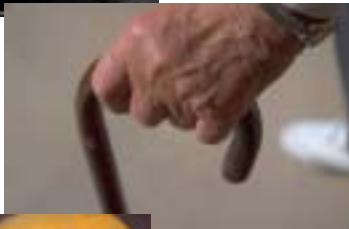


CASA Association of New York State, 2002

*New Worlds,
New Users,
Old Systems:*



*A Perspective on
Long Term Care
in New York
State*

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A Message from the Co-Chairs



The Community Alternative Systems Agency (CASA) Association of New York State (NYS) represents local government and county based agencies, which focus on the long term care system (LTC), particularly home care. Members may be located in county departments of Social Services, Long Term Care, Health or Office for the Aging. In general, they are responsible for the management of NYS Medicaid funded long-term care programs for persons who are chronically ill and/or disabled. Key functions include information and referral; systems development; assessments; program planning and development; case management and coordination.

The purpose of the Association is to share information and expertise in order to improve the long term care systems in the member counties and across New York State. Historically these programs have primarily served the frail elderly. Over the last several years, however, about one third of the clients have been under the age of 60, including a significant number of children and young adults. Developing, planning and implementing services for consumers needing both long term care and mental health or developmental disabilities programs has emerged as a major problem. The unique needs of this population require coordination and cooperation among discrete and disparate programs sponsored by several different State agencies. This paper focuses on the services of the New York State Department of Health, Office of Mental Health, and the Office of Mental Retardation and Developmental Disabilities because these systems operate Medicaid funded programs, which are open to all ages. We recognize that other state agencies, which do not meet these criteria, have not been included in this report. This paper attempts to analyze trends, approaches and problems in the current system and to make recommendations for improvement.

Contributors to this paper include representatives of local government agencies, NYS Department of Health (DOH), NYS Office of Mental Health (OMH) and NYS Office of Mental Retardation and Developmental Disabilities (OMRDD) Writers include:

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Committee members who made invaluable contributions include:

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We also would like to thank the many speakers from OMH, OMRDD, and DOH who helped us gain a better understanding of the issues.

The views put forth in this paper are solely those of the CASA Association and not necessarily those of the County Executive's or of the Commissioner's Associations or any other agency.

On behalf of the CASA Association, we hope that the information and ideas offered will promote useful discussions and encourage effective actions among and on behalf of all the stakeholders.

Michelle Berry (Co-Chair)
Director, Broome County CASA

Paula Freedman (Co-Chair)
Director of Planning
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CONCLUSIONS OF THE STUDY



The intent of this study was to gain some understanding about how people with developmental disabilities and/or mental illness who also need long term care services are served. This population has been identified as difficult to serve and is often the source of considerable confusion and conflict among treatment professionals at the local level. It is clear that the difficulty results from structural differences, approaches, and resources among the three systems involved, along with a lack of mutual understanding. It is also clear that these conclusions and recommendations are equally applicable to the community and system as a whole. There is no blame or failure to be assigned. Given certain factors or premises, particular outcomes are more likely to occur.

1. There are three key distinctions between the long term care (LTC), mental health (MH), and developmental disability (OMRDD) systems which affect the delivery of service:
 - a) ***Mandated vs. Non-Mandated Services*** - The only fully Medicaid funded LTC program mandated state-wide by the Department of Health is the Personal Care Program which has neither caps on funding or limits on the number of people who can be served. Anyone who is eligible for the Personal Care Program must be served. On the other hand, there are no OMH/OMRDD programs that are mandated in every county.
 - b) ***Entitlement vs. Eligibility*** - Most LTC programs are entitlement based. If you meet the program criteria established in legislation or regulation, you are entitled to, and will be authorized to receive the service subject to staff availability. OMH/OMRDD programs are based on eligibility. You must meet the criteria in order to be eligible for services, but that doesn't automatically guarantee receiving services, which are dependent upon funding. There are waiting lists for services in many counties.
 - c) ***Capped vs. Uncapped Program Funding*** - Outside of waived programs, LTC programs funded by Medicaid are not subject to a statewide budget cap. The only criteria to receive services are medical necessity and financial eligibility. Sufficient Medicaid funds must be allocated to cover all eligible recipients. All OMH/OMRDD programs have an annual budget - a capped amount. That appropriation is determined by the New York State Legislature annually. When a county (under OMH) or a region (under OMRDD) expends its budget, additional eligible clients will only receive services when the county or region has sufficient dollars to include them.
2. Case management is defined differently across programs. There are differences both across State agencies and within programs in each State agency. These important differences include which tasks or activities are part of case management; the qualifications of staff; the initial

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and ongoing training required of staff; funding; and the philosophical approach which underlies each program.

3. Case managers in LTC programs may have caseloads of 80 - 120 clients and are expected to determine eligibility, assess need, authorize payment for services, develop care plans, and provide case management as needed. OMH/OMRDD case managers often have capped case loads (generally around 26 clients per case worker) and they are expected to develop a plan, coordinate services and advocate for the client. Intensive Case Managers (ICM) through OMH generally serve 12 to 16 clients.
4. LTC dollars are very specific and apply to care for the client. Reimbursement is directly to the provider. OMH/OMRDD dollars are more flexible, due to the nature of the waivers, and can be used broadly to support the individual in the community in a variety of ways, both medically and socially.
5. Generally speaking, LTC systems are “deficit” based using medical models. They are based on the consumer’s inability to perform vital tasks. On the other hand, OMH/OMRDD programs are generally “strength” based or person centered and focus on what the consumer can and/or wants to do in order to be as independent as possible.
6. The goal for LTC programs is to provide medically necessary care at home or in other community settings. The goal for OMH/OMRDD programs is to maximize the client’s inclusion in community life.
7. LTC programs were designed for the elderly yet, over the last decade, they have increasingly served young adults and children with disabilities whose influence on public policy is growing and will continue to sway the direction of long term care and supported community care. The percentage of those less than age 65 receiving personal care in counties in New York State ranges from 22% to 59%.
8. The transition from the child to the adult system in OMRDD and OMH can be difficult and frustrating to clients and their families. Services for children are augmented by school programs that are mandated for children up to the age of 21. Adult services may be less enriched or supplemented. Unfulfilled expectations and efforts to make other systems fill gaps sets up potential conflicts among workers in different systems at the local level.
9. Collaborations across State systems are not mandated and cross training opportunities are virtually non-existent. None of the three State agencies involved (DOH, OMH, OMRDD) requires or offers formal mechanisms to local staff on how to link across State systems or

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programs in order to maximize coordination, agree on common outcomes or effectively share resources on behalf of a consumer. This situation may inhibit the ability to maximize the use of the limited dollars available.

10. Overall, our systems are poorly integrated. In large measure this is due to the history of adding new programs and regulations (usually in response to a current crisis) but never eliminating or consolidating any existing ones. The LTC, OMH and OMRDD “systems” have created a patchwork of separate boxes with overlapping boundaries rather than an integrated, coordinated continuum of care.
11. While there is extensive data collected at the State level, it is not easily accessible or user friendly. It is difficult to analyze and not readily available to counties in a comprehensive way that lends itself to evaluation.

RECOMMENDATIONS



We make the following recommendations to improve the long term care services in New York State.

