPM | FY03 PMPM | FY99 – FY 03 Annual Growth Rate |
| Drugs | \$154 | \$240 | 11.8% | \$15 | \$20 | 7.4% |
| Community Supports | \$135 | \$182 | 7.7% | \$10 | \$11 | 2.6% |
| Inpatient | \$79 | \$90 | 3.5% | \$31 | \$32 | 0.9% |
| HMO | \$82 | \$86 | 1.2% | \$49 | \$52 | 1.6% |
| Long-Term Care | \$60 | \$70 | 3.8% | \$1 | \$1 | -4.8% |
| Outpatient Hospital | \$35 | \$50 | 9.1% | \$16 | \$18 | 3.7% |
| Physician Services | \$30 | \$35 | 3.9% | \$19 | \$18 | -0.5% |
| Medicare Cross | \$33 | \$30 | -2.2% | \$0 | \$0 | -3.6% |
| Transportation | \$12 | \$23 | 16.8% | \$1 | \$2 | 20.5% |
| Dental | \$7 | \$7 | -0.7% | \$6 | \$8 | 8.6% |
| Total | \$628 | \$814 | 6.7% | \$148 | \$163 | 2.5% |

Source: TRAP claims data

Section 4 Notes

²⁴ Of course, these MassHealth spending figures give only a partial picture of *total* spending for members with other coverage, since they do not include the cost of services that are covered by Medicare or private health insurance

Profile: Ray

In 1968, Ray was a guy who had everything: a sociology degree from Harvard, a promising job at a startup research company, a beautiful young wife, robust health, and a brand new forest green English Ford Cortina he'd named Cedric. Until one winter day when he was driving that Cortina from Boston to visit his gravely ill grandmother in Ohio. "There was a blinding snow-storm," he recounts. "These two idiots in front of me had a minor fender-bender, and decided to back up to the turnpike exit to report it. So I come out of the snow and suddenly see white lights coming at me. I couldn't go around them because somebody was passing me."



Though he was going slow at the time, his car was totaled, and the impact was enough to fracture his wife's vertebra and Ray's skull. "When I opened my eyes," he says, "there was a broken tooth on my lap. I'd hit my chin on the steering wheel, and all my front teeth had come through my lower lip. So I said okay, I can live with that."

What he didn't know was that all the talking he was doing to the police who had arrived at the accident scene was causing a jagged edge of his skull to scrape against an artery in his brain, eventually severing it. He walked into the hospital's emergency room and collapsed, waking after a month in a coma to find himself paralyzed on his left side. He spent seven more months in Mass. General's rehab unit, and was released in a wheelchair to enter a world of barriers.

"The doctor said he had never seen such physically devastating brain injuries with no cognitive consequences," Ray says. "I said, 'You didn't know me before.'"

Kidding aside, IQ tests have shown Ray to be at full mental capacity—which he proved by returning to work part-time the week after he was discharged from the hospital. He would eventually become his firm's longest tenured full-time associate; and in 1999 he earned a social policy Ph.D. from Brandeis. Still, the intervening years have been rough, with bouts of severe depression, divorce, and even a couple of suicide attempts. With the small settlement he got from a lawsuit over the

crash, Ray paid off his remaining hospital bills—having exhausted three insurance policies and finding himself 6000 1970 dollars in debt—and put a down payment on a small house in Belmont.

Since 1970 he has had at least two personal care assistants at all times. Because employer health plans do not cover the help he needs to get out of bed and off to work each morning, he paid for the PCAs out of pocket until CommonHealth came along. "I was barely making it," he says, "even with a full-time job and my wife working." With CommonHealth as supplemental insurance coverage, Ray receives the paid in-home assistance he needs, and he credits it with allowing him to return to graduate school after a long hiatus and earn his doctorate. Since his wife divorced him four years ago, Ray finds his Medicaid coverage especially crucial. "Without CommonHealth," he says, "I'd be sunk. I'd be in a nursing home."

As it stands, he is the proud father of two sons, a dedicated member of the workforce, a Massachusetts taxpayer, and a leader in his community. "Your job defines who you are," he says, "and it's partly a social thing as well. My church activities are also very important to me, and I wouldn't have those if I couldn't live independently. I'm on a couple of town committees, and am chair of Belmont's Disability Access Commission."

He pauses, contemplating a future without these things. "If I were in a nursing home," he concludes, "I'd probably become suicidal again."

Section 5 How Does Massachusetts Compare to Other States In Terms of Medicaid Coverage for People with Disabilities?

It is difficult to make meaningful comparisons among Medicaid programs for several reasons. First, although Medicaid is co-financed and regulated by the federal government, there are tremendous differences in Medicaid programs from state to state, in terms of eligibility, covered benefits and other program features that have major implications for enrollment and spending. Second, it is very difficult to get current comparable data across state Medicaid programs. In particular, most of the readily available information on Medicaid spending for people with disabilities includes both non-elderly and elderly members who are eligible for coverage by virtue of disability.

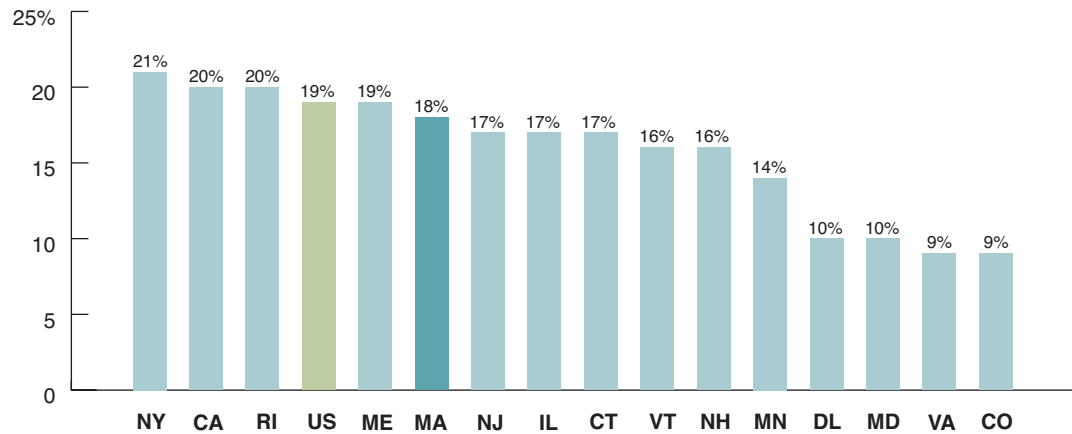
Nevertheless, it is important to try to put the MassHealth program in a broader context. This section of the report attempts to compare the MassHealth program for people with disabilities to national averages, as well as to a set of “peer states” that includes other New England states and other high-income states, defined as states that qualify for the same federal medical assistance percentage (FMAP) as Massachusetts.²⁵ Since the FMAP varies inversely with state income, these peer states are similar in the state resources they could make available to support the Medicaid program.

The other FMAP states included in our comparison group are: California, Colorado, Connecticut, Delaware, Illinois, Maryland, Minnesota, New Hampshire, New Jersey, New York, Virginia, and Washington. Maine, Rhode Island, and Vermont are also included.

The prevalence of disability in Massachusetts is comparable to the national average and most other peer states, using a range of measures

Massachusetts is similar to the national average in the proportion of the population that has a disability, based on a number of different measures. For example, based on U.S. Census data, 18% of Massachusetts residents age 21-64 report that they are disabled, comparable to the national average and to many other states. (See Figure 32) The proportion of the state’s population that receives SSI is also very similar to national averages, at 2.6% and 2.2% respectively. (Figure 33) In addition, as shown in Figure 34, 16% of adults with disabilities in Massachusetts have incomes at or below the federal poverty level, slightly lower than the national average but similar to the poverty level in most peer states.

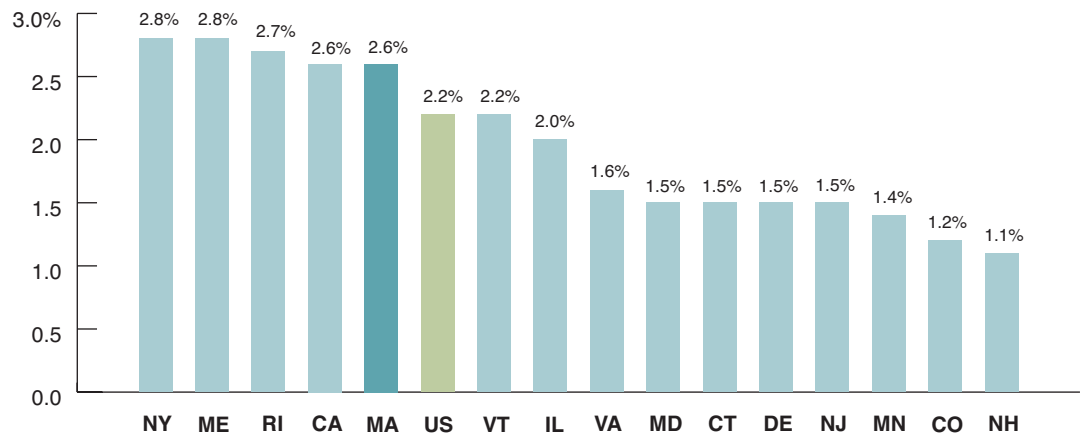
Figure 32 Percent of State Population Age 21–64 Who Are Disabled Using the U.S. Census Definition



Source: U.S. Census 2000, Summary File 3

Note: Percentage equal to the number of people 21–64 who reported a disability, divided by total population of the state, age 21–64, according to the U.S. Census 2002

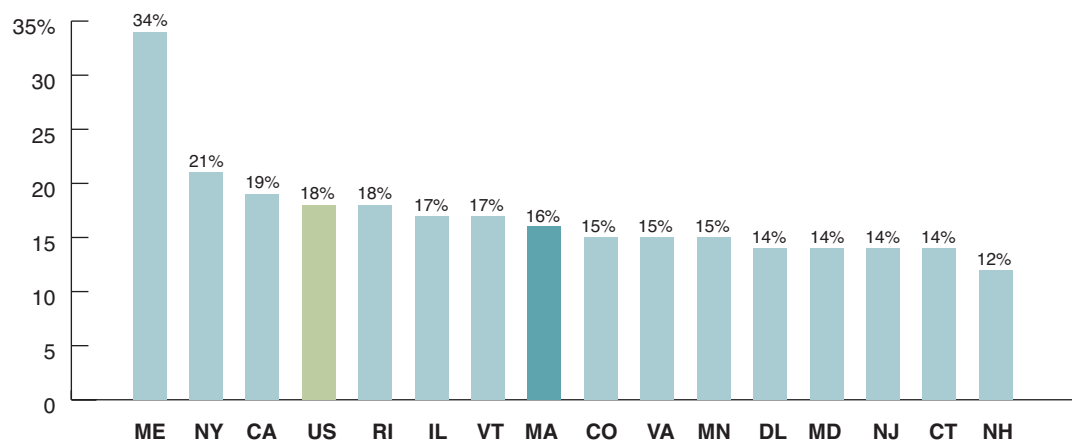
Figure 33 Percent of State Population Age 18–64 Receiving SSI Benefits, 2002



Source: SSA, SORD file. SSI Recipients by State 2002

Note: Percentage is equal to the number of persons receiving SSI during 2002, ages 18–64, divided by the total number of people in the state according to the U.S. Census 2000.

Figure 34 Percent of People with Disabilities Age 21–64 Whose Income Is At or Below the Federal Poverty Level

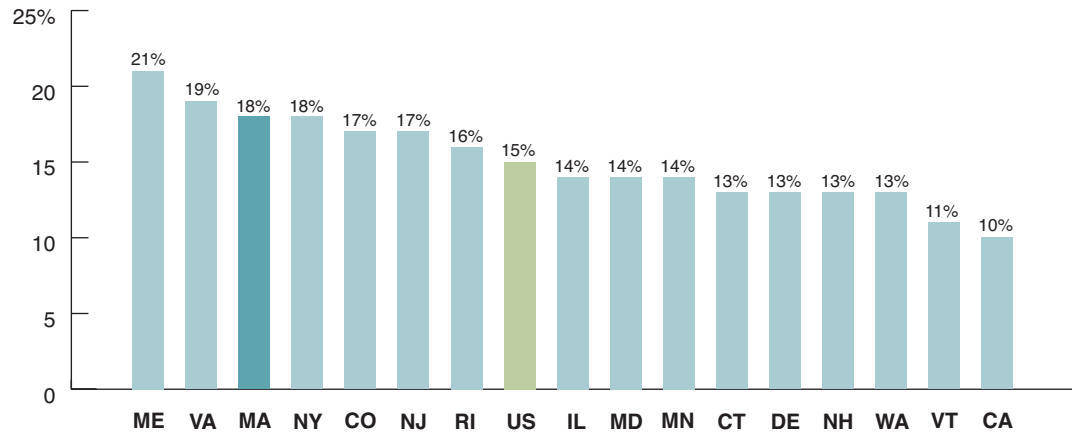


Source: Census 2000, Summary File 3

The percent of total MassHealth members eligible on the basis of disability is slightly higher than the national average but comparable to most peer states.

In 2000, the proportion of Medicaid members with disabilities varied widely across states, from 10% in California, to 21% in Maine. At 18%, the proportion in Massachusetts was higher than the national average of 15%, but comparable to many peer states. (Figure 35)

Figure 35 Percent of Total Medicaid Members Eligible on the Basis of Disability in Massachusetts and Peer States

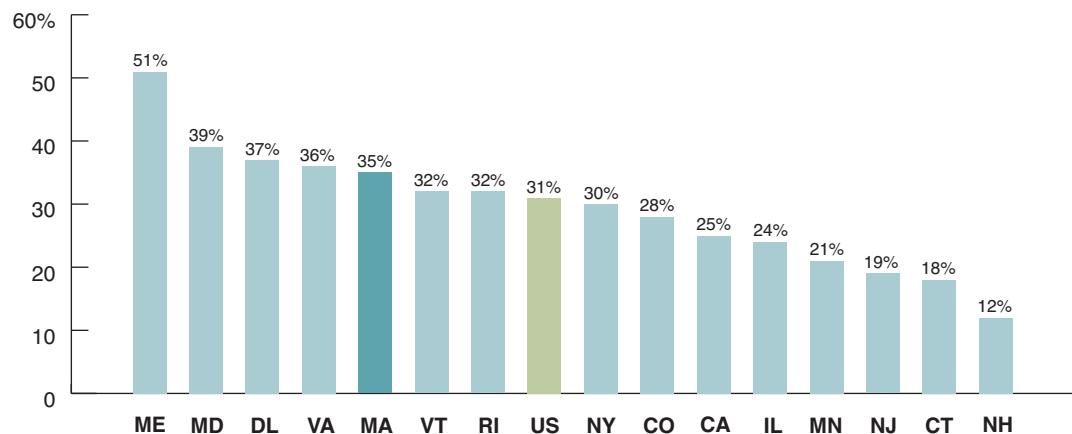


Source: MSIS Data 2001

The proportion of state residents with disabilities who are enrolled in the MassHealth program is higher than the national average but close to levels in many peer states

As shown in Figure 36, the number of people with disabilities in Massachusetts covered by MassHealth is approximately 35% of non-elderly adults with disabilities in Massachusetts. This is higher than the national average of 31%, but similar to the percent of adults with disabilities who have Medicaid coverage in many peer states. The higher proportion in Massachusetts likely reflects the success of deliberate state policy decisions to expand Medicaid eligibility to meet the range of state policy goals outlined earlier.

Figure 36 The Proportion of State Residents Age 21–64 with Disabilities Who Are Enrolled in the Medicaid Program in Massachusetts and Peer States



Source: MSIS Data, 2000 US Census Summary File 3, *2001 MSIS File without Hawaii which did not report.

The growth in the number of Medicaid members with disabilities is a national trend.

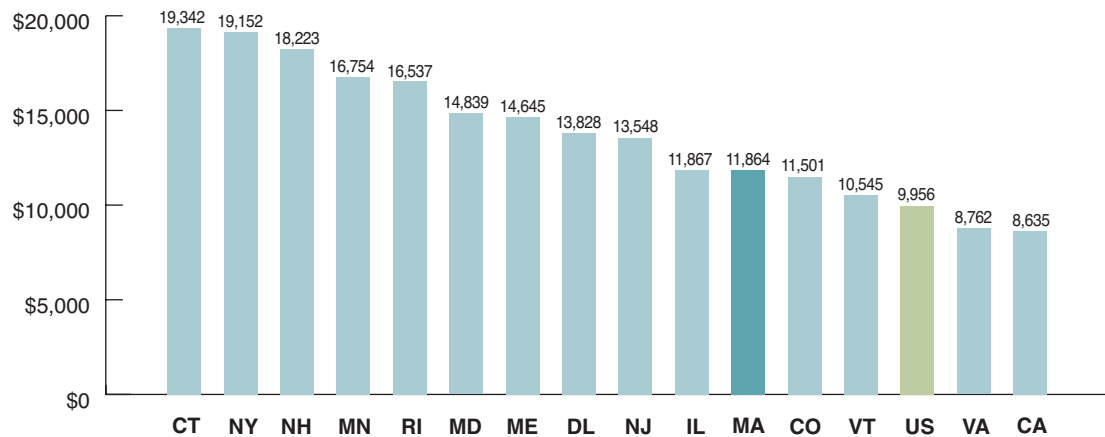
The total number of Medicaid members with disabilities has grown rapidly in the last decade, increasing from 6.5 million in 1995 to 6.9 million in 1999 to 8.6 million in 2003. In fact, the recent rate of growth nationally exceeds the rate of increase in Massachusetts.²⁶

Several factors underlie this growth. First, some expansion is due to advances in medical technology and pharmaceutical developments that allow children with disabilities to survive birth and childhood, and adults with disabilities to live longer lives while managing multiple chronic conditions and disabilities. Some of this expansion is due to policy decisions, made by states, to expand Medicaid eligibility to uninsured individuals with disabilities. The main vehicle for this expansion has been the Medicaid waiver process, which has allowed states to expand Medicaid eligibility to a range of new population groups, including many people with disabilities. A third reason for the growth in the number of Medicaid members with disabilities has been the implementation of Medicaid buy-in programs as work incentives to support individuals with disabilities who want to work and who would otherwise lose their essential Medicaid benefits as their income increased. The Massachusetts CommonHealth program, established in 1988, is the longest standing of these work-incentive programs and is the basis for the national Medicaid buy-in program. These work-incentive programs have the additional benefit of allowing individuals to accrue quarters of work needed to become eligible for SSDI and thus Medicare, which benefits both the individual and the state.

Average spending per Medicaid member with disabilities is higher in Massachusetts than the national average but is lower than in most peer states.

According to the federal Center for Medicare and Medicaid Services (CMS), MassHealth spending per member with disabilities was about \$11,900 in 2000, or approximately 20% higher than the national average. However, when compared to other states, Massachusetts ranks only 19th in spending per member, and has lower average spending than all but four peer states.²⁷ (Figure 37)²⁸

Figure 37 Massachusetts Ranks 11th Among Peer States in Annual Spending per Medicaid Member with Disabilities



Source: MSIS Data, *2001 MSIS File without Hawaii which did not report.

Section 5 Notes

²⁵ The FMAP for Massachusetts and peer states for FY 2004 is ~53% due to the temporary increase in the federal matching rates enacted in the Jobs and Growth Tax Relief Reconciliation Act of 2003..

²⁶ One possible explanation for the faster growth rate nationally in recent years may be that Massachusetts, as a forerunner in expanding Medicaid eligibility for people with disabilities, experienced membership increases earlier than in many other state Medicaid programs.

²⁷ MSIS data are used by CMS to produce Medicaid program characteristics and utilization information for state Medicaid programs. The MSIS cost estimates are slightly different than state estimates for the disabled population because in order to produce measures that are comparable across states, CMS uses a somewhat different population definition than is used for the MassHealth spending figures in other sections of this report.

²⁸ Total Medicaid spending per member in Massachusetts, for all members is 29% higher than the national average and Massachusetts ranks 12th in spending per member among all states. For other categories of member, Massachusetts ranks #10 in spending per elder Medicaid member (33% higher than the national average), #38 for adults (3% higher), and #21 for children (28% higher). (Kaiser Family Foundation, State Facts-On Line at www.kff.org)

Profile: Larry

Though Larry, 47, has worked most of his life—usually as a deliveryman or driver—it hasn’t always been easy. His bipolar disorder, diagnosed when he was in high school but improperly treated for many years, made him by turns irascible and depressed. “Sometimes I’d get real excited and be very outgoing,” he says, “and then I’d turn around and be real sad, unable to leave the house. I’d blast off on the other employees or my boss and get real worked up with nervousness or anger. I had trouble keeping a job.”

As if his luck weren’t bad enough already, it got worse the day he was standing in back of his truck on a slight hill, unloading pallets packed with muffins. The truck parked behind him slipped and rear-ended him. “You have to have a good back to deliver,” he says. “That accident knocked me out of work.”

For a few years, Larry got disability payments through Social Security, but “it wasn’t taking care of things well enough,” he says. He felt the treatment he was getting at one of the large local teaching hospitals was cursory and impersonal, and it was getting harder and harder to keep up with all the bills. That was when someone directed him to PACT, the Program for Assertive Community Treatment, in Worcester. The counselors there helped him move from his mother’s house, where he’d been staying since the accident, to a rooming house. They worked to get his finances in order, introduced him to an in-house doctor who tried various treatments until his bipolar disorder became more manageable. He now even has a job as a van driver for PACT. But perhaps most important, the PACT counselors enrolled him in MassHealth so that he could get the treatment he needed without having to worry about how he was going to pay for it.

He says without MassHealth, he never would have achieved the level of independence he now has. “That’s a fact, right there,” he says. “Without Medicaid I couldn’t afford the medical bills. And without the doctor and the counselor I see, I wouldn’t have my medication”—the medication that keeps him on an even keel, so that he can enjoy the people he works with and the lifelong friend with whom he now shares an apartment.

“I really rely on those prescription drugs,” he says. “I make sure I take them every day. I still have mood changes, but now I get through them all right. And I feel really good about the work I’m doing for PACT. It gets me up in the morning, you know?”

Section 6 Innovative Programs for Medicaid Members with Disabilities

Managed Care Programs

Massachusetts is at the forefront among states in fostering the development of special Medicaid programs for children and adults with disabilities. Some of these initiatives are specialized managed care initiatives that operate as part of the MassHealth MCO program, while others operate within the PCCP, often as initiatives of the Massachusetts Behavioral Health Partnership.

These initiatives include:

- **Community Medical Alliance Program for Persons with HIV/AIDS**, operated by Neighborhood Health Plan, which serves people with symptomatic HIV disease who meet special clinical criteria (180 members)
- **Boston Community Medical Group/Neighborhood Health Plan program**, which serves individuals with severe physical disabilities who require personal care services or equivalent services as an alternative to institutionalization. (220 members)
- **Commonwealth Care Alliance Pilot Program at Brightwood Health Center**, a pilot program operated as part of the PCCP, to coordinate medical and behavioral health care for certain MassHealth enrollees with disabilities and chronic illnesses who receive their primary care at the Brightwood Health Center in Springfield. (450 members)
- **Network Health initiative for adults with physical disabilities**, which is operated by one of the managed care organizations that contracts with MassHealth, and seeks to improve care for adults with physical disabilities by preventing secondary complications of disability through provision of case management, care coordination, and health education. (750 members)
- **Mental Health Service Program for Youth (MHSPY)**, a program for children and adolescents with serious emotional disturbances, that is a collaborative effort between Neighborhood Health Plan, Medicaid, the Departments of Social Services (DSS), Mental Health (DMH), Education (DOE), and Youth Services (DYS), and local school departments in Cambridge, Everett, Malden, Medford and Somerville. The goal of the program is to help keep children in community settings by providing individualized services planned in partnership with families and other care providers. A key feature of MHSPY is providing integrated medical, mental health, social support and non-traditional services. (80 children)
- **Coordinated Family-Focused Care (CFFC)**, a new program, similar to MHSPY, which is a collaborative effort of Medicaid, DMH, DSS, DHS, EOHSS, DOE, the Massachusetts Behavioral Health Partnership (MBHP) and parents from the Parent/Professional Advocacy League (PAL), the Federation for Children with Special Health Needs and Adoptive Families Together. CFFC serves children with serious emotional disturbances who are either at risk of out-of-home placement or in residential care but able to live at home with supports. (220 children)
- **Essential Care**, a new voluntary case management program administered under the state's contract with the Massachusetts Behavioral Health Partnership, targeting MassHealth Essential members with high medical or behavioral expenses, complex physical illnesses, a pattern of receiving primary care in emergency rooms, and/or who are not adhering to their medication regimens. (103 members)

- **“Special Kids ♥ Special Care,”** a program for medically complex foster children operated by Neighborhood Health Plan, and jointly sponsored by Medicaid and the Department of Social Services (DSS). To be eligible for the program, children must have full foster care status and need skilled nursing services. Many of the eligible children are technology dependent. (90 children)
- **Program of Assertive Community Treatment (PACT),** administered by the Massachusetts Behavioral Health Partnership, which provides ongoing and long-term community-based psychiatric treatment, outreach, rehabilitation and support for people with serious mental illness, many of whom have co-occurring disorders such as substance abuse, homelessness, or involvement with the judicial system.
- **Community Case Management Pilot,** a program for children with complex medical needs who require private duty nursing services. This program, administered by Commonwealth Medicine at the University of Massachusetts Medical School provides needs assessment and intensive case management to authorize, facilitate, and coordinate community-based long-term care services. (170 children)

Appendix 4 provides a more detailed description of each program.