1. Align funding, program design, consumer needs and preferences, and systems capability. Once a public policy has been set, it must be fully supported. Regulations must clearly support and define the desired outcomes and be consistent with State expectations of counties.
2. Develop legislation and regulations that maintain sufficient flexibility to allow each county or region to plan for services based on local resources, geography, population, history and political climate but which requires common elements to insure quality programs that lead to measurable, positive outcomes. The CASA Association paper “Towards a Coordinated Long Term Care System” (February, 1995) is an example of how to describe a broad framework combining essential elements with local flexibility.
3. All involved State agencies need to collaborate in order to develop and implement a common public policy that affects the chronically ill and/or disabled populations. Long term care services need to meet the needs of affected individuals from birth to death and the complexity of those needs requires an integrated approach. There should be a clearly articulated long term care policy which guides program development and money spent in New York State.
4. Recognize that systems originally designed to serve the frail elderly are now expected to serve children, young adults, the mentally ill and the developmentally disabled in a community integration model. A new approach based on need rather than age is overdue.
5. Replacing the current fragmented long term care system (which is a multitude of program “boxes”) with a menu of services within a continuum of care is a high priority. Such a continuum or menu would make it more likely that consumers receive those services which meet their needs in a cost effective and quality manner.
6. Improve the data collection system in New York State in order to do effective planning. Information should be as current and as user friendly as possible in order to determine, at a minimum, the number and characteristics of program users, the total cost of each program broken down by federal, state and local share, the number of consumers who use multiple Medicaid funded programs (e.g., users of the Personal Care Program and OMH and/or OMRDD program) and costs incurred across multiple programs.
7. An evaluation component, based on accurate data, should be built into each Medicaid funded program. The results of these evaluations should be used to restructure, improve, prioritize or eliminate programs. It is important to regularly review the status and utilization of each

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program, as well as the outcomes for consumers. Without ongoing data collection, program evaluation and policy re-assessment, we cannot be assured that these costly programs are effectively meeting needs.

8. Each state agency should determine if cost is one of the factors to be considered in program development and implementation. If so, costs, in the context of quality care, should be applied across all programs. One program should not be able to work outside of cost considerations if others have constraints (e.g., programs for younger adults with disabilities vs. programs for the elderly). Cost effectiveness should be a factor for all community care programs.
9. State agencies need to be proactive in defining and describing case management. Workers in DOH, OMH, and OMRDD programs concerned with long term care need:
 - a) initial training on the other systems their clients are likely to use.
 - b) training in collaboration and team building.
 - c) ongoing updating and technical assistance.
 - d) a clear definition of what is meant by “case management” in each program and, therefore, what a worker is expected to do.
 - e) direction that supports and facilitates coordination of services across State agency boundaries.
10. Paperwork should be streamlined and minimized within the framework of federal regulations. Repetitive records, redundant assessments and extraneous information do not necessarily contribute to positive client outcomes or quality programs and have been cited as reasons why practitioners devoted to client care leave the field.
11. Consumers need access to information about their rights and responsibilities including information on how systems work and what to expect. Consumers must be treated with dignity and their decisions respected when they are made with an understanding about consequent risks.
12. Consumers must be informed about their responsibilities and how to enhance the consumer/caseworker relationship (e.g., recognition that the consumer’s home is also the caregivers workplace; understanding that verbal abuse, sexual harassment, drug activity, etc. may be grounds to terminate service).

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13. More focus and funding should be directed toward services that bolster the informal care systems. These include respite care and access to assistive technology and equipment that would help the informal, unpaid caregiver.
14. There should be a long term care information and referral service/network, which is available to consumers of all ages, disabilities and income, and to workers, which would provide generic information as well as help direct people to the most appropriate programs available in their communities.

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The goal of this paper is to understand how history, trends, demographics, public policy and program design, have resulted in certain outcomes for those consumers (and their families) receiving Medicaid funded community-based long term care services as well as mental health and/or developmental disability services. This population was selected because, although a myriad of programs funded by Medicaid exist to care for their diverse needs, lack of coordination across programs and State agencies has complicated the delivery of quality, cost effective programming. While this paper focuses on this special population, many of the conclusions and recommendations are broadly applicable to the entire home care community.

In the past the frail elderly were the primary recipients of home care services. More recently, those in receipt of home care have expanded to include not only the elderly but also a growing number of infants, children, young and middle-aged adults. These groups are served by a wide variety of programs, many of which overlap and some of which directly conflict with one another. This study attempts to understand how the various program histories and trends have led to our current system and have therefore impacted case management, service delivery systems and barriers to service. Services available in any county are the result of federal and state policies and regulations played out against local resources and history. This in turn impacts what consumers receive, what providers give and how government allocates resources.

HISTORY

With the introduction of Medicare and Medicaid in 1965, the federal government funded home care to the elderly through the certified home health agencies (CHHA). Under Medicaid, the federal government requires all states to provide nursing home care to those over the age of 21 and home health care (through the CHHA agencies) to all that are eligible. Medicaid also provided states with the option to develop other community-based programs. Those optional Medicaid services include but are not limited to: skilled home health care, case management, personal care, private duty nursing and the ability to apply to provide special services under a federal waiver. Many states restrict their programs to mandated services. However, NYS developed a rich array of mandated, optional, and waived services as needs arose within special populations. While these services provide many benefits to a variety of consumers, they were not organized into a long term care system but rather added to the Medicaid menu of available programs and services. Therefore, it is up to the consumer, provider and local government to negotiate this rich but complex variety of services.

The first home and community based programs developed in NYS were home health care nursing, private duty nursing, Adult Day Health Care, Long Term Home Health Care Program (LTHHCP), and the largest home care program to date, the Personal Care Program (PCP). In the late 1980s and early 1990s, new Medicaid programs were developed through a number of federal waiver initiatives. The initiatives included programs for: children with physical and developmental disabilities known as Care at Home waivers, the Office of Mental Retardation and Developmentally Disabled (OMRDD), Home and Community Based (HCBS) Services waiver to

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serve the developmentally disabled population, the Traumatic Brain Injury (TBI) program for people who experience a brain injury after the age of 22, and the Office of Mental Health (OMH) HCBS for Severely Mentally Emotionally Disturbed Children. During the decade of the 1990s, there was also an expansion of the personal care program through the Consumer Directed Personal Attendant Program (CDPAP). Other Medicaid funded services available in NYS include Hospice, AIDS case management, Early Intervention, and Medicaid Service Coordination (MSC) through OMRDD. As these programs have been added to the service mix, and across a broader span of age and disabilities, Medicaid home care costs for long term care in NYS have grown dramatically and are projected to increase still further.

Medicaid is an entitlement program that is designed to help states meet the costs of necessary health care for low-income and medically needy populations. States qualify to receive Federal matching funds to help finance these costs by filing a state Medicaid plan document with the Center for Medicare and Medicaid Services (CMS), formerly known as Health Care Financing Administration (HCFA). States have substantial flexibility to design their programs within certain broad federal requirements related to eligibility, services, program administration and provider compensation. Table 1-1 reviews the major federal legislation related to Medicaid long term care services.

Table 1-1. Medicaid's Legislative Provisions Regarding Long term Care Services

1965	Establishment of Medicaid - Mandatory coverage of Skilled Nursing Facilities (SNFs) - Optional coverage of home health services and rehabilitation services.
1967	Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) mandate for children under 21. States given the option to provide services under EPSDT that were not covered by their state plans.
1970	Mandatory coverage of home health services for those entitled to skilled nursing facility services.
1971	Optional coverage of intermediate care facilities (ICFs) and ICFs/MR (Mental Retardation)
1972	Optional coverage of children under 21 in psychiatric hospitals. (This institutional coverage provides the "institutional alternative" for Home and Community Based Services (HCBS) waiver services for this group.)
1973	Option to allow people receiving supplemental security income (SSI) to return to work and maintain their Medicaid benefits.
1981	Establishment of home and community based services (HCBS) waiver authority.