While these innovative programs serve different populations and have different structures, they generally share a number of common features, including:

- A multi-disciplinary approach to clinical care;
- Integration of physical and behavioral health;
- Care coordination;
- Attention to primary and preventive care, in addition to specialty care, equipment and therapies;
- “High touch” interventions provided by a wide range of clinicians and non-clinicians, depending on the model, designed to engage members in care and help solve both clinical and social problems in a timely manner;
- Health risk adjusted payment rates and financial risk-sharing arrangements to make it possible to serve members with complex medical needs and to provide flexible or non-traditional benefits to help keep people with disabilities living in the community and out of institutions.

Most of these programs are relatively small, serving in total a very small proportion of members with disabilities, and operate in limited geographic areas. All of them are voluntary for members.

Many other states have developed special programs to serve Medicaid members with disabilities. Appendix 4 provides information about several innovative programs in other states. In general, programs in other states share many features in common with those in Massachusetts, including a multi-disciplinary team approach to care, integration of physical and behavioral health, and care coordination. As in Massachusetts, many of these programs are voluntary for Medicaid members.

However, some programs in other states have features that distinguish them from those in Massachusetts, including:

- Integrating long-term care with medical care
- Enrolling individuals who are dually eligible for Medicare and Medicaid
- Achieving much larger scale, even with voluntary enrollment.

As discussed in Section 7, one of the key questions for policymakers in Massachusetts is how innovative managed care approaches that have been successful can be brought to larger scale and serve a larger number of MassHealth members with disabilities.

Long-Term Support Programs

Massachusetts also operates several important community-based long-term support programs.

- **Personal Care Attendant Program,** one of the oldest consumer-directed personal care attendant programs in the country. Once MassHealth members are approved for PCA services, they may employ their own caregivers (with assistance from surrogates or legal representatives, if needed) rather than being required to obtain PCA services through agencies. (More than 8,000 non-elderly MassHealth members with disabilities, including 1,800 children)

MassHealth has a “PCA Evaluation Change Project” under way, in which it is planning to hire and train clinical staff to conduct face-to-face assessments of all members who request PCA services, in an effort to standardize the assessment process, provide timely referral and authorization to approved services, identify third-party coverage options, inform members of their range of choices for community-based care, and coordinate services across EOHHS agencies.

- **Self Determination Project.** Through the Department of Mental Retardation, approximately 200 people, mostly in the greater Boston area, purchase their own community-based services and supports, either through family governing boards or through direct purchase of services and supports. A fiscal intermediary organization (ISO) supports families in issuing requests to obtain community-based services, if the services they seek are not available from existing providers. The ISO keeps records and pays employees.

These initiatives provide a strong foundation for expanding the involvement of MassHealth members with disabilities in managing their own long-term support services, an approach that has resulted in increased access to community-based services, increased client satisfaction, and reduced or equivalent overall costs in other parts of the country.

Profile: Lauren

When Lauren's mother, Treseanne found herself expecting at age 19, she didn't do what many college girls might have done and terminate the pregnancy. She and her boyfriend, Peter, married and continued school. They even elected to continue the pregnancy when, at 12 weeks along, Tresanne learned the baby she was carrying had "a pretty serious birth defect."



But Tresanne was young and in love—and besides, “at the time it seemed to us like a relatively simple thing to fix.” Her baby was diagnosed in utero with gastroschisis, a condition in which the abdominal wall doesn’t close properly and the organs become herniated. “We knew she’d go right from the delivery room

into surgery,” Tresanne continues.

“They’d put everything back and sew her back up, and she’d come home two weeks later.”

Unfortunately, things did not go quite so smoothly for little Lauren, now 12. Before her premature birth by emergency C-section, her intestines got twisted on themselves and she developed gangrene. She went right into surgery, as planned, and that was when doctors realized exactly how much intestine she’d lost—90 percent.

A second crisis came when Lauren was three months old, and she went into total liver failure, because all her nutrition was being metabolized through that organ. In a 16-hour surgery, Lauren became the third child in the country to have a liver, small bowel, and large bowel transplant, and the second to survive the procedure. It gave her life, but took away a great deal as well. “She has to be on immunosuppressant drugs for life, so she gets a lot of infections, and they’re more serious for her than they might be for someone else,” says Tresanne. “She’s been hospitalized for pneumonia probably 100 times. She gets ear tubes every year, and is constantly battling diarrhea and electrolyte imbalances. She’s nutritionally compromised, so she’s on growth hormone, and she’s had 28 surgeries, for everything from tonsillitis to chronic reflux.”

But “she’s a tough cookie,” says Tresanne. “She’s doing great on so many levels. She walks to school every day and is very functional and active. She always wants to be in the thick of things. She’s incredibly empathetic and sensitive to other children, because she understands different kinds of suffering herself.”

In addition to her physical traumas, Lauren has developmental delays and learning disabilities, due at least in part to her many hospitalizations; she has an aide in school and has had occupational, physical, and speech therapy.

Throughout it all—including the birth of a second daughter, Julia, 8, who had a prenatal stroke that did not significantly affect her development—Peter and Treseanne remained focused on their long-term goals. Both finished school; Peter is now a lawyer, and Treseanne is an adjunct professor of English at Boston College. But despite their professional status, says Tresanne, “we’re not in great shape financially.” They have had to contend with high rents, school loans, and car payments, as well as Lauren’s healthcare issues, which “would cripple people with a lot bigger incomes than ours.”

Lauren is covered by the MassHealth CommonHealth program, as well as by her family’s private health insurance plan. Tresanne calls CommonHealth “the greatest thing,” and adds, “I don’t know what we’d do without it.”

“It’s the only way we’ve been able to have some kind of shot at making it and the having security that there won’t be some catastrophic medical issue that winds up wiping us out.” Speaking of the program’s sliding-scale fees, she says, “We would pay whatever we could for however long, just to have that program. What it means to us is hard to quantify.”

What it means to Lauren is easy to see.

Section 7 Policy Challenges

A. The Current Situation

Massachusetts has successfully used the Medicaid program to offer comprehensive benefits to many low-income people with disabilities at relatively low cost to the state.

MassHealth members with disabilities receive good coverage at a cost that compares favorably with peer states, especially given the generally high costs of health care in Massachusetts. The state has maximized federal financial participation in covering these vulnerable populations and taken advantage of federal waivers and other means to use community-based services to support people in the community and decrease the percentage of people with disabilities who are in institutions. In addition, MassHealth has developed and financed a number of innovative pilot programs that are directed at coordinating care and meeting the complex needs of those with the most severe disabilities.

The current mix of programs and financing of care and community supports for people with disabilities has developed over many years in response to population needs, failures in the health care marketplace, and political and fiscal opportunities. Generally, Massachusetts has taken an innovative approach to leveraging state and federal resources to fill in substantial gaps and introduce new programs and benefits.

The MassHealth program for adults and children with disabilities is currently challenged by increasing enrollment and spending.

The number of non-elderly MassHealth members with disabilities is increasing, reflecting the limited health insurance coverage available to this population and deliberate state policy initiatives to extend Medicaid coverage to more people with disabilities. At the same time, rising medical costs are making it more expensive to provide medical care, particularly to members who have significant and chronic medical needs. As a result of these trends, more than half of the increase in MassHealth spending during the past five years has been to provide services to non-elderly enrollees with disabilities.

MassHealth members with disabilities are primarily a low-income population with significant mental and physical disabilities and multiple chronic medical conditions. In order to live in community settings, they typically require a mix and intensity of services that are not covered by commercial health insurance and the bulk of their care is therefore financed through public programs such as Medicare and Medicaid. The fragmented financing and variation in benefits across programs presents a particular challenge to the efficient organization and delivery of services.

MassHealth has taken many actions, and others are under way, to moderate growth in spending and improve care for members with disabilities.

Two general approaches to containing spending growth related to people with disabilities have been proposed and/or implemented in the recent past:

- controlling medical cost growth by interventions aimed at reducing utilization and the amount paid for medical services, and
- reducing the growth in the number of people with disabilities covered by MassHealth through changes in eligibility rules and processes.

The Massachusetts Medicaid program has recently taken aggressive actions to moderate the growth of MassHealth spending for people with disabilities by instituting or improving prior

approval processes in high growth areas, such as prescription drugs and community long-term care. Other efforts to reduce utilization focus on increasing “patient responsibility” through the use of increasing co-payments for pharmacy and other services. Provider rate reductions have been implemented for personal care services, and some services (e.g., most adult dental care, eyeglasses) are no longer covered by MassHealth. The state has also increased efforts to ensure that payment by private health insurance is pursued whenever available.

There is also some interest in expanding existing specialized programs that offer coordinated care to people with disabilities. These programs appear to have been successful at addressing the primary, preventive care, specialty care and social needs of their members. However, they cover relatively few people (less than 1% of the under 65 members with disabilities) and have not yet demonstrated significant cost savings or the ability to operate on a larger scale.

MassHealth has also considered a number of actions to limit enrollment growth. For example, enrollment caps for CommonHealth adults were authorized in the FY04 budget, although not yet implemented. New asset tests, which would have the intent of limiting the number of people eligible for financial reasons, are under serious discussion. Although these types of approaches may in fact slow the growth of enrollment in the MassHealth program, they are unlikely to make the need for services go away. In fact, many observers have pointed out that by making it more difficult to enroll in the MassHealth program, overall state costs are likely to increase as the state risks losing the federal Medicaid match for services offered under MassHealth. In addition, limiting MassHealth enrollment has the effect of shifting care to more expensive settings, particularly institutional settings, including fully state-funded public health and mental health hospitals, and increasing costs for the state’s uncompensated care pool.

B. Key Issues Going Forward

Key policy questions remain to be answered in order to develop the next generation of programs and initiatives for MassHealth members with disabilities; these require broad discussion, including the involvement of MassHealth members and families. Among the most important areas for action are the following:

The state must continue to refine and articulate its vision for health care and community supports for the MassHealth population with disabilities, with the active involvement of MassHealth members with disabilities and their families in setting goals, designing programs, evaluating progress, and identifying unintended results.

In December 2003, EOHHS and the Executive Office of Elder Affairs released a joint report that presented a vision for long-term supports (also known as long-term care) in Massachusetts. Since long-term supports refer to “a wide range of goods, services and other supports to help people with disabilities or chronic conditions meet their daily needs and improve the quality of their lives,” this vision includes health care as well as community-based long-term care services. Therefore, many key components of the state’s vision for health and community supports for people with disabilities are encompassed in the report’s vision statement for long-term supports:

Massachusetts residents with long-term support needs will receive person-centered, coordinated, high-quality, cost-effective supports that are accessible, primarily community-based, and that reflect collaborations among individuals, families, other private partners and government.

(“Transforming Long-Term Supports in Massachusetts,” EOHHS/EOEA, December 2003)²⁹

Focusing on MassHealth, EOHHS recently articulated four themes as part of its overall strategy to manage spending for MassHealth members with disabilities:

- increased use of managed care
- getting people to work
- shared financial responsibility
- aligning Medicaid with other state programs.

Movement from these general themes, however, to successfully implemented programs requires the resolution of a number of policy and program design questions. Although MassHealth offers several creative and innovative small-scale programs, there is a need to develop a comprehensive strategy for care of MassHealth members with disabilities. This population is extraordinarily diverse and complex, and while the state has long had a quality improvement approach to managing the MassHealth managed care program, most members with disabilities are not enrolled in this program, and hence do not benefit from its population-based program management approach. The recent state and federal budget cutbacks have forced EOHHS agencies to institute a number of short-term savings projects that have further complicated the picture for MassHealth.

Some of the key areas for action are outlined below. MassHealth members with disabilities and their families need to be active participants in developing new programs and strategies. Members and their families understand best what makes programs effective and have the most to gain from program innovation and improvement. Program planning and effectiveness can be strengthened by actively involving MassHealth members with disabilities and their families, particularly because of the need to integrate medical, social and family supports along with multiple funding sources.

Critical areas for action include the following:

1. Continue to pursue aggressive actions to contain prescription drug spending:

Since prescription drugs are the largest and fastest growing component of MassHealth expenditures for people with disabilities, containing drug spending is essential. Further, to the extent that prescription drug costs can be reduced by price reductions rather than coverage restrictions, the impact on patient care can be minimized. To date, due to federal restrictions, the majority of drug cost containment initiatives have focused on prior authorization and generic substitution. Innovations in purchasing and price negotiation for drugs, including liberalization of federal rules that currently limit state options, are a potential source of significant savings and should be actively pursued.

Unfortunately, the new Medicare drug benefit will have significant (and likely negative) implications on the state's ability to effectively manage drug costs. Responsibility for drug costs for dual eligibles (38% of under 65 members with disabilities) will move to Medicare, outside of the control of MassHealth. MassHealth will not recognize any savings from this move as it will be required to make "maintenance of effort" payments and will be unable to continue the interventions it has made in the past. Restrictions in the Medicare drug benefit legislation prohibit the federal government from instituting many types of controls.

2. Expand efforts to develop and expand new systems and models of care:

Improved care coordination and management of care hold perhaps the greatest potential for moderating spending growth and improving quality of care for MassHealth members with disabilities, particularly given the chronic and persistent nature of their medical conditions and the high prevalence of co-morbidities. Despite their diversity, most members with

disabilities have common needs for comprehensive primary and preventive care that is well coordinated with specialty care and other services; better integration of physical and behavioral health; care coordination and case management to reduce fragmentation of care; and support in navigating health and social service systems.

Most MassHealth members with disabilities are currently covered through the fee for service program, which provides no care coordination or care management. Only 40% of members are covered by the Primary Care Clinician Plan (PCCP) and only 8% enrolled in managed care organizations. Although MassHealth has a variety of specialized managed care programs for individuals with disabilities, most of these programs are small, both because of stringent eligibility criteria and because they are pilots designed to test different models of care coordination.

A number of issues must be considered when designing and implementing new models or systems of care for MassHealth members with disabilities. Approaches must take into account the complex needs of members, their existing provider relationships and patterns of care, and unique physical and/or cognitive barriers to accessing and complying with prescribed care. Due to the diversity of disabilities and related care needs, traditional managed care approaches often need to be modified in order to address distinct sub-populations based on type of disability, level of physical and/or cognitive disability, living situation, and available support. Some of the distinct sub-populations of MassHealth members with disabilities are:

- adults with a primary diagnosis of mental retardation and severe physical disabilities living in state facilities or ICF-MRs
- homeless adults with a primary diagnosis of mental illness and other complicated medical conditions that require strict adherence to medication regimens
- cognitively intact hemi- or quadriplegics living independently in the community
- individuals with brain injuries
- adults with a medically unstable neurological condition (for example, multiple sclerosis or ALS) living at home with family support
- children or adults with a primary diagnosis of mental retardation or mental illness living in a staffed group residence in the community
- adults with developmental disabilities or mental retardation living with aging caregivers
- children with severe chronic conditions and physical disabilities living at home or in a pediatric nursing home
- individuals with persistent substance abuse and/or mental illness.

There is a unique array of medical, psychological, and supportive services that must be identified or developed, coordinated and accessible for each sub-population, if not for each individual. No one model of care or system of care will be appropriate for every member.

MassHealth could pursue a variety of approaches to developing new systems of care for MassHealth members with disabilities, including:

- **Increase membership in existing MCOs and/or the PCCP.** This approach would require offering MCOs rates that they regard as adequate, which may not always have been the case in the past.³⁰ In addition, any decision to permit members with other insurance coverage to enroll in managed care plans would require a change to the existing federal 1115 waiver, and in the case of enrollment in MCOs, it would also require a solution to the problem perceived by Medicaid of calculating a capitation rate that adequately adjusts for the alternate revenue source, as well as developing methods to manage care that is financed by a different primary payer.

- **Develop and/or expand specialized programs for adults and children with disabilities within the general framework of the MCO and PCC Plan.** This would require the identification of a set of goals and best practices to guide program development, including determining which members are most likely to benefit from which program model, as well as an extensive client outreach/enrollment/education program. The state would also need to allocate dedicated agency clinical and administrative staff to oversee program growth and maintenance.
- **Create entirely new managed care approaches,** similar to the new Senior Care Organizations (SCOs) and Program of All Inclusive Care for Elders (PACE) model (see Appendix 4), which would build on Medicaid's experience of merging funding streams from multiple payers into a single program but be focused on younger MassHealth members with disabilities rather than elders.
- **Contract with managed care plans or other entities to develop and provide care management, coordination services, and disease management programs** to members with disabilities who are enrolled in the fee for service system or the PCCP.

These approaches are not mutually exclusive. A range of approaches can be used to tailor and target the most appropriate approach to the most appropriate population group.

Any strategy to expand or develop new systems of care must answer a range of questions, including:

Which members to target? Although in the short-run reducing spending on high cost members might hold the most potential, in the longer-term, taking steps to better manage care for other members who are at high risk of becoming high cost members in the future will likely produce significant savings as well. Thus, any strategy should not be narrowly focused on members who are high-cost. Individuals with disabilities are not static in their acuity level, and it is counterproductive to create programs that employ eligibility definitions based on strict and narrow clinical criteria because they limit the number of members served and can create enrollment churning (i.e., enrollment, disenrollment and re-enrollment in specialized programs as member acuity changes).

Which approaches have been or could be most successful? Traditional managed care structures and tools are insufficient, and may be inappropriate for many individuals with disabilities. The most successful managed care programs for people with disabilities rely on narrow networks of providers who are experienced, competent and committed to serving individuals with disabilities, have tailored their practices to address accessibility issues (e.g., do home visiting) and have adopted a collaborative multidisciplinary team practice that augments traditional medical care with social supports. Most managed care organizations would need to “reinvent” themselves to address the needs of members with disabilities, which is challenging given established cultures, embedded operations and limited understanding of the necessity of these strategies.

How to continue to find better ways to coordinate behavioral and physical health services? A significant proportion of MassHealth members with disabilities have mental health conditions and, as a result, the issue of behavioral health care is profoundly important. The trend currently in both public and private programs is to carve out behavioral health services and manage them separately from physical health. This trend is based on a belief that separate management by mental health specialists leads to better quality networks, improved access for consumers, more effective use of resources, and ultimately better outcomes.

In the case of children and adults with disabilities, however, where mental and physical disabilities overlap and are interrelated, there is concern that managing behavioral and physical conditions separately will create communication problems leading to discontinuity in care, if not outright conflicts or omissions. Some managed care plans, in Massachusetts and elsewhere, that have carved-out behavioral health services have concluded that this approach has not been a successful one for Medicaid members with disabilities and have returned to an integrated approach.

As noted earlier, MassHealth contracts with the Massachusetts Behavioral Health Partnership (MBHP) to manage behavioral health care for the PCC Plan, through which 40% of members with disabilities get their care. The MBHP also provides PCC network management and quality improvement functions for the PCC Plan. Published reports have indicated that the initial introduction of managed mental health care into MassHealth dramatically improved access to outpatient services and cut overall costs. Medicaid's most recent evaluation of MBHP's performance concluded that the carve-out program has improved access to behavioral health services, although there was little if any analysis of the experience of members with disabilities.

Based on the experience to date, there does not appear to be one single best approach to improving the coordination of behavioral health and physical health. It is, however, imperative that this issue continues to be addressed in program development, management and evaluation. Medicaid should continue to assess carefully the experience of specialized programs in Massachusetts and other states to understand the relative strengths and concerns about integrated and carve-out approaches for individuals with disabilities. In addition, improved coordination between MassHealth and the Department of Mental Health is particularly important for members who have chronic and persistent mental conditions.

Would there be significant cost savings from developing new models of care?

While new models of care may offer many potential benefits for members, including better coordination of care, it is prudent to be cautious about expecting major cost savings from new programs. Some innovative programs that serve Medicaid people with disabilities have achieved costs savings or cost-neutrality, while others have not. There is disagreement about whether or not some of the MassHealth programs for members with disabilities have produced cost savings for the state. Some commercial managed care companies that have focused on improved management of chronic diseases and conditions can demonstrate savings, while others cannot. Even where savings can be demonstrated, they may be difficult to replicate in the MassHealth population, which is likely to have higher levels of mental illness and mental retardation and may lack the in-home supports that facilitate more effective use of services. Standard approaches to disease management may well have to be modified for the MassHealth members with disabilities due to the prevalence of multiple chronic conditions, which may need different approaches than single disease-specific interventions.

One advantage of managed care programs is their willingness to accept capitation as a form of payment, which can facilitate more flexible approaches to care and care management. This flexibility makes it possible to maximize community resources, provide comprehensive preventive and primary care, and engage the member or the member's family in self-care and health promotion. While none of these approaches are a "quick fix" to rising costs, they do potentially offer a more long-term strategy for promoting health and reducing avoidable hospitalizations or institutional placements. Such longer-term investments make particular sense for members with disabilities since they are a relatively stable and long-term group of the MassHealth population.

A necessary caveat is that while capitated financing approaches offer more flexibility in the use of funds, they also carry the risk associated with variations in case mix. It will be important to the sustainability of managed care programs that any risk-sharing payment model also include adequate risk-adjustments, either based directly on the expected cost of the population served or through the use of risk corridors, outlier payments, or some element of retrospective adjustment.

3. Develop a strategy to address the special issues related to the dually eligible population.

Thirty-eight percent of under 65 MassHealth members with disabilities is dually eligible for Medicare and Medicaid. This population has not been able to enroll in existing MassHealth managed care programs, primarily because of concerns about how to meet the operating requirements, integrate financing from both programs, and achieve coordinated care. Nonetheless, improved integration of funding and coordination of care could be a source of reduced spending, increased efficiency, and improved quality of care.

Two program models, the Program of All Inclusive Care for Elders (PACE) and Senior Care Organizations (SCOs) have been developed to combine funding streams and coordinate care for dually eligible seniors. (See descriptions in Appendix 4) PACE is focused on seniors who are eligible for nursing home placement, while SCO focuses more broadly on seniors regardless of their placement status. Enrollment in PACE has been slow, due to restrictive program requirements, and SCO has only recently been implemented. Neither program is currently open to younger members with disabilities, but both provide models as to how approaches can be developed for non-elderly members with disabilities who are dually eligible. In addition, Massachusetts could learn from the approaches taken by other states that allow dually eligible individuals with disabilities to enroll in managed care programs.

4. Continue to explore other promising approaches to moderating spending and improving care, including:

- **The use of Medicaid and Medicare Waivers (1115, 1915c, 222) as a vehicle to test innovative approaches**

Because Massachusetts has operated a large PCA program, there has been less pressure here than in other states to develop specific, targeted home and community-based services waivers. However, there may be opportunities for the state to target additional supports to persons most likely to use high cost services, such as institutions. Home and Community Based Services (HCBS) waivers provide the state with controls to limit the number of individuals who may qualify and the specific services they may be eligible for, and in combination with managed care approaches, such programs can be developed to provide a capitated benefit which allows for management of the individual's overall service needs.

EOHHS has begun exploring options for developing policy changes, through waivers or other authority, to increase opportunities for individuals to be served in the community rather than in costly institutional settings. As mentioned earlier, a variation on the Senior Care Options program, one that is specifically designed for younger persons with disabilities, could be developed to test innovative approaches to complex care management. Variations on the Community Medical Alliance or other options that serve individuals who are dually eligible for Medicare and Medicaid as well as those who qualify only for Medicaid are avenues worthy of exploration. Again, a critical factor to the success of such models would be the need to develop risk-adjusted rates that provided appropriate incentives for managing costs while maintaining or improving quality of life.

- **Consumer direction and flexible individual budgets**

Early evidence, from the national Cash and Counseling Demonstration Project and elsewhere, indicates that giving consumers with disabilities more control over the use of resources to meet their needs results in increased access to community-based services, increased client satisfaction, and reduced or equivalent overall costs.

Massachusetts already operates several small state-funded programs that provide this flexibility, and has received grants to plan and pilot new approaches to consumer-directed care. With a grant from the federal Center for Medicare and Medicaid Services' "Real Choice Systems Change" initiative, the state will test a similar approach for a small group of individuals with disabilities who do not currently qualify for existing services. An Independence Plus Grant will help support the state in developing the necessary infrastructure to broaden such a program under a Medicaid waiver.

In the coming year, under the President's "New Freedom Initiative," legislation has been proposed to assist states that want to develop programs in which "money-follows-the-person." The proposal includes funding to allow states to receive 100% federal matching funds for up to a year for individuals who move from institutions to the community. If such funds are approved, there will be a strong incentive for states like Massachusetts to accelerate their efforts toward consumer directed programs. In pursuing these approaches, the state should strongly consider a cross-disability and lifespan approach to eligibility for consumer-directed services, rather than a more narrow targeted population approach.

- **Initiatives to provide nursing home transition services to younger members with disabilities**

Massachusetts has a number of initiatives underway, including "Bridges to the Community," and the elder home care waiver program, to identify and assist individuals who want to move from nursing homes to the community. Nursing home transition services can include transportation (to visit potential residences), assistance with rental security deposits, funds to purchase essential home furnishings, case management while the person is still in the facility, and other non-traditional supports to assist elders in moving from nursing home to the community. Except in the pilot project under the nursing home transition project, such funds are not available to younger persons with disabilities who are attempting to move out of institutions. The state should consider expanding the target population for these programs to younger members with disabilities. However, the state should be careful about predicated this policy approach on cost savings through reduction of spending on institutional care, since spending on community supports for many of these members is likely to be very high.

5. Evaluate the potential for moderating demand for services through co-payments and deductibles, but with very careful consideration of the significant limitations and potential consequences of this strategy.