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|------|--|
| 1982 | Option to allow states to extend Medicaid coverage to certain children with disabilities who live at home but who, until this 1982 provision, were eligible for Medicaid only if they were in a hospital, nursing facility, or ICF/MR. Also known as the Katie Beckett or Tax Equity and Fiscal Responsibility Act (TEFRA) Provision. |
| 1986 | Option to cover targeted case management. States are allowed to cover such services without regard to the statewideness and comparability requirements.

Option to offer supported employment services through HCBS waiver programs to individuals who had been institutionalized some time prior to entering the HCBS waiver program. |
| 1988 | Establishment of special financial eligibility rules for institutionalized persons whose spouse remains in the community, to prevent spousal impoverishment. |
| 1989 | EPSDT (Early and Periodic Screening, Diagnosis and Treatment) mandate amended to require states to cover any service a child needs, even if it is not covered under the state plan. |
| 1993 | Removal of requirements for physician authorization and nurse supervision for personal care services provided under the state plan. States were given explicit authorization to provide personal care service outside the individual's home. <i>(These provisions were optional; NYS requires physician orders and nurse supervision. In personal care, service authorization is for home care.)</i> |
| 1997 | Removal, under the Balanced Budget Act of 1997, of the "prior institutionalization" test as a requirement for receiving supported employment services through an HCBS waiver program. In addition, states were given the opportunity to create a Medicaid "buy-in" for people with disabilities. |
| 1999 | Additional options were provided under the Ticket to Work and Work Incentives Act for states to create a buy-in program for people with disabilities in an effort to remove employment barriers. |

(Source: Understanding Medicaid Home and Community Services: A Primer, U.S. Department of Health and Human Services, October 2000)

This table denotes some of the historically relevant provisions of Federal Medicaid law in regard to long term care. These provisions have enabled states the option to incrementally move Medicaid long term care services away from institutional long term care to home and community care. These initiatives allowed a plethora of programs to be developed in NYS to care for children, adults, and the elderly.

Consumers and their families are encouraged to maximize whatever services are available in the community to meet their service needs. (For example, children may receive school-based services and private duty nursing, adults may receive day habilitation services and personal care program services, elderly can receive medical day care and LTHHCP)

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TRENDS IN LONG TERM CARE

In 2001, the U.S. long term care population was estimated to be about 12 million people. The elderly make up half of the long term care population at 6.4 million; 5.3 million non-elderly adults and 400,000 children also require long term care. Long term care includes both medical and social services provided to the chronically ill and disabled of all ages, including children. Long term care can be delivered in a variety of settings including the home, supported housing, and nursing facility. Although diverse, the assistance required by people with disabilities involves many similarities and often includes assistance with personal activities of daily living, hygiene and household maintenance. *(Source: Direct-Care Health Workers, the Unnecessary Crisis in Long Term Care, The Aspen Institute, January 2001)*

When we think of long term care we tend to think of residents in nursing homes or frail elders being cared for at home by family caregivers. Most of the long term care programs and policies developed in this country in the 1970s were developed with this population in mind. If a child with a disability or a mentally retarded adult was cared for outside of the home, that care setting was most likely an institution. Today, we can paint a very different picture of long term care. Long term care is no longer a catch phrase for elders who require care. Long term care now encompasses the needs of persons with physical and developmental disabilities, mental illness, and chronically ill children and adults; and it is increasingly occurring in the home setting. In this section, we will examine some of the trends in long term care.

Declining Rates of Disability in the Aging Community

Nationwide, disability rates among the elderly have declined. The National Long Term Care Survey (NLTC) notes the annual rate of decline in disability between 1982 and 1994 was about 1.3 percent per year among people age 65 and older. This resulted in 1.2 million fewer elderly persons with disabilities in 1994 than if the disability rate had not declined. However, a growing absolute number of elderly people, coupled with increasing life expectancy, means that the number of people who need assistance is expected to increase, though not as rapidly as once envisioned.

In New York State, contrary to commonly held perceptions, the size of the 65 to 85 age cohort will actually decline until 2012. This trend is more pronounced in NYS than the rest of the country, probably due to outmigration patterns of the younger elderly. The age 85+ cohort, much smaller in size, is projected to grow steadily both in the short and long run. As previously noted, rates of chronic disability of the elderly appear to be declining at the national level. If the trends found in these studies are applicable to NYS and extend into the future at the rate of decline measured for 1982 through 1994, the total number of elderly disabled persons in NYS would not exceed the current census at least through the year 2025. *(Source: Assisted Living in New York Preparing for the Future)*

Just as the National Long Term Care Survey noted a decline in rates of disability for the elderly between 1982 to 1994, in 1999, the Congressional Budget Office projected that disability rates

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for the US population over the age of 65 would decline as a percentage of the whole, even as the number of people with disabilities continues to grow.

Projections of the U.S. Population Age 65 and Older by Disability Status (In Millions)					
	2000	2010	2020	2030	2040
Total	35.7	40.6	53.0	71.0	77.9
Non-disabled	26.9	31.3	43.5	58.6	65.7
Disabled*	8.8	9.2	10.4	12.3	12.1
Disabled as % of total	24.6	22.7	19.3	17.4	15.6
* People unable to perform one or more activities of daily living, such as toileting and bathing, or instrumental activities of daily living, such as preparing meals and using the telephone.					

We know both through research and anecdotally that people are aging better. This has been good news for government planners who anticipated disability rates to hold steady or increase as the population ages. The decline in rates of disability has a number of causes, one of which is education, leading to better income and improved health care.

In 1965, when Medicare and Medicaid were enacted, only 25% of people over the age of 65 had graduated from high school and 30% of elders lived in poverty. Today, 70% of people over the age of 65 have a high school diploma and just 10% meet the standards for federal poverty levels. The poverty rate for those over age 85 is 14%. (*Source: Older Americans 2000: Key Indicators of Well-Being*)

Increasing Rates of Disability for Children and Young Adults

Disability rates for children and young adults have risen considerably since 1990. Prior to 1990, disability rates for both groups remained steady for two decades. Among children under age 18, disability rates increased from 5.6 percent to 7.9 percent for boys, and from 4.2 percent to 5.6 percent for girls between 1990 and 1994. Among younger adults, ages 18 to 44, disability rates increased slightly for both men and women between 1990 and 1994, in part due to the increase in orthopedic impairments and mental disorders.

Traditional home care providers are acutely aware of the growth in non-traditional populations seeking long term care. The ability to provide care in the community for this population was greatly enhanced by the advent of the federal government's 1915c waiver initiatives legislated in 1981. Under 1915c waiver authority, states can provide services not usually covered by the Medicaid program, as long as these services are required to keep a person from being institutionalized. In New York State and the nation, the waiver initiatives grew significantly in the 1990s.

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Medicaid's Home and Community Based Services (HCBS) program affords states the flexibility to develop and implement creative alternatives to institutionalization. States have the flexibility to design a waiver program and select the mix of services including certain non-medical, social and supportive services, such as, homemaker services, adult day care services, etc., to best meet the needs of the population they want to serve in the home or community. (*HCFA Chartbook 2000*)

The waivers have led to a significant increase at both the state and federal level in Medicaid spending on home and community care. Nationwide most of the growth has been directed at younger persons with disabilities, especially those with mental retardation or developmental disabilities. In 1997, about 77 percent of the total spending for Medicaid HCBS were for individuals with mental retardation or developmental disabilities, compared to 21 percent for the aged and elderly disabled populations. (*Source: Defining Common Ground: Long term Care Financing Reform in 2001, Citizens for Long term Care, February 2001*)

In New York State, the Home and Community Based Services, Care at Home, Traumatic Brain Injury, Long Term Home Health Care Program and the OMH HCBS for Severely Emotionally Disturbed Children are waiver programs. In addition to waiver services, most of these consumers are also eligible for Medicaid State plan services. All of these programs are staffed with their own treatment professionals and relate to the Personal Care Program and its treatment professionals.