The use of co-payments and deductibles is an increasingly common aspect of private health insurance, where tiered co-payments and coinsurance is used to increase consumer awareness of the relative costs of various services and sites of care. Studies have shown that for those with economic means, the use of co-payments does in fact decrease demand for services. Because of the effectiveness of co-payments in decreasing demand, attention must be paid so that patients do not go without certain effective services (e.g., preventive care) that would otherwise prevent or mitigate more expensive treatments and therapies.

There are special challenges in developing a cost-sharing strategy for MassHealth members

with disabilities. First, this population is extraordinarily poor. More than 92% have family incomes below 133% of FPL; only 3% have incomes above 200% of FPL. It is unlikely that the vast majority of members with disabilities, therefore, could afford significant co-payments, and the risk of them choosing to avoid medical care to avoid the co-payments could further exacerbate access to essential care and increase costs. Second, because of their disabilities and complex medical conditions, MassHealth members with disabilities may have fewer options regarding the type or site of care that is necessary for them to obtain adequate and appropriate services.

For both these reasons, the potential for reducing spending through use of cost-sharing is limited and the potential for negative unintended consequences is high.

6. Assess any potential changes to eligibility very carefully.

All of the recent growth in membership of MassHealth members with disabilities has been in the two optional categories, Medicaid-Only and CommonHealth. This growth has, therefore, come largely from state policy decisions. Massachusetts does not appear to be out of line with peer states in terms of its eligibility criteria for Medicaid coverage by virtue of disability and most of the increase in spending on the MassHealth population with disabilities has come from rising medical costs rather than increases in membership. Nevertheless, it is important to consider whether current eligibility policies continue to be sound, including the likely consequences of any changes.

As part of the Transition Team review in January 2003, the Boston Consulting Group reported that changes in MassHealth eligibility requirements for people with disabilities could yield savings, but with difficulty, since there would be other offsetting impacts such as an increase in the costs of the uninsured or an increase in the number of “categorical” disabled because of spend down or job loss. Because the majority of MassHealth is financed by the federal government, and the fact that MassHealth members with disabilities have long-term and complex needs of, it is unlikely that reductions in eligibility will save Massachusetts money overall, although it might shift the financial burden. The costs would likely shift to other MassHealth-funded services areas, particularly institutional settings; to fully state-funded public health and mental health hospitals; to other state-funded safety net programs in the community; to providers in the form of charity care costs; and to the state’s uncompensated care pool, which is funded by insurers, hospitals and the state.

Proposed limits in asset accumulation for people with disabilities are of special concern. Savings projections should not assume that the main effect of an asset test would be disenrollment of a certain number of CommonHealth members. It is just as likely that people will leave work, or cut back on work hours, because they no longer have the ability to accumulate significant assets, resulting in little or no net savings to the state.

7. Continue to support and encourage participation in the community and workplace.

Many MassHealth adult members with disabilities have the potential to return to meaningful work and more fully realized lives. Independence and self-sufficiency is a personal as well as a program goal. However, the complex and confusing structure of financing, benefits, requirements, and obligations contains many opportunities to put barriers in the path of progress and to frustrate the best intentions of all involved.

A productive way to help manage program spending might be to invest in care so that enrollees have a greater chance of returning to work or staying in the workplace despite their disability. Buy-in programs like CommonHealth—which are designed to increase independence and employment of people with disabilities—successfully address health care

barriers faced by people with disabilities who are seeking employment. Incentives to retain coverage through Medicaid are substantial for this population, as costs of private insurance for people with disabilities is high, and certain necessary services, such as personal attendant services or durable medical equipment may not be covered outside of Medicaid. In many cases, Medicaid coverage provides benefits that make work possible, such as pharmaceuticals for people with psychiatric and cognitive disabilities, or personal care services for people with physical disabilities. People with disabilities who work not only contribute to the cost of their care through premiums, but as tax payers. Currently, more than 7,000 CommonHealth members are working and contributing to the costs of their MassHealth services. State policy should continue to encourage and support other MassHealth members with disabilities to participate in the workplace, and increase their income and independence without risking essential health care coverage.

8. Enhance the MassHealth administrative and information infrastructure to better support program development, implementation, monitoring, and evaluation.

There is a substantial need for more, better coordinated and more easily accessible information on MassHealth members with disabilities, including their medical, risk, and cost profiles, and the impact and outcome of the services they receive. Currently no comprehensive database exists that easily allows a review of the population as a whole or by subset. MassHealth claims data allows only an episodic view of client interaction with the health care system, and only for those services provided by MassHealth contracted providers. Eligibility data is limited. There is no information available on housing, social supports and utilization of other programs in a way that allows it to be integrated with medical utilization data. There is limited ability to profile, and no standard reporting, by parameters that would allow better and more timely intervention, such as high cost clients or high cost incidents. There is very little quality measurement and improvement focused on care and access for members with disabilities; few of the traditional quality measures are specific to this population. There should be a concerted effort, as part of the development of a comprehensive strategy for MassHealth members with disabilities, to develop an information base that will facilitate better program design and evaluation.

In addition, program development and evaluation require administrative resources, expertise, and collaboration across multiple agencies and service delivery systems. Although the recent reorganization of EOHHS holds some promise for enhancing close collaboration and coordination across multiple agencies, this will continue to be a major challenge. There are few more important investments that the Commonwealth could make than to increase the administrative and technical resources available to the MassHealth program, which is among the largest and most rapidly growing items in the state budget.

Section 7 Notes

²⁹ As part its analysis, EOHHS/EOEA identified a number of critical initiatives: a comprehensive needs assessment process; an improved information and communication infrastructure; increased consumer direction and control; institutional diversions and closings; encouraging the development of affordable, accessible housing; nursing home diversification; and increasing the direct support workforce.

³⁰ MCO rates are developed based on spending in the PCC Plan for a comparable population.

Appendix I Data Sources and Population Definitions

MassHealth data for this report were derived from the following sources:

Eligibility data:

Massachusetts Medicaid Information System (MMIS) UBER eligibility file was used to identify the study population. An enrollment snapshot on 6/30 of each fiscal year was used. Data are current as of January 2004.

Claims data:

MMIS TRAP claims data were used to capture the MassHealth expenditures.

- FY01-FY03 data current as of Jan 04
- FY99-FY00 data current as of Oct 03
- Only disburse = 0 (Pass-through dollars were excluded) was used for majority of the data analysis.
- BMC and Cambridge capitation \$ amounts were not included
- Data include all 11 invoice types

(Note that both UBER and TRAP data are extracts of MMIS.)

Population definitions and other variable information:

- The population categories SSI, Medicaid Disabled and CommonHealth (CH) were defined to be consistent with previous analysis by Medicaid (e.g., presentations to Governor Romney), with exception of aid categories 16, 18, and 44:
 - SSI – aid categories: 03, 14
 - Medicaid Disabled – aid categories: 07, 15, 17, 21, 42, 43, and 45
 - CH – aid categories : 11, 12, 50, 51, 52, 53, 54, and 55
- Non-disabled aid categories : ‘40’ ‘02’ ‘48’ ‘46’ ‘37’ ‘06’ ‘08’ ‘61’ ‘93’ ‘95’ ‘97’ ‘47’ ‘35’ ‘72’ ‘74’ ‘05’ ‘92’ ‘20’ ‘04’ ‘AB’ ‘98’ ‘90’ ‘77’ ‘80’ ‘00’ ‘60’ ‘65’ ‘88’ ‘73’ ‘96’ ‘70’ ‘91’ ‘AC’ ‘01’ ‘24’ ‘78’ ‘79’ ‘41’ ‘62’ ‘68’ ‘71’ ‘AA’
- Only the richest aid category was used.
- Age is calculated as of the end of each fiscal year.
- Payments per member per month (PMPM) = total annual Medicaid payments by population category / (total annual eligibility days by population category/30.5)
- Duration of enrollment was established for all members included in the FY 2003 enrollment snapshot by calculating total days of enrollment in MassHealth over the previous five fiscal years for each member. Only enrolled days were included. Gaps in enrollment were ignored.
- Multum Drug Lexicon grouping was used to group NDC-codes into clinical categories. <http://www.multum.com/Lexicon.htm>
- Chronic conditions were classified by using the Chronic Illness and Disability Payment System (CDPS). Conditions are not mutually exclusive. A member could have more than one condition. A total of 18 chronic conditions were classified.
 1. Cancer
 2. Cardiovascular
 3. Diabetes
 4. Eye disease

5. Genitourinary system
6. Gastrointestinal system
7. Hematological
8. Infectious
9. Metabolic
10. Pregnancy
11. MR/DD
12. Psychiatric
13. Pulmonary
14. Renal
15. Skeletal
16. Skin
17. Central nervous system
18. Cerebrovascular

Specific detail on selected figures:

- Figure 9 and 10:
 - CDPS (Chronic Illness and Disability Payment System) method was used for this grouping. Conditions are not mutually exclusive. A member could have more than one condition.
- Figure 23:
 - Multum data grouping was used in order to group the pharmacy NDC codes.
- Appendix 3
 - Numbers reported are snapshot on 6/30/03.
 - Percent FPL variable in eligibility data was used for “Income Level”.
 - LTC flag variable in eligibility data was used for “Residence”.
 - Combination of TPL and Medicare variables in eligibility data were used for “Other Insurance”.

Medicaid Statistical Information System (MSIS) Reporting

<http://www.cms.hhs.gov/medicaid/msis/>

<http://www.cms.hhs.gov/medicaid/msis/msis99sr.asp>

MSIS data are used by the Centers for Medicare and Medicaid Services to produce Medicaid program characteristics and utilization information for those States. These data also provide CMS with a large-scale database of State eligibles and services for other analyses. The purpose of MSIS is to collect, manage, analyze, and disseminate information on eligibles, beneficiaries, utilization, and payment for services covered by State Medicaid programs. States provide CMS with quarterly computer files containing specified data elements for: (1) persons covered by Medicaid (Eligible files); and, (2) adjudicated claims (Paid Claims files) for medical services reimbursed with Title XIX funds. These data are furnished on the federal fiscal year quarterly schedule, which begins October 1 of each year.

Each State Eligible file contains one record for each person covered by Medicaid for at least one day during the reporting quarter. Individual eligible records consist of demographic and monthly enrollment data. Paid Claims files contain information from adjudicated medical service related claims and capitation payments. Four types of claims files representing inpatient, long-term care, prescription drugs and noninstitutional services are submitted by the States. These are claims that have completed the State's payment processing cycle for which the State has determined it has a liability to reimburse the provider from Title XIX funds. Claims records contain information on the types of services provided, providers of services, service dates, costs, types of reimbursement, and epidemiological variables.

MSIS definition of disabled:

"Aged" includes all people age 65 and older. "Disabled" includes younger persons (age 64 and under) who are reported as eligible due to a disability. "Adults" are generally people age 18 to 64 and "children" are generally people age 17 and younger.

Appendix 2 Further Information on How People with Disabilities Qualify for MassHealth

Medicaid eligibility rules are complex, representing incremental reforms at the state and federal levels throughout the years since the initial enactment of the Medicaid program in 1965.

The rules vary depending upon a number of factors, including age, income, residency, and immigration status. A detailed discussion of these latter two factors is beyond the scope of this paper, but the issues of age and financial status are described below in more detail.

Federal law requires that state Medicaid programs offer coverage to certain groups of people, such as recipients of federal Supplemental Security Income (SSI) cash benefits, which in 2004 equal \$678.39 per month (SSA 2004).³¹ Furthermore, states are required to extend coverage to all individuals who apply and meet the eligibility requirements of such mandatory Medicaid programs.

Having a serious medical condition is not, by itself, enough to qualify for Medicaid on the basis of disability. For example, someone with multiple sclerosis or HIV disease might not qualify in the early stages of their disease. Rather, eligibility for many government programs, including Medicaid, has historically been tied to the ability to work. Only if the disability is one that might be considered as compromising the ability to work will it qualify an individual for Medicaid. Massachusetts uses the same disability standard that has been adopted by virtually all federal and state programs for this purpose.³²

The income standards are set by federal law in most instances and vary somewhat depending upon the population. Individuals on SSI are subject to a federally determined asset limit of \$2000 for an individual and \$3000 for a married couple. Asset limits differ for other populations and, in Massachusetts there are some populations with disabilities where there is no asset limit.³³

Under federal law, states may also cover additional groups based upon income, medical need, institutionalization, and other criteria. The largest of these groups in Massachusetts consists of individuals who meet the disability standard described above and who have incomes below 133% of the federal poverty level. The higher income standard signifies the Medicaid program's recognition of the central importance of medical coverage to persons with disabilities and the large proportion of income that many persons with disabilities spend on health care.

Many of these individuals receive Social Security Disability Insurance (SSDI) benefits. Individuals receiving SSDI benefits comprised 21% of Massachusetts Medicaid recipients in 2003 (BCG 2003). Nine percent of Massachusetts Medicaid recipients received Medicaid only and did not receive SSDI or any other federal cash benefit.

To expand eligibility while exerting the greatest degree of control over the related budgetary and programmatic implications, many states, including Massachusetts, have opted to expand coverage to individuals with disabilities by obtaining a "waiver" of federal rules. States apply to the Centers for Medicare and Medicaid Services (CMS) for permission to disregard or "waive" certain federal rules, such as income and asset limitations, as part of a plan to enroll new populations and offer services that they might be reluctant to undertake if they had to comply with ordinary Medicaid rules. This approach enables states to experiment with bold new policy approaches while maintaining their ability to manage the budgetary and programmatic implications of new initiatives and tailor the program to meet the needs of specific populations. The individuals described above who qualify because their incomes are less than 133% of the federal poverty level are an example of a "waiver population."

Another example is individuals with disabilities who wish to work. Massachusetts has made work incentives for people with disabilities a major policy priority. The low income and asset limitations that have traditionally marked the Medicaid program act as disincentives to work for this population for whom the loss of Medicaid and the package of services it provides is potentially devastating. In response to the dilemma faced by many people with disabilities who want to work, in the mid-1990s the state applied for a waiver of federal rules to incorporate the CommonHealth program into its Medicaid program. The CommonHealth program reduces the disincentives to work posed by the traditional Medicaid program by removing the income and asset limits and by permitting people with disabilities to “buy-in” to Medicaid coverage by paying a premium determined by an income-based sliding fee scale. This program originally started as a state-funded initiative, but now receives federal dollars because the state incorporated it into the Medicaid program through the waiver mechanism. The waiver of federal income and asset rules has enhanced the state’s ability to provide this program on an ongoing basis and CommonHealth recipients now comprise approximately 7% of all Medicaid recipients with disabilities. In addition, this important work incentive initiative has the highest rate of growth of all Massachusetts Medicaid programs. This program has served as a national model and 28 states now have a Medicaid buy-in program for working adults with disabilities, albeit with more restrictive income and asset rules than Massachusetts (Kaiser 2003).

Massachusetts also extends coverage to individuals with certain income and asset levels who would be eligible for institutionalization, but who choose to live in the community with support from certain specialized programs. Virtually all (49) of the states have this option for individuals enrolled in the Home and Community Based Services (HCBS) program, consistent with a national policy of encouraging community living over institutionalization for persons with disabilities (Kaiser 2003). Thirty-eight states extend eligibility for this program to individuals with incomes up to 300% of the SSI level. Of the fourteen states with levels of federal financial participation similar to Massachusetts, ten of them use this income standard, including New England states such as New Hampshire and Connecticut. In contrast, Massachusetts extends eligibility only to individuals with incomes at 100% of the federal poverty level, a substantially lower standard (Bruen, et al, 2003).

Massachusetts has two HCBS programs targeted toward working-age persons with disabilities. Like every state except Arizona, Massachusetts has an HCBS waiver program targeted toward individuals with mental retardation. It is also one of 19 states that cover individuals with head injuries as part of the HCBS waiver (CMS 2003). This approach differs from that of other states, most of which offer HCBS waiver services to individuals with physical disabilities and children as well (CMS 2003).

Special eligibility issues for children (Birth through Age 17) with disabilities:

Because work activity is not ordinarily expected of children, public benefits (cash and health coverage) for children are not tied to the ability to work. This difference from the adult population has made it difficult for policymakers to settle definitively on an eligibility standard for children and there have been several changes in the last 10-15 years.³⁴

As with adults, states must cover children who are eligible for SSI and children in this category comprise the largest number of Medicaid recipients under age 18. Eighty percent of children on Medicaid receive SSI (BCG 2003). Another group that must be covered is children who have been identified as having “special needs” under the Title IV-E Adoption Assistance and Foster Care Maintenance program. The term “special needs” in this program actually encompasses a wide array of children, many of whom do not have disabilities, but for whom place-

ment may be difficult because of older age or other reasons. To qualify as having a special need because of a disability, a child must meet the Social Security standard (See Table 4).

Massachusetts has additional “Medicaid Disabled” programs for children and, in 2003, nearly 7% of children qualified for Medicaid under these programs (BCG 2003). In keeping with the policy of promoting community living rather than institutionalization for people with disabilities, Massachusetts has adopted an optional Medicaid program called the “Kaileigh Mulligan” program.³⁵ Ordinarily, in determining Medicaid eligibility, the state considers parental income to be available to a child living in the community, but does not consider parental income available to a child living in an institution. This creates a perverse incentive for families to institutionalize children with disabilities. Under the Kaileigh Mulligan program, the state may disregard the income of parents for children with the most severe disabilities who live in the community, but who would qualify for institutionalization in certain facilities, thereby making it easier for families to care for children with disabilities at home. Twenty states offer the Kaileigh Mulligan program, but the program actually covers relatively few children because of the requirement that the disability must be among the most severe in order to qualify .

In addition, Massachusetts extends CommonHealth coverage to children whose disabilities meet the Social Security standards, but are not severe enough to qualify for the Kaileigh Mulligan program. This program enables parents to buy Medicaid coverage for their children by paying a premium on a family income-based sliding fee scale. Most children on CommonHealth live in the community, but there is also a very small category of immigrant children with disabilities who are institutionalized and qualify for the program as well.

Appendix 2 Notes

³¹ Except in 11 “209(b) states” named for a provision of the Social Security Act that permits states to use their own income eligibility standards, as long as they are no more restrictive than those in effect when the SSI program was enacted in 1972. In all but two of the 209(b) states, Illinois and Minnesota, these alternative standards restrict eligibility more than the SSI standard would under the same circumstances. Connecticut and New Hampshire are both examples of 209(b) states with these more restrictive standards.

³² Under this standard, an individual is considered unable to work if s/he is either statutorily blind OR meets the following standard:

S/he has demonstrated “an inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.” 20 C.F.R. 416.905(a).

³³ For example, under federal law “Specified Low-Income Medicare Beneficiaries” have an asset limit of \$4000 for an individual and \$6000 for a couple, double the usual standard.

³⁴ The current federal disability standard for Supplemental Security Income for children is:

“(A)n individual under the age of 18 shall be considered to be disabled, if that child has a medically determinable physical or mental disability, which results in marked and severe functional limitation, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of at least twelve months.” 20 C.F.R. 416.906.

For many other children on Medicaid, the state uses an older standard that may make Medicaid available to a somewhat broader population of children.

³⁵ This program takes its name from a Massachusetts child whose parents were among the early advocates for the program. At the federal level, this program is referred to as the “Katie Beckett” program for similar reasons.

Appendix 3 Overview of MassHealth Members with Disabilities

| | TOTAL | Total % | SSI Disabled | SSI Disabled | Medicaid Disabled | Medicaid Disabled | Common-Health | Common-Health |
|-----------------------------|---------|-------------------|--------------|--------------|-------------------|-------------------|---------------|---------------|
| | Number | Percent of Column | Number | Percent | Number | Percent | Number | Percent |
| <i>Adults</i> | 180,883 | 90% | 111,227 | 55% | 57,932 | 29% | 11,724 | 6% |
| <i>Children (age<21)</i> | 19,842 | 10% | 16,065 | 8% | 897 | 0% | 2,880 | 1% |
| <i>Total</i> | 200,725 | 100% | 127,292 | 63% | 58,829 | 29% | 14,604 | 7% |
| | | | | | | | | |
| <i>Income Level</i> | | | | | | | | |
| <i><100% FPL</i> | 164,706 | 82% | 127,292 | 100% | 36,806 | 63% | 608 | 4% |
| <i>100-132% FPL</i> | 20,553 | 10% | 0 | 0% | 20,355 | 35% | 198 | 1% |
| <i>133-200% FPL</i> | 8,659 | 4% | 0 | 0% | 1,265 | 2% | 7,394 | 51% |
| <i>>=201% FPL</i> | 6,807 | 3% | 0 | 0% | 403 | 1% | 6,404 | 44% |
| | | | | | | | | |
| <i>Residence</i> | | | | | | | | |
| <i>Community dwelling</i> | 195,080 | 97% | 125,370 | 98% | 55,193 | 94% | 14,517 | 99% |
| <i>Institution</i> | 5,645 | 3% | 1,922 | 2% | 3,636 | 6% | 87 | 1% |

Source: UBER Eligibility Snapshot Data FY03

Appendix 4 Innovative Programs for Medicaid Members with Disabilities

Current Programs in Massachusetts

Community Medical Alliance (CMA)

CMA, a wholly-owned affiliate of Neighborhood Health Plan, operates two special programs for members with disabilities. One is a program for individuals with severe physical disabilities in the greater Boston area, and the other is a program for individuals with active or advanced AIDS in the greater Boston area, New Bedford, and Worcester. Both programs serve adults and children, although most enrollees to date have been adults. The physical disability program enrolls approximately 220 members and the AIDS program has approximately 180 members.

To be eligible for the physical disability program, an individual has to be diagnosed with a severe physical disability and require personal care services or equivalent services as an alternative to institutionalization. The most common types of disabilities for CMA members are severe cerebral palsy, spinal cord injury, muscular dystrophy, and ALS. The AIDS program enrolls people with symptomatic HIV disease who meet special clinical criteria. Determinations for program participation are performed by Medicaid medical staff to ensure that the members' clinical conditions require the special and intense nature of the services provided by CMA. CMA's receives a risk-adjusted capitated payment for each member, based on the member's clinical condition.

Both programs uses nurse practitioners, who provide primary care in collaboration with the enrollee's primary care physician, often in the enrollee's homes or other community-based settings, and are responsible to ensure that all services are well coordinated for the enrollee. In addition to the nurse practitioners, each enrollee has a care team that includes a designated medical director, behavioral health and addiction specialists, and a durable medical equipment specialist, all of whom work with the primary care physician and other providers to make decisions and allocate care for the enrollee. For the physical disability program, a physical therapist is also part of the enrollee's team. CMA support staff facilitate referrals, authorizations and arrange for transportation. CMA members can receive a range of other services, including acupuncture treatment, massage therapy, adherence support, and home-based HIV care.

The CMA programs have been successful, with high levels of member satisfaction and demonstrated results in reducing hospitalization and per member costs. However, the programs are very small. One limiting factor is the narrow definition of severe physical disability and HIV/AIDS that is used to determine eligibility for the programs. CMA would like to expand the program to other parts of the state, but this would require approval from the Medicaid agency with assurances that CMA can identify providers who are dedicated to maintain this population in a home and community based setting whenever appropriate as supported by a nurse practitioner/behavioral health specialist model of health care delivery.

PCCP/Commonwealth Care Alliance Pilot Program at Brightwood Health Center

Commonwealth Care Alliance (CCA), a new consumer-governed specialized care delivery system, operates a pilot program to coordinate medical and behavioral health care for certain MassHealth enrollees with disabilities and chronic illnesses who receive their primary care at the Brightwood Health Center in Springfield. The pilot program began as a capitated managed care program through Neighborhood Health Plan but recently transitioned to a fee-for-service program through the PCCP, administered by the Massachusetts Behavioral Health Partnership. Approximately 450 members are enrolled in the program.

Care is provided to enrollees by a team of nurses, nurse practitioners, mental health and addiction counselors, and support service staff based at the Brightwood Health Center, who work with primary care providers (PCPs) to address the complex needs of health plan members with a disabilities or chronic illnesses, including HIV/AIDS. Brightwood Health Center and CCA program staff have developed a range of clinical interventions, including health risk assessment, reminder calls for preventive services, follow-up after emergency room visits and inpatient admissions, intensive care management of individuals with complex medical needs, and enhanced bilingual behavioral health services. In this model, medical and behavioral health services are provided on a fee-for-service basis, while Medicaid provides additional funding for the care coordination and support services.

According to a recent evaluation of the Brightwood program when it operated as a capitated model, overall costs of care declined for MassHealth SSI members who enrolled in the program, even when figuring in the additional funding for the enhanced services. This was accomplished mainly by a dramatic decline in inpatient hospital expenditures. In addition, SSI members at Brightwood had increased expenditures for primary care, outpatient behavioral health services, and prescription drugs, but these spending increases were more than offset by the reduction in inpatient care. In-depth interviews with selected members revealed high satisfaction with the program, and increased member knowledge of their chronic medical conditions, medications, and health promotion strategies.³⁶

However, the transition of this program from NHP to the PCCP has caused some loss of membership and program flexibility. MassHealth has contracted with the University of Massachusetts Medical School Commonwealth Medicine Center for Health Policy and Research to evaluate this pilot care management program and to gather information on the operation of the program in a fee-for-service environment.

Network Health initiative for adults with physical disabilities

Network Health, one of the four managed care organizations that contracts with MassHealth, has implemented a program to improve care for adults with physical disabilities.³⁷ The goal of the program is to avoid secondary complications of disability by providing case management, care coordination, and health education.