Providing Long Term Care to Diverse Populations

People with disabilities under the age of 60 may have different needs than the elderly. They may be raising young children, have aging parents themselves, or be involved in a relationship. Most younger adults want to live, work and be active in their communities with the supports that enable them to do so. In January, 2002, advocates for people with disabilities were successful in working with the New York State legislature to pass the "Medicaid Buy-In" provision.

"Medicaid Buy-In" will permit most Medicaid eligible disabled individuals to work without the loss of their Medicaid benefits. The program, designed for people between the ages of 16 and 65, will allow people with severe medically determinable impairments, whose net available income is at least one-hundred and fifty percent of the federal poverty line, to retain their Medicaid benefits by paying a premium. Those with incomes between 150% and 250% of poverty will be required to pay annual premiums of 3% of net earned income and 7.5% of net unearned income. Currently 250% of the poverty level equates to an annual income of about \$45,000 for an individual and \$58,000 for a couple. (*Source: STIC, AccessAbility, Spring 2002, Number 66*)

Medicaid Buy-In will allow people with disabilities to retain their attendant care in the home. In the past, people with severe disabilities found it difficult to work, due to the potential loss of Medicaid benefits, and thus their attendant care and insurance coverage.

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Children receiving long term care services represent a different challenge in that they must also receive an education. This challenge requires coordination and collaboration between long term care and the educational systems. Public schools are educating more and more children with disabilities by integrating them into the traditional classroom setting. However, the issue of how to define disability has been contentious. To what extent should cognitive limitations or learning deficits be considered disabilities? In the late 1990s, amid much furor from parents afraid that their children were going to lose their SSI benefits, the federal government changed the definition of childhood disability.

Under the new law childhood disability is no longer linked to the definition of disability for adults. The new definition says: (1) an individual under the age of 18 must be considered to be disabled under SSI if that child has a medically determinable physical or mental impairment that results in marked and severe functional limitations 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; and (2) no individual under the age of 18 who engages in substantial gainful activity may be considered disabled. (*HCFA: Fact Sheet #2: Link Between Medicaid and SSI Coverage of Children Under Welfare Reform*)

In addition to the new definition of disability for children, the law mandates two changes to current evaluation criteria in the Social Security Administration's (SSA) regulations. SSA must: (1) discontinue the individualized functional assessment (IFA) for children; and (2) eliminate maladaptive behavior in the domain of personal/behavioral function in determining whether a child is disabled. (*HCFA: Fact Sheet #2: Link Between Medicaid and SSI Coverage of Children Under Welfare Reform*)

The issues of education, supported work and the right to live in the community have led advocates for the disabled to equate their struggle for integration into the community with the civil rights movement. An outgrowth of this movement is the consumer directed philosophy of care.

Consumer Directed Care

Home care programs are frequently criticized for operating under a so-called medical or professionally managed model. Consumer directed programs grew out of the independent living movement for people with disabilities during the 1960s and 1970s. In a consumer directed model, individuals hire, fire, train and manage their own attendants. They may hire certain family members, friends, or community members. Since 1995, New York State law has required that all local social services districts provide a consumer directed option to any qualified Medicaid consumer of personal care services that wishes to self-direct. (*Source: Understanding Medicaid Home and Community Services: A Primer/October 2000*)

Advocates for the aging are beginning to incorporate the consumer directed approach into their advocacy work. In 1996, The National Council on Aging published a paper titled *Principles of*

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Consumer-Directed Home and Community Based Services. The paper stated that individuals have the primary authority to make choices that work best for them, regardless of the nature or extent of their disability or the source of payment for services. From this, the Council derived five principles:

- Systems should be based on the presumption that consumers are the experts on their service needs.
- Different types of services warrant different levels of professional involvement.
- Choice and control can be introduced into all service delivery environments.
- Not only do consumer-directed services systems support the dignity of people requiring personal assistance, but they can be less costly, when properly designed.
- Consumer direction should be available to all, regardless of payer.

Aging Baby Boomers

The baby boomers (those born between the late 1940's and early 1960's) are the most educated generation in history. Furthermore, as educated consumers, the baby boom generation will probably demand a different mix of long term care services, focusing on community care. The parents of the baby boomers are already demonstrating this trend toward actively engaging in the marketplace as they lead the way toward the idea of aging in place.

The trend toward aging in place has been established in the assisted living movement that gained prominence on the West Coast, particularly in the state of Oregon. Assisted living allows a person to live independently in an apartment setting with services being brought in on an as needed basis. The resident can have overnight guests, pets, and doors that lock, yet have access to congregate meals and nursing and aide services as needed. In theory, as the resident ages and becomes more frail, the services would increase and the resident could stay in his/her apartment. This model has been adopted with varying degrees of success around the country. The aging in place theory can also apply to receiving services in one's home and is in contrast to the model of multi-level campuses where people are moved from building to building as their condition changes. For some residents on multi-level campuses, this has resulted in as many as three or four moves in one-year as the residents cycle through hospital stays and recovery.

Decreased Occupancy in Skilled Nursing Facilities

Nationwide and statewide, Medicaid spending on nursing homes remains higher than Medicaid spending for other long term care services such as home care and waiver services yet occupancy rates continue to decrease. In 1999, NYS spent 20.2% of its Medicaid budget on skilled nursing facilities and 10% on non-institutional long term care (192,395 people received non-institutional LTC while 130,210 people were in a skilled nursing facility). (*"Medicaid Expenditures Data", NYS Association of Health Care Providers, 2001*)

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The National Center for Health Statistics found that nursing home occupancy declined from 93% in 1985 to 87% in 1995. An analysis of nursing home trends from 1987 to 1996 by the Agency for Healthcare Research and Quality suggests that home and community based services, including personal care and assisted living, provide alternatives to nursing homes for people with functional impairments. While the absolute number of nursing home beds increased from 1.48 million to 1.76 million, the rate per thousand elders over age 75 declined from 141 per thousand to 117 per thousand, and occupancy rates dropped from 92.3% to 87%. (NYS has reported occupancy rates in the high 90th percentile despite having the largest personal care program in the U.S. and the only Long Term Home Health Care Program in the U.S.). In addition, the characteristics of nursing home residents have changed. The percentage of nursing home residents with one or two Activities of Daily Living (ADL) impairments dropped from 21.8% in 1987 to 14.3% in 1996. Almost 83 % of nursing home residents in 1996, needed help with three or more ADLs, for example compared with 72 % of residents in 1987. During this same period of time, the proportion of nursing home residents who were 85 and over rose from 49 to 56% for women, and from 29 to 33% for men. (Source: *State Assisted Living Policy: 2000*)

If current trends continue, nursing home care will be reserved for the oldest and most infirmed. Throughout the 1990s there has been a marked increase in other types of long term care services available for elders and people with chronic disabilities. Housing options include assisted living and elder apartment complexes. Home care supports include a variety of Medicaid and Medicare funded options as well as Meals on Wheels and social day care. OMRDD and to some extent OMH, have developed extensive networks of housing and support services. Even if disability rates continue to decline, more people will need some type of long term care services than at any other time in our nation's history.

Worker Shortage

Direct care paraprofessionals typically work under the titles of home health aide, personal care aide, home attendant, homemaker, housekeeper or certified nurses' aide. Historically, women have performed aide work. Nation-wide, paraprofessionals total more than 2.1 million workers; 86% are women, 30% are women of color, and most are between the ages of 25 and 54. The need for aides is expected to grow geometrically during the next 30 years:

- The population of those requiring paraprofessional care is increasing;
- The preference for living in home and community based settings is increasing;
- The pool of likely entry-level workers, women in the civilian workforce within the age range of 25 to 44, is projected to decline by 1.4 percent during the next six years;
- The general quality of direct care job tends to be extremely poor;
- The full-employment economy offers better jobs alternatives; and
- Post-baby boom demographics in the U.S. have created a "care gap" that will worsen over the next 30 years.

(*Direct-Care Health Workers, The Unnecessary Crisis in Long term Care, The Aspen Institute, January 2001*)

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U.S. Supreme Court Olmstead Decision

In 1999, the U.S. Supreme Court made a landmark decision in applying the Americans with Disabilities Act (ADA) to people residing in long term care institutions. This ruling addressed the case of two mentally retarded/developmentally-disabled women living in institutions in Georgia. These women wanted to live in the community and their treatment professionals had determined that they could live in the community. The Court ruled that continued institutionalization was a violation of their right under the ADA to live in the most integrated setting appropriate. However, the Court also noted that this ruling does not require states to make fundamental alterations to their current mix of Medicaid long term care services.

Under the Court's decision, states are required to provide community based services for persons with disabilities who would otherwise be institutionalized when:

- The state's treatment professionals reasonably determine that such placement is appropriate.
- The affected persons do not oppose such treatment: and
- The placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others that are receiving state-supported disability services.

(Source: Victimization of the Elderly and Disabled, Volume 3 No.2, July/August 2000, pg. 19)

While this case was determined in regard to two mentally retarded/developmentally disabled women, the ruling applies to all individuals in any long term care setting. Even within the community, consumers should be in the least restrictive and appropriate setting. States across the country are now struggling with developing the infrastructure needed to assist people to leave institutions, or keeping them out of institutions in the first place.

Within this ruling, this paper discusses the first criterion: "The state's treatment professionals reasonably determine that such placement is appropriate." The questions arise, which treatment professionals and in what setting? New York State has a myriad of programs for assisting people of all ages and disabilities with their long term care needs. Each of these programs has treatment professionals. These treatment professionals may differ in their opinion as to whether or not someone is capable of staying in the community or being discharged back to the community.

If the treatment professionals in the institution feel the person should be in the community, but the treatment professional in charge of community services feels the person cannot be "reasonably accommodated" in the community, which treatment professional's judgment takes precedence? And where do the desires and preferences of a consumer or his/her advocate's opinion reside?

Financial Trends

The majority of care given in the U.S. is given by family members and is thus informally financed by the caregivers. However, once a person engages formal caregivers, the majority of

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the care is paid for by Medicare and Medicaid. The previously cited Direct-Care Health Workers report notes that 60 % of the \$123 billion spent on long term care for the elderly in 2000 came from public sources, Medicare and Medicaid. Just 4% were funded by private insurance and 36% came from out-of-pocket. Of the total dollars spent nationally on Medicaid, 35% flows to meet long term care needs.

Projections of National Long term Care Expenditures for the Elderly (In billions of 2000 dollars)					
	2000	2010	2020	2030*	2040*
Medicare	29.4	39.8	50.6		
Medicaid	43.3	66.9	75.4		
Private LTC Insurance	5.0	16.7	36.2		
Out of pocket	42.8	35.5	42.9		
Other payer	**	**	**		
Total	123.1	160.7	207.3	295.0	346.1
Total expenditures, assuming no increase in LTC insurance	120.7	153.8	195.1	269.5	308.1

* Estimates of each payer's expenditures cannot be determined.
 ** Less than \$5 billion
 Congressional Budget Office (1999). Projections of expenditures for long term care services for the elderly.

With this heavy reliance on public funding, NYS has joined other states in supporting the development of private long term care insurance policies. The total number of long term care policies in NYS increased by 63% between 1997 and 1999 from 96,076 to 156,929. To encourage participation, some states as well as the federal government have developed cooperative efforts between government entities and private insurance companies. NYS has the "New York State Partnership for Long term Care Insurance", referred to as the "Partnership". Under this program, purchasers of long term care insurance can qualify for Medicaid once their insurance benefits are exhausted without "spending down" their life savings. The Partnership policies increased from 14,888 to over 30,000 between 1997 and 2000. The policies have been refined over the years to include care in the home as well as nursing home care. As employers, both the state and federal government are leading the way in making long term care insurance coverage available to these employees. NYS now offers a long term care insurance product to people covered by its retirement system. The federal government has an offering scheduled for 2002. While acceptance of these policies among consumers has been slow, it is anticipated that these offerings will focus attention on the need for long term care insurance and significantly increase the number of policyholders.

Other trends in financing long term care are demonstration programs that attempt to combine the funding streams of Medicare and Medicaid. It is believed that this will lead to more efficient delivery of services, leading to better patient outcomes, thus slowing the rate of growth in

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program expenditures. These managed care capitated programs, such as PACE (Program for All-Inclusive Care of the Elderly) or SHMOs (Social Health Maintenance Organizations), serve a small number of people but are being studied as models that may be expanded.

Mental Health

The focus of care for adults who are seriously and persistently mentally ill (SPMI) has continued to shift from providing services in psychiatric hospitals to providing services in the community. About 5% of the population are considered to have a serious mental illness. SPMI includes, among other diseases, schizophrenia, bipolar disorder, and major depression. SPMI is a chronic condition that can substantially limit a person's ability to function in many areas of life such as employment, self-care, and interpersonal relationships.

The ability to care for more people in the community has been facilitated by the continued development of new medications that produce fewer side effects and are more effective in helping people manage their illness. Medicaid and Supplemental Security Income (SSI) are major sources of economic support for people with SPMI.

Due to the lack of supportive services in the community, paid for through the OMH system, this population has been accessing regular Medicaid programs, such as the personal care program, in growing numbers. However, the nature of their illness can make it very difficult for traditional home care services to meet their needs. Personal care services are task driven services. Many OMH/OMRDD clients need training in life skills management, something that the personal care program is not designed to provide.

Mental Retardation/Developmental Disability

Since the 1970's, the New York State Office of Mental Retardation/Developmental Disabilities (OMRDD) has been working to restructure a system that previously housed people with developmental disabilities in large institutions. Enlightened and motivated by consumer advocacy, federal legislation, and court decisions, OMRDD worked hand in hand with not-for-profit providers to move thousands of people into the community. These efforts have been so successful that twelve of the original twenty developmental centers in New York have been closed. During this time, New York has expanded its community system of services dramatically. A wide variety of services are now provided to over 95,000 people through the network of programs sustained by OMRDD and the not-for-profit sector.

In 1991, New York began its Home and Community Based Services Waiver. This waiver now serves approximately 37,000 individuals and spends approximately 1.6 billion dollars. The people served through the waiver would otherwise need the level of care provided in an intermediate care facility for persons with mental retardation. OMRDD's mission statement charges the agency with the following responsibilities:

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1. To develop a comprehensive, integrated system of services which has as its primary purpose the promotion and attainment of independence, inclusion, individuality, and productivity for the persons with mental retardation and developmental disabilities.
2. To serve the full range of needs of persons with mental retardation and developmental disabilities by expanding the number and types of community based services and developing new methods of service delivery.
3. To improve the equity, effectiveness, and efficiency of services for persons with mental retardation and developmental disabilities by serving persons in the community as well as those in developmental centers, and by establishing accountability for carrying out the policies of the state with regard to such persons.
4. To develop programs to further the prevention and early detection of mental retardation and developmental disabilities.

OMRDD operates 13 regional Developmental Disabilities Services Offices (DDSO) located throughout the state. DDSOs provide direct services, support and technical assistance to an extensive network of voluntary not-for-profit agencies that also provide services and supports to individuals.

The current trend from OMRDD, implemented through the waiver as well as other funded programs, embraces consumer empowerment and inclusion. There have been significant increases in the number of people enrolled in the Home and Community Based Services waiver and living at home or in family care. People are deciding that it is better to request services that enable them to live in settings that are more integrated with the community than to live in certified residences operated by either the state or voluntary agencies. As OMRDD has increased its emphasis on person-centered approaches to service planning and delivery, more and more support packages are being tailored to individual needs and desires than are typically offered through program models. This is also reflected in services being provided from a variety of different resources in the community.

Trend Summary

While the programs and services developed by the HCBS have been innovative, they have perpetuated the silo approach to delivering long term care services. With few exceptions, long term care is a long way from being integrated. With the new programs come different philosophies of care and services, differing approaches to service planning and goal setting, as well as a variety of treatment professionals who do not always agree on the same course of action.

As noted, long term care is no longer the purview of the frail elderly. It now encompasses infants, children, and adults less than age 60. Providing and organizing services to these

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populations will continue to challenge local government, health care and social service organizations for years to come. The key to service delivery is case management.

CASE MANAGEMENT

Case management is a frequently used but poorly defined concept, with tremendous variability across programs. All case managers assess clients' needs, design treatment plans, and coordinate and monitor the delivery of services. The Commission for Case Manager Certification (CCMC) defines case management as follows: "Case management is a collaborative process that assesses, plans, implements, coordinates, monitors, and evaluates the options and services required to meet an individual's needs, using communication and available resources to promote quality, cost effective outcomes." To be effective, case managers require broad-based knowledge. They need to be part general practitioner, part social worker, part psychologist, and part minister or rabbi. A case manager needs to be aware of the psychosocial, environmental, family, economic, and religious dynamics that can impact patients.

Case Management Across Programs

In the past, each system provided and paid for care for its own clients; i.e., the OMRDD cared for its clients, the OMH cared for its clients, etc. Each system was responsible for the coordination of care and use of resources both human and fiscal. Now however, when clients seek long term care in the community, they may be referred to multiple programs across different systems. Case management is the key to using these services efficiently and effectively. There are several major differences in the concept of case management among the different systems of services that can lead to false expectations and frustration. For instance, CASAs or county Departments of Social Services, (e.g. Personal Care Services or Long Term Home Health Care), often coordinate LTC programs. The case manager follows the medical model, assessing clinical needs, developing nursing plans, and coordinating services within that program. OMRDD sponsored case management delivered through the service coordinator, follows a person centered approach for adults and a family centered approach for children. OMRDD service coordination blends services across agencies and systems looking at the total needs of the individual (and family), including financial issues, medical rehab, housing, etc. The OMH approach, via the Intensive Case Management program, follows a person centered, strength based recovery focus with rehabilitation and recovery as the underlying philosophy. In recent years, the Intensive Case Management system has begun to take more of a cross systems approach, but this is not universal.

Barriers to Coordination of Services

When clients receive services from multiple Medicaid funded programs, they have multiple case managers – typically one for each program - and there is no organized case management protocol. Too often, services are not coordinated across programs. Key barriers to coordination

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include variations in the responsibilities of case managers, differing perspectives regarding cost-containment, variations in philosophies and goals between programs, potential for bias (based on relationship of case managers to provider agencies), lack of cross-training, and in some instances, no regulatory accountability for the overall coordination of care.

Key Areas

For purposes of this paper, we reviewed five major areas of case management across the different programs and service systems. The areas include:

- Tasks and activities
- The role of the case manager as part of the organization: case management as coordinator or hands-on provider; focus within the organization or across agencies; the training of the case managers
- Qualifications and training
- Cost issues, including cost effectiveness and separate fees for case management services
- The philosophy/approach/goals for the client

1. Tasks and Activities

As the term is most commonly used, the goal of case management is to improve client outcomes. In some cases, cost containment is also a goal. However, the scope of case management responsibilities differs markedly across NYS Medicaid programs. Key differences include responsibility for advocacy, cost containment factors, and responsibility for coordination of multi-program plans of care.

At one end of the spectrum, case management is not specified in program regulations for the Private Duty Nursing Program, which serves medically fragile clients with continuous nursing needs. In this program, a physician orders care and there is a gate keeping review by NYSDOH or local government staff. Some children may receive case management through specialty pediatric case management programs (Care at Home, Early Intervention, etc.). However, other severely disabled children and many adults receive no case management services. Thus, the private duty nursing population, which according to DOH data served 2,808 clients in calendar year 2000 with costs of over \$152,052,502 (over \$54,000 per client), may not receive any mandatory case management.

Personal Care Services (PCS) case managers are primarily responsible for completing or arranging for required assessments, authorizing Medicaid payment to providers of PCS, and monitoring care and services. In actual practice, PCS case managers find that clients have complex needs, and many try to coordinate other aspects of clients' care. Some PCS recipients choose to receive their services through the Consumer Directed Personal Attendant Program. In

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this program, self directing clients assume responsibility for directing their own care. However, no training in case management is required for clients entering this program.

Agencies such as Certified Home Health Agencies (CHHA), Long Term Home Health Care Programs (LTHHCP), Assisted Living, Hospice, and Adult Medical Day Care have broader case management responsibilities. In theory, they are responsible for linking with the interdisciplinary health team, making referrals to outside agencies, monitoring outcomes, etc. In practice, however, they primarily manage their agency's own medical model services - nursing, therapy, nutrition, etc. - and communicate with physicians regarding clients' medical needs.

In contrast, some case managers coordinate services across programs. For example, Early Intervention (EIP), Care At Home, Office of Mental Health, and Medicaid Service Coordination case managers explicitly serve as the single point of contact for clients/families. These case managers assess needs (both medical and social) and often refer clients to multiple programs. The case managers are expected to monitor and evaluate the total plan of care, and to coordinate services across all agencies and programs that are involved in the plan of care.

When multiple programs are involved, there are multiple case managers - usually one for each program. Typically there is no "case management hierarchy" when multiple case managers are involved. In other words, there is a lack of regulatory direction for overall case management. If case managers in Care at Home or Early Intervention, for example, develop a service plan and refer to other programs, the other program's case managers make decisions on whether to admit clients based on their own assessment and understanding of the clients' needs and their own regulations. Not infrequently, the case managers have different opinions, and no case manager has ultimate authority for deciding the total plan of care. The different opinions may result in multiple conferences and hearings, with resulting delays in care and uncertainty for clients and case managers during the process.

2. Role of the Case Manager

One of the critical questions faced by systems and agencies is whether service coordinators/case managers work on the case within their own system or whether their focus is across agencies. Are they only responsible for developing the plan within their agency for the services which will be provided by that agency or that specific service system; or are they responsible for looking at the total needs of the individual and perhaps even the family? Many agencies and, more so, individual staff persons may assume the function of looking across systems to analyze and evaluate needs and services available in other systems while only being responsible for the services provided by their own agency. This larger focus often creates problems. Staff make inaccurate assumptions about what services other systems should provide. Also, clients and/or families may not understand the system of services nor who the many people are. Often times a family will think of the nurse supervisor as their case manager.

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Another complicating factor is whether the case manager is a person who coordinates, refers, and arranges services or is available to provide actual hands-on services. For example, if a person is receiving HCB service and is having trouble at a day program, will the service coordinator come to the rescue, pick up the person or intervene? Often, day program staff may have this as the expectation, but the service coordinator is very likely to be unavailable to perform this function because of large caseloads. Another example may be the personal care aide who calls in sick and is unable to fill the shift. Who is the backup for the individual? The home care agency may feel that the service coordinator should fill in, but this is not the role of the case manager. Oftentimes, the arrangements are not made and agencies are left frustrated because of unmet expectations. The actual role of the case managers may change depending on the ability of the client and/or his or her family. For example, the family may choose to arrange services or transport the client themselves. However, for individuals who do not have the supports, understanding, or ability, then the case manager may provide a more hands-on approach to services.

As described in many of the case studies at the end of this chapter, the cases are complicated by the involvement of multiple service providers and the client's need for a variety of services. These range from personal care aides, CHHA services, and day programs to waiver programs and services. In theory, the family/client and staff from agencies involved should meet and determine everyone's roles so there are no misconceptions and duplication of services. It may be helpful to identify who is the primary case manager or service coordinator and to specify who is responsible for what aspects. In practice, these types of case conferences rarely occur.

3. Qualifications and Training

Qualifications and training for case managers are not consistent. Qualifications range from a high school diploma or its equivalent on one end to baccalaureate or graduate degrees on the other end. These differences in qualifications do not appear to be linked to any objective differences in the roles or responsibilities of the case managers.

There is no specific training for case managers in any of the traditional, medically oriented long term care services. Although regulations for the LTHHCP, CHHA, and Limited License Home Care Program specify that case managers must be registered nurses, the regulations do not specify additional training requirements. Assisted Living Programs and Adult Medical Day Care Programs may use nurses or social workers as case managers. No specific initial or on-going training is required by regulation for these programs. An individual agency may specify its own training requirements, and most, if not all have some on-the-job training, but this varies across agencies. Similarly, local departments of social services determine the qualifications for Personal Care Program case managers. They generally require a bachelors degree, preferably in human services. There is no specific training for PCS case managers.

In contrast, initial and on-going training is specified for other programs. Medicaid Service Coordinators are required to have 40 hours of initial training and 15 hours per year of ongoing

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training. Care at Home case managers receive some training from their parent organizations, as well as technical assistance from NYSDOH. The Office of Mental Health requires on-going training. Funding is provided for training and attendance at in-services is documented.

Although case managers routinely refer clients to other programs, none of the programs require cross systems training. Any knowledge about other programs is obtained through individual case manager research or on-the-job training.

The requirements for Program for All Inclusive Care of the Elderly (PACE) are different than other programs. PACE does not identify case management as a required service, but rather requires multidisciplinary teams (ranging from physicians, drivers, therapists, nurses and personal care attendants) to hold team meetings; and, through consensus, to consolidate discipline-specific assessments into a single, multidisciplinary plan of care. Although federal regulations identify the minimum education and experience for each discipline, no specific case management training or experience is identified.

Overall, well-qualified staff provides case management services with varying degrees of success. Unfortunately, there are many providers who understand their own system well but are unfamiliar with other systems. There has been no routine way to insure that information regarding other features of the programs are made available on a consistent basis. Consequently, widely varied and inconsistent qualifications and training contributes to the inefficiency and dysfunction of the cross-agency, cross-program, long term care system.

4. Cost Issues

A. Fee for Service. Most agencies and systems have a Medicaid fee or rate for case management. The only services that do not are Foster Care, Assisted Living Programs, Hospice, Limited License Home Care Agencies and the Personal Care Program. The other services all bill Medicaid and clients select the agency from which they wish to receive service coordination/case management. Only one system at a time can bill Medicaid for case management, so it is important to select the primary provider. On complicated cases, when several systems are involved, the billing mechanism often precludes this multi-system program approach.

B. Cost Containment. Programs operated by different state agencies, have different philosophies on whether or not cost should be a consideration in developing care plans. While quality care is the goal of all programs, delivering such care cost effectively is a silent sub-agenda for many Medicaid funded programs currently regulated by the NYS Department of Health. Programs such as the LTHHCP must stay within a budget. The PACE (Program of All-Inclusive Care for the Elderly) program models are capitated. And most county run personal care programs have historically taken cost into consideration when developing care plans. The children in the Care at Home Program are

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subject to a monthly budgetary cap for services. On the other hand, programs operated by OMRDD, such as Medicaid Service Coordination (MSC), advocate for the client to have a complete service package regardless of cost. As a department philosophy, the service coordination component is to be separate from service delivery. This is to enable the service coordinator to remain independent in advocating for adequate services for their client regardless of cost.

5. Philosophy/Approach/Goals

Philosophies of programs and goals for clients differ markedly across programs. Many long term care programs grew out of the medical model and reflect that bias in their services. For example, the Personal Care Program is limited to assisting the person with activities of daily living that they cannot accomplish independently - bathing, dressing, meal preparation, etc. The goal is to provide quality, cost-effective services that are essential to maintaining the client safely at home. Other programs focus primarily on medical care and other health related activities. For example, Adult Medical Day Care and Long Term Home Health Care programs provide mostly nursing, medical social work, and aide level care to try to prevent nursing home placement. Certified Home Health Agencies provide primarily nursing care, therapy and aide service to resolve acute medical episodes and to restore client independence. Hospice provides skilled nursing care, aide service, and additional pastoral counseling to help people die with dignity.

In contrast, other programs have much broader philosophies and approaches. Medicaid Service Coordination has a very expansive philosophy. The goal for clients is to be as independent as possible - helping clients and their families to optimize their choices and maximize inclusion in society. Case managers are advocates for clients in helping them to meet their individual goals, and cost containment is not a priority. Similarly, Care at Home case managers tend to be involved beyond medical aspects of care, such as advocating with the school district on behalf of the child, and being involved in a broad range of community services that promote quality of life for a medically frail child. As well, case managers in the Office of Mental Health strive to help mental health clients develop strengths and return to independence. They teach and advocate, and assist clients to recover and develop skills they need to live fuller lives in the community.

CASE HISTORIES

The study made clear that because of the enormous variety among programs (even those run by the same state agency), the “system” for mentally ill and/or developmentally delayed consumers who also need long term care services is complicated and frustrating for all involved.

When clients are served in multiple programs that have different philosophies/goals, they can receive conflicting messages from the numerous case managers about what to expect. Case managers may disagree about which services should be provided by which system or by the client or family themselves. The following case histories illustrate these points.

Case Summaries



CASE #1 (For each case, all names have been changed.)

This is an example of how well the system can work when agencies work together and communicate.

When he was 19 years old, Jim received severe traumatic brain injuries as the result of being struck by a train in March of 1993. Rehabilitation was extensive and in July of 1994, Jim was evaluated by the personal care program and the Home and Community Based Waiver (HCBW) and was able to return to the community with parental support. HCBW provided case management. They arranged for the down payment of a handicapped accessible trailer for Jim and his family. The case manager and mother requested eight hours daily of personal care service. The personal care program approved 24 hours per week. Jim also received other services such as physical, speech, and occupational therapies, counseling services, attended a socialization program, and received residential habilitation. The local school system also arranged a tutor.

As a result of his accident, Jim was unable to walk, needing the assistance of an electric wheelchair. Therapies were provided on an outpatient basis at a local hospital. Jim is able to stand, pivot and walk a few steps with the assistance of two people. He does need maximum assist with bathing, meal prep and is incontinent of bowel and bladder. Jim needs wheelchair transportation to and from his daytime activities and was able to access Medicaid transportation services.

Due to his age, Jim needed a full range of services from the community. Personal care service, though difficult to fill at times due to the rural location of the family home, has been steady. In order to successfully make the transition from high school to work, his case coordinator has involved BOCES for computer training and GED. VESID assisted with his education plan. Community Options provided 4 hours residential rehabilitation to teach him skills in the home.

In January 2001, his parents informed the personal care program that Jim would be moving into a group home in the community. He works at the Association for Retarded Children and volunteers in the local school system promoting railroad safety.

Throughout his rehabilitation, Jim's care management team worked well together.

Case Summaries



CASE #2

This case illustrates the need for clarifying care plans and agency responsibilities for clients who are receiving care from more than one agency.

Kris is a twenty eight year old female with severe cerebral palsy. She uses a wheelchair for mobility, pivots to transfer and requires assistance with all of her personal care and household chores.

Kris began receiving personal care services in 1991 while residing with her mother. In 1999 Kris moved into an Individual Service Environment, “non-certified” apartment with two other developmentally handicapped individuals receiving OMRDD services. One of Kris’ roommates private pays for any care he requires, however her other roommate, Tom, is also a Medicaid recipient who requested personal care services. Kris and Tom were opened as a shared aide case to personal care in March of 1999.

Kris’ care plan consisted of a personal care aide seven hours per week that provided services to both Kris and Tom. Kris also received personal care 28 hours per week herself. When Kris and Tom were assessed for services in their present setting, staff from the personal care program were aware that an independent living agency was involved in their case for case management, however, it was difficult to obtain clarification of the full extent of services provided for both clients.

The personal care case manager began receiving complaints because the aides sent to service Kris and Tom were being hired privately by their third roommate. The case manager from the independent living center contacted the personal care case manager regarding the consumer directed program. The difficulties in servicing Kris and Tom raised enough questions that the personal care case manager requested and reviewed the adjudicated claims for both clients and discovered that both clients were receiving 24 hour Residential Habilitation in their home setting. It was discovered that the Residential Habilitation plans duplicated services being provided by the personal care program.

Since the OMRDD’s residential habilitation plan included personal hygiene, dressing, grooming, housekeeping, laundry, and grocery shopping, personal care services constituted a duplication of services and Kris’ and Tom’s personal care services were discontinued. A fair hearing decision by the NYSDOH affirmed this decision, indicating that “The determination of the agency to discontinue the appellant’s personal care services is correct.”

Case Summaries



CASE #3

This case represents the importance of fully disclosing all programs servicing clients.

Tim is 24 years old and mentally retarded. Other diagnoses include autism and seizure disorders. He has lived with his mother, who is a single parent, all of his life. His mother sought services from the county for personal care during the hours that she was at work in the evening and for some time on Saturday's. Tim also has a 12 year-old brother. At the time of the initial assessment, the mother noted that no other home care services were involved. Tim attended a day program Monday through Friday from 7:30 am to 4:30 pm. Tim was found to be alert and oriented but non-verbal. His mother noted that he functions at an 8 or 9 year old level.

Upon the initial assessment personal care was approved for a total of 12 hours per week. At the recertification assessment, the caseworker learned that the client had a service coordinator and was approved for 209 residential habilitation visits per year (each visit was equal to 5 hours). The total hours available were 1,045. It was the decision of the personal care program to discontinue the personal care aide service, as the residential rehabilitation service was sufficient to meet Tim's needs in providing for hours of care while the mother was out of the house.

In this case, personal care services were found to be duplicative of the residential habilitation services. Since Tim was enrolled concurrently in the Home and Community Based Services waiver, he should have been receiving his respite hours from that program. A denial letter was issued and the case was closed to personal care.

Case Summaries



CASE #4

This case illustrates how difficult it can be to fill all of the hours clients are authorized to receive and how programs are asked to fill in the gaps when some providers can't find care.

At the time of her referral to personal care, Diane was 30 years old and living with her mother. Diane is mentally retarded and was waiting for an opening in a group home. She was initially authorized for personal care services 5 hours per day, 5 days per week under the Consumer Directed Personal Assistance Program. Diane was also in the Home and Community Based Waiver and received service coordination and residential habilitation.

The service coordinator was able to secure an apartment for Diane, but was unable to secure all of the hours she was entitled to under residential habilitation. Therefore, her personal care hours were increased under CDPAP.

Diane is not cognitively impaired, but is severely limited in her physical abilities and requires total assistance with all ADLs and IADLs. Diane is out of her apartment Monday through Friday to attend a day program.

Her personal care has become complicated by the fact that even her CDPAP hours cannot be filled. Therefore she has had to depend on a mix of CDPAP, licensed agency personal care and residential habilitation hours. Her parents and sister also fill in when aides are not available. If it were not for her family's ability to back up her care, she would not be able to stay in her own apartment, as her extensive care plan has not proven to be consistently reliable.

Since Diane is involved with so many agencies, she receives a myriad of assessments in the home. The personal care program assesses her every six months and they are involved on a routine basis to insure that her schedule is met. Diane also receives routine visits from the licensed agency for home care aide supervision and she is routinely assessed by her service coordinator. Other assessments occur at the day program she attends. Yet, as her personal care coordinator reports, all are involved, and no one is in charge. It is not standard practice for the personal care coordinators to be invited to the other assessment meetings, yet Diane could not remain at home if it were not for the services she receives from the personal care program.

Case Summaries



CASE #5

This case illustrates the problems created by difficult behaviors and how they can be resolved.

Dan, a 22 year old, was involved in a motor vehicle accident in 1998. He was not wearing a seat belt and sustained traumatic brain and life-threatening injuries. He has seizures, significant behavior problems, experiences disorientation and requires constant supervision to complete tasks. He is totally incontinent, has an unsteady gait and relies on his mother as his primary caregiver. Dan and his mother live in an apartment where he now receives most of his services.

Dan was already certified as disabled prior to the accident due to a hearing impairment and was already in receipt of Medicaid. Dan applied to the TBI waiver program and was accepted. The Personal Care Program completed the PRI/Screen for this service and assessed the client for home care services. At first Dan's mother declined to accept personal care services, preferring to use the services of a CHHA and provide the rest of his care on her own. Having aides and nurses in the home can be very intrusive. When Dan's mother returned to work, the Personal Care Program approved 16 hours/week of personal care. CHHA therapies were discontinued at about this time as Dan had attained his maximum level of functioning. Dan also began attending day habilitation programs outside the home five days a week. His independence increased to the point where he would occasionally toilet himself. However, personal care aide time was reassessed to 20 hours/week, as Dan's mother was unable to cope with caring for him and her job.

Unfortunately, Dan began to exhibit inappropriate touching behavior toward both male and female members of the day program he was attending. Dan was no longer allowed to participate in the program and all waiver services were changed to the home setting. The Personal Care Program service was also changed and is now provided through the Consumer Directed Personal Assistance Program.

Dan is presently receiving 28 hours/week through this program with his sister as his caregiver. Prior to this, some hours were unfilled due to difficulty in obtaining an aide for evening hours. TBI also provides residential habilitation services five times a week in the home setting and a weekly counseling session. Dan has been able to stay in the community due to the changing involvement of both programs and their flexibility in working with the family.

NYS Personal