Network Health identifies members with disabilities through a variety of methods, including claims review and a health risk assessment screen conducted for all new members. Once identified, members are stratified into high, medium, or low risk categories based on their risk for developing secondary complications of their disability, such as pressure ulcers, respiratory infections, urinary tract infections, depression or constipation. Approximately 30% of identified members are considered high risk. Seventy-three percent of these high-risk members have either received or been offered a home visit by the local VNA. A future goal is to have an individual care plan developed for all members who have also had the home evaluation performed by the VNA, which then develops an individualized care plan for the member. Network Health is also developing self-management tools to assist members in identifying early signs and symptoms of complications, and to provide information on preventive care. All members with disabilities are eligible to also receive care coordination services from a Network Health nurse or social worker in order to facilitate access to services. An integrated care team at Network Health, consisting of behavioral health, medical care, social service, and pharmacy representatives meets weekly to discuss patient care.

Network Health originally anticipated that only 200-300 members would enroll in this program, but so far 750 members are participating, about 3% of the plan's total membership but

a significant portion of members with disabilities. As this program is fairly new, Network Health does not have outcomes data, but per member per month costs show a positive trend. This program does not receive any special capitation rates or financing from Medicaid, but is instead part of the plan's quality management and improvement program. Limits in the plan's administrative budget and staffing shortages have meant delays in the plan's ability to complete assessments and care plans in a timely manner.

Mental Health Service Program for Youth (MHSPY)

MHSPY is a program for children and adolescents with serious emotional disturbances. Originally begun as a demonstration with funding from the Robert Wood Johnson Foundation, it has continued as a collaborative effort between Neighborhood Health Plan, Medicaid, and the Departments of Social Services (DSS), Mental Health (DMH), Education (DOE), Youth Services (DYS), and the local school departments in Cambridge, Everett, Malden, Medford, and Somerville. The goal of the program is to help keep children in community settings by providing individualized services planned in partnership with families and other care providers. A key feature of MHSPY is providing integrated medical, mental health, social support, and non-traditional services. The program began in Cambridge and Somerville, and has expanded to Everett, Malden, and Medford. A maximum of 80 children can be enrolled at any point in time and the program has a waiting list.

In order to be eligible for MHSPY, a child must be at risk of placement in a residential institution, be eligible for DMH, DSS, DHS, or special education services. In addition, the child's family must agree to be active participants. Clinical management is provided by the MHSPY medical director (a psychiatrist) as well as by the primary care physician. MHSPY contracts with a range of non-traditional health care and offers flexible benefits.

NHP receives an enhanced capitation rate for MHSPY members, which includes Medicaid funding as well as funding from the other state agencies involved. This funding from the other state agencies enhances the program's ability to provide whatever services are required to help keep the child out of an institutional setting.

Young people enrolled in the MHSPY program show significant and sustained improvement in their functioning at home, school, and in the community as demonstrated by scores on widely used measures of function. In addition, the MHSPY members spend approximately 85% of their time living at home with their families even though all are at high risk of institutional placement. Finally, the program has also effectively managed emergency room and prescription drug use.³⁸

Coordinated Family-Focused Care (CFFC)

CFFC is a new program, similar to MHSPY, which is a collaborative effort of Medicaid, DMH, DSS, DHS, EOHSS, DOE, the Massachusetts Behavioral Health Partnership (MBHP), and parents from the Parent/Professional Advocacy League (PAL), the Federation for Children with Special Health Needs and Adoptive Families Together. This program is administered through a contract between Medicaid and MBHP, and extends services to children age 3–18 in Worcester, New Bedford, and Brockton. Children who enroll in the program have serious emotional disturbances, and are either at risk of out-of-home placement or in residential care but able to live at home with supports. Care is provided through agencies that employ a two-person team to develop individual care plans for children, and arrange family supports such as respite care, group counseling, crisis response, and after school care. The team consists of a licensed clinical care manager and a family partner (parent of an individual with a childhood history of serious emotional disturbance), and supported by administrative staff and a part-

time psychiatrist. Unlike MHSPY's capitated payment model, CFFC pays the provider agencies a "case rate" per enrolled child for care management and family support services. Other services such as medical care, acute mental health care, and residential care are reimbursed on a fee-for-service basis. To date, 220 children have enrolled in the program.

Essential Care

Essential Care is new voluntary case management program, administered under the state's contract by with the Massachusetts Behavioral Health Partnership since November, 2003. Members with MassHealth Essential coverage who are PCC Plan members are eligible to enroll if they have had high medical or behavioral expenses in the past year, have complex physical illnesses, have a pattern of receiving primary care in emergency rooms, and/or are not adhering to their medication regimens. Potential members are identified by predictive modeling software, and prior claims histories, and through referrals from providers, homeless shelters, and other entities.

MBHP nurses or social workers serve as care managers and work with members and PCCs to develop care plans. They also coordinate services across state agencies, medical providers, behavioral health providers, and community agencies. MBHP receives an administrative fee to provide these care coordination services.

Essential Care is in its early stages and so far has enrolled 103 members. Medicaid hopes the program will eventually serve many more members, although identification of eligible members and enrollment will likely continue to be challenging because this is a difficult population to find and then engage in care.

Special Kids, Special Care

"Special Kids ♥ Special Care" is a program for medically complex foster children operated by Neighborhood Health Plan and jointly sponsored by Medicaid and the Department of Social Services (DSS). To be eligible for the program, children must have full foster care status and need skilled nursing services. Many of the eligible children are technology dependent. Approximately 90 children are currently enrolled in the program. The program started in the Boston area, and now operates also in the central and northeastern parts of the state.

Under this program, DSS identifies children and initiates the application process. A Nurse Coordinator at Medicaid screens potential enrollees and assists with the enrollment process. Once a child is enrolled, a pediatric nurse practitioner provides day-to-day clinical management of the child's care, working closely with the child's primary care physician. The nurse practitioner takes first call for new problems, manages durable medical equipment vendors, home health, and private duty nursing, and facilitates coordination of care with school systems. NHP, Medicaid, and DSS hold regular meetings to coordinate clinical and administrative operations. The DSS case manager remains responsible for the delivery of social services and non-medical supports.

NHP receives a special capitation rate for children enrolled in Special Kids Special Care and also has a special financial risk-sharing arrangement with Medicaid to protect NHP from undue financial risk. In turn, NHP pays providers enhanced fees for the types of primary care services most commonly used by these children, including certain types of outpatient visits, case management, telephone consultation, home, and hospital visits.

Some of the challenges of this program have included bringing together people from very different agencies and systems to accomplish a shared outcome and finding sufficient numbers of eligible children in a geographic area to justify the infrastructure costs of developing the clinical management systems that are required by the program.

Program of Assertive Community Treatment (PACT)

PACT is a team approach to active, ongoing, and long-term community-based psychiatric treatment, outreach, rehabilitation, and support for people with serious mental illness. The program is administered by the Massachusetts Behavioral Health Partnership, which provides ongoing and long-term community-based psychiatric treatment, outreach, rehabilitation and support for people with serious mental illness. Many of the members have co-occurring disorders such as substance abuse, homelessness, or involvement with the judicial system. Team members include a psychiatrist, case manager, nurse, mental health professionals, and consumer advocates.

Community Case Management Pilot

The Community Case Management Pilot (CCMP) is a statewide program for children with complex medical needs who require private duty nursing services. Approximately 500 children are eligible to join the program because they are high risk, technologically dependent, or medically fragile. On average, these children use nearly \$60,000 in private duty nursing services per child per year. Commonwealth Medicine at the University of Massachusetts Medical School administers the CCMP through a contract with DMA. Case management is provided by nurses, social workers, and therapists who conduct in-home or in-person comprehensive needs assessments; authorize, facilitate, and coordinate community-based long-term care services; participate in hospital discharge planning meetings; and help to identify third-party payments. The program was implemented in August, 2003, and has a current caseload of 170 children.

Personal Care Attendant Program

Massachusetts has one of the oldest consumer-directed personal care attendant programs in the country, unique in that PCA services are a state-plan benefit rather than provided through a home and community-based waiver benefit. Over 8,000 non-elderly MassHealth members with disabilities, including 1,800 children, receive personal care services through this program (as do 2,000 MassHealth members over the age of 65).

Once MassHealth members are approved for PCA services, they may employ their own caregivers (with assistance from surrogates or legal representatives, if needed) rather than being required to obtain PCA services through agencies. Members have the option to delegate the fiscal and state and federal employer-required obligations to a fiscal intermediary or manage this process themselves. Most people delegate the functions to one of four organizations that keep payroll records, including taxes, insurance and W-2 transactions, and pay the attendants, on behalf of consumers.

MassHealth has a new initiative underway, the “PCA Evaluation Change Project,” in which it is planning to hire and train clinical staff to conduct face-to-face assessments of all members who request PCA services, in an effort to standardize the assessment process, provide timely referral and authorization to approved services, identify third-party coverage options, inform members of their range of choices for community-based care, and coordinate services across EOHHS agencies.

The Massachusetts PCA model is now being replicated by other states that hope to introduce more consumer-direction in their long-term care benefits, and also potentially achieve cost-savings by eliminating agency supervision and overhead.

Self-Determination Project

The Department of Mental Retardation received funding from the Robert Wood Johnson Foundation to initiate self-determination programs for DMR consumers in the mid-1990's.

Approximately 200 people, mostly in the greater Boston area, are involved in self-determination activities either through family governing boards or through direct purchase of services and supports. Families can work through a fiscal intermediary organization (ISO) to issue a request for response in order to obtain community-based services if the services they seek are not available from existing providers. The ISO keeps records and pays employees.

DMR would like to expand this program as much as possible. However, DMR's existing Family Support Program already allows consumers to hire their own staff. Therefore, people have to be dissatisfied with their broad service package in order to assume the time, responsibility, and overhead of overall self-direction.

Aging and Disability Resource Center

The Executive Office of Elder Affairs was awarded a grant from the Administration on Aging and CMS in 2003 to develop systems to integrate information and referral, benefits, and choice counseling services to elders and working-age adults with disabilities in the Northeast Region of the state. The grant is being administered by Elder Services of Merrimack Valley, Inc., and the Northeast Independent Living Program. The project has a Community Partners Advisory Group and Consumer Advisory Group to assist in planning and design of the project.

MassHealth Programs for Elders That Might Be Adapted to Non-Elderly Individuals with Disabilities

Programs of All-Inclusive Care for the Elderly (PACE)

PACE is a national managed care program for people age 55 or older who are eligible for nursing home placement and are dually eligible for Medicaid and Medicare. PACE provides a full continuum of preventive, primary, acute, behavioral, and long-term care services, generally structured around an adult day health program that participants are required to attend. In joining a PACE program, participants receive their care from the multidisciplinary PACE clinical team or contracted providers, and thus are generally required to switch their primary care to a PACE physician. There are 43 PACE sites nationwide, including several in Massachusetts (in Lynn, Cambridge, Worcester, East Boston, and Dorchester). The purpose of PACE is to use the blended funding streams of Medicaid and Medicare to integrate services for this high-risk population, and maintain people in the community who would otherwise likely enter nursing homes. PACE programs receive special capitation rates from both Medicaid and Medicare to serve this population. Although only a few PACE enrollees are working age adults, the model has been adapted elsewhere for younger adults and children with disabilities.

Senior Care Organizations (SCO)

This is a new program in Massachusetts (beginning enrollment in the spring of 2004) for older adults who receive Medicaid or Medicaid/Medicare benefits. It expands the PACE concept to cover elders who are not yet at risk of nursing home placement, using a more flexible model of service delivery in that members are not required to participate in adult day health programs and may have a broader choice of primary care providers. SCOs offer a team approach to care that includes social services and care coordination, and individual care planning for members. This program is expected to serve a much broader population than PACE, and will be operated by three managed care organizations in Massachusetts, Commonwealth Care Alliance, Senior Whole Health, and EverCare. SCOs will receive special capitation rates for this program. Again, the SCO model, if it is successful with seniors, may be applicable to a younger adult population as well.

Innovative Programs in Other States

Independent Care (ICare)

ICare in Milwaukee, Wisconsin, is one of the oldest specialty managed care programs for people with disabilities in the country. Founded in 1994, ICare enrolls Medicaid SSI beneficiaries over the age of 18 on a voluntary basis and provides medical, dental, behavioral health, vision, and prescription drug coverage. Care coordination benefits include health education programs, treatment and follow-up information, and social, recreational, and wellness programs. Every new enrollee receives a face-to-face assessment and individual care plan within 60 days of enrollment. Originally operated as a joint venture between Humana health plan and the Milwaukee Center for Independence, ICare now has its own HMO license and provides managed care services to over 5000 members in Milwaukee County. People who enroll in ICare can be dually eligible for Medicaid and Medicare, but cannot be enrolled in a Home and Community-Based waiver program.

Health Services for Children with Special Needs (HSCSN)

HSCSN is a voluntary managed care program for SSI children in the District of Columbia. All Medicaid benefits, including acute medical care, behavioral health care, and residential care are covered in this program, as well as care coordination, outreach services, respite care, home modifications, and behavioral and developmental wraparound services. A central feature of the program is a care management team that works with each family and the child's primary care provider.

HSCSN began as an 1115 waiver demonstration project in 1995, and currently serves 2800 of the children who receive SSI benefits in the District of Columbia, more than 80% of the eligible population. The program operates under a risk sharing agreement between Medicaid and the managed care organization. An independent evaluation found that access to care was equal or better than the previous fee-for-service arrangements; however, the demonstration program experienced financial losses and difficulty coordinating with other agencies serving the same children.³⁹ Although the program experienced financial losses, it proved very popular with families, and thus the contract between the District of Columbia and the health plan was converted to a no-risk contract.

Vermont Medical Home Project

The Vermont Medical Home Project is a grant-funded program to integrate primary care case management services with mental health services for people with diabetes and serious and persistent mental illness. It is a partnership between the state Medicaid program and the Department of Mental Health, and operates out of three of the state's community mental health centers.

The origin of this project was analysis that showed that 20% of mental health consumers were diabetic, and most of the remaining 80% were at risk of diabetes, in large part due to weight gain associated with taking anti-psychotic medications. A major goal of the program is to develop systems of care and self-management supports for mental health consumers. Consumers have been actively involved in program planning. Participants complete an on-line health risk assessment at club-house venues, and most frequently identify nutrition and exercise as their primary concerns. Nurses at each of the community mental health centers are developing interventions for individual participants as well as group activities and educational materials. Interventions include diabetes educational groups and a mall walkers program.

Minnesota Disability Health Options Program

Minnesota Disability Health Options Program (MnDHO) is a voluntary managed care program for working age adults with physical disabilities who are either eligible for Medicaid or dually eligible for Medicaid and Medicare. MnDHO is operated by a partnership between a commercial managed care organization (UCare) and an organization formed by a partnership of disability advocates and providers (Axis). Axis is responsible for the coordination and authorization of care, and played a major role in the development of the provider network and preventive primary care protocols for members. Axis also uses a consumer advisory committee to assist in developing and reviewing the managed care organization's policies, procedures, and operations. MnDHO currently has approximately 360 members in the Twin City area.

Wisconsin Partnership Program (WPP)

WPP is a voluntary managed care program that serves approximately 1400 elders and people with physical disabilities in two areas of Wisconsin, modeled after the PACE program, but available to working-age adults as well as older adults. Enrollees must be eligible for Medicaid, may also have Medicare coverage, and must be certified by their state as eligible for nursing home care. The Partnership Program receives capitation payments from both Medicaid and Medicare (through both 1115 and 222 waivers) and integrates medical, behavioral health and long-term care services, including personal assistance. The multi-disciplinary team includes the enrollee and the physician, along with nurses and social workers, who work together to create a care plan for the enrollee. Deviating from the PACE model, Partnership enrollees are not required to participate in an adult day health program and may keep their existing primary care providers. Two of the organizations that operate the Partnership program evolved out of Independent Living Centers, and were established by people with disabilities.

While WPP has been very successful in voluntarily enrolling members and integrating care, they have faced several challenges, including building an effective interdisciplinary team of nurses and social workers, and working with a wide network of primary care physicians, many of whom do not always understand or buy in to the concept of a team approach to care, and who often have very few program enrollees on their patient panels. In addition, the small community-based organizations that took up the challenge of serving as managed care organizations had a steep learning curve in developing management systems with limited resources.

Medically Fragile Children's Project (MFCP)

MFCP is a voluntary managed care program that began as a program for medically fragile children in Columbia, South Carolina in 1996. The founders of MFCP modeled this program for children after the PACE programs, using a multi-disciplinary team to provide care. However, the setting for care is a daycare center rather than an adult day health program, and none of the children have Medicare insurance coverage. The program began as a partnership between the state's child welfare system and Medicaid for foster children, but is now available to any Medicaid child who meets clinical criteria and has expanded to other parts of South Carolina. Approximately 100 children have enrolled.

The team approach to care includes parents, a pediatrician, a pediatric nurse practitioner, nurses, social workers, pharmacists, physical therapists, occupational therapists, speech therapists, a dietitian, psychologists, and home care technicians. One of the challenges MFCP faced is that children whose health improved had to be discharged from the program because they no longer met program eligibility criteria. However, some of these children's health deteriorated after discharge because they no longer received the services that helped to keep them healthy. MFCP recently introduced a "Step-Down" program for graduates in order to continue providing support services.

CalOptima—A Specialized Disease Management for Medicaid Members with Diabetes and Multiple Co-Morbid Conditions

CalOptima, a county-operated health system in California, piloted a disease management program for Medicaid members who had claims for medications in at least ten other drug classifications, demonstrating high levels of co-morbidity. CalOptima already contracts with a disease management vendor to manage the care of approximately 10,000 members with diabetes, but their contracted vendor was not able to provide services to members with complex co-morbidities who spoke languages other than English. So CalOptima developed an in-house disease management that could address, both culturally and linguistically, the needs of members who spoke Spanish or Vietnamese, and could address multiple medical and social conditions in addition to diabetes.

Over 50 members enrolled in the pilot project that provided care coordination and management from a health plan nurse/community liaison team that was specially trained in diabetes, and could speak the languages of the enrollee population. Through a needs assessment they identified barriers to care including transportation, low literacy levels, physical disability, insufficient knowledge about diabetes, and lack of motivation to change habits. CalOptima conducted a motivational assessment, along with a clinical assessment, provided linguistically appropriate educational materials and support groups, one-on-one dietary consultation, and linked members to resources in the community. They also began to pilot-test motivational interventions. After one year, pilot members experienced better HBA1C control, had more retinal exams and LDL testing, and better LDL control. Total hospital days decreased, as did pharmacy costs even though there was an increase in member complications of retinopathy and renal failure. Member participation in educational activities increased dramatically. However, due to the fact that most of the pilot members were dually eligible for Medicaid and Medicare, and CalOptima does not receive payment for Medicare services, most of the cost-savings accrued to the Medicare program rather than the health plan.

Health Net program for children with special health care needs

Health Net is a 2.8 million member health plan in California with approximately 600,000 Medicaid members. Health Net developed a project within the health plan to increase the identification of children with special health care needs (CSHCN), increase referrals to California's 20 carved out public health programs, and to support the development of medical homes for children with special needs within the plan. The plan implemented a screening instrument in three languages as part of its new member welcome calls, and increased the identification of new members who were children with special needs from 1% to 20%. Of the nearly 2000 children identified, half were eligible for and referred to other public health programs. HealthNet also piloted a medical home project with one of the largest physician groups in California. The plan paid for a health coordinator to conduct family education sessions and distribute a parent notebook to help parents of CSHCN keep track of their child's doctor's visits, ER visits, and medication history. In addition, the plan worked with the practice to increase its identification of CSHCN within the practice. Health Net then expanded the pilot to a second large provider practice. This practice hired a health coordinator with clinical expertise in order to help families with health education. When the grant-funding to the practices ended, both practices continued funding the health coordinator because of the benefit of care coordination to both families and physicians.

Access II Care program for children with special health care needs

Access II Care is a primary care case management program (PCCM) in North Carolina. Nine provider practices constitute the provider network for Access II Care; these practices serve a total of 200,000 Medicaid members, approximately 700 of whom are children with special health needs who receive care coordination through the program. Although the providers are all paid on a fee-for-service basis, the state Medicaid program also pays one of the larger pediatric practices \$2.50 PMPM for care coordination for CSHCN. In addition, the Medicaid program pays for a special needs coordinator to help the practice create a medical home for CSHCN.

One of the goals of Access II Care is to ensure that each child who needs a care coordinator has one, and that children with multiple care coordinators have unduplicated services. In this part of North Carolina 19 other state, county, and community-based organizations provide case management services for CSHCN. Many of these case managers had no contact with primary care providers, and the physicians had limited knowledge of these services. Access II Care worked with 17 of these case management programs to create a set of protocols for case managers and primary care providers to work together. Six agencies adopted these protocols, including the Department of Social Services, the Health Department, Mental Health, the Infant and Toddler Program, MRDD and Head Start, as well as the pediatric practice. Access II Care prioritizes its own care coordination resources to target services for those children most in need who are not receiving care coordination elsewhere. This pilot program is now being expanded to other practices in the network.

Cash and Counseling

Starting in 1996, CMS and the Robert Wood Johnson Foundation co-sponsored a demonstration program, Cash and Counseling, for Medicaid beneficiaries in Arkansas, Florida, and New Jersey who are eligible for personal assistance services. Individuals of all ages with disabilities—children, working age adults with physical and developmental disabilities, and elders—were eligible for the program. Participants receive a cash allowance or grant to purchase and manage their own long-term care services, rather than receiving these services through a home care agency. The goals of the program are to enhance control and autonomy, reduce unmet needs, and improve quality

Medicaid members receive a monthly allowance and may use it to hire relatives as care providers, or purchase other disability-related equipment and services. Participants are able to designate representatives, including family members, to make decisions on their behalf. An evaluation of the project found that individuals receiving consumer-directed services had much higher satisfaction and fewer unmet ADL, IADL and transportation needs than those receiving agency services.

The initial cost evaluation found that after 12 months, Cash and Counseling program participants in Arkansas spent more than individuals in the control group, largely because half of the control group members were unable to obtain any of the personal assistance for which they had been authorized. However, after 24 months, this initial increase in expenditures was offset by reductions in nursing home and inpatient hospital care among Cash and Counseling participants.⁴⁰ In the other two Cash and Counseling states, Florida and New Jersey, control group members did not have the same difficulty accessing personal assistance services, and the early indication is that these programs may prove to be cost effective more quickly.⁴¹

Self determination—for people with developmental disabilities

The self-determination movement for people with cognitive disabilities was launched in the early 1990s, with funding from the Robert Wood Johnson Foundation (RWJF). The initial populations were individuals with developmental disabilities and individuals with acquired brain injury. Since the initial pilot in New Hampshire, self-determination programs were launched in at least 20 additional states. Core features of these programs include:

- Person-centered planning whereby individuals and families could define their own needs;
- Independent professional support to help individuals and their families identify needs and choose services;
- Individual budgets, an allocation of funds to pay for services;
- Fiscal intermediaries who purchased services and handled legal and accounting matters on behalf of participants. (RWJF website, Jan., 2004)

Although the programs are widespread, most serve fewer than 200 people with developmental disabilities. Results of an evaluation of several of the programs revealed that people with developmental disabilities experienced greater empowerment and control, and an improvement in their quality of life while participating in the program. In addition, some of the programs resulted in increased community integration. (Conroy et al., 2002)

Disease Management in Florida Medicaid Program

The state of Florida is a leader in Medicaid managed care purchaser initiatives to implement disease management strategies to improve care and control costs for beneficiaries with chronic illnesses. Initiated as a cost-saving measure, the first disease management contracts were signed in 1999, and since then the state contracted with ten vendors to manage diabetes, HIV/AIDS, asthma, hemophilia, congestive heart failure, end stage renal disease sickle cell anemia, cancer, or hypertension. Every Medicaid recipients enrolled in the Florida PCCM program (approximately one-third of Medicaid recipients) who is identified as having one of these chronic illnesses is automatically enrolled in the disease management initiative, but can disenroll at any time. The goals of these disease management programs include: improved care and health outcomes; reduction in hospitalizations and emergency room visits; reduction in overall costs, and better educated providers and consumers.

These initial programs have had mixed results in terms of cost savings. The first three disease management programs, for diabetes, HIV and hemophilia, produced overall savings without factoring in the cost of the disease management contracts, with reduced hospitalizations and outpatient services offsetting increases in pharmacy costs. However, the next wave of disease management initiatives had mixed results. On the other hand, nearly all of the programs demonstrated improvements in clinical indicators of health care quality. Among the many challenges that Florida encountered in initiating this ambitious program were the definition and measurement of evaluation measures, and the fact that so many members had multiple chronic illnesses. Currently, Florida is seeking to contract with disease management vendors that can manage multiple diseases in order to address the presence of co-morbidities.

Appendix 4 Notes

³⁶ Bachman, Tobias & Tierney. Brightwood Evaluation Results. Presentation to the Division of Medical Assistance, April 13, 2004.

³⁷ This program was developed as part of the Best Clinical and Administrative Practices (BCAP) work group convened by the Center for Health Care Strategies.

³⁸ Massachusetts Mental Health Services Program for Youth (MHSPY) Program. DMA Fact Sheet, 2004.

³⁹ Coulam, R et al., Evaluation of D.C.'s Demonstration Program, "Managed Care System for Disabled and Special Needs Children. US DHHS Report, 2000.

⁴⁰ Dale S, Phillips B, Schore J, Lepidus C. The effects of Cash and Counseling on personal care services and Medicaid costs in Arkansas. *Health Affairs*. 2003;(web exclusive).

⁴¹ Key informant interviews with researchers and policy-makers involved in the Cash and Counseling Demonstration regarding unpublished results, February, 2004.

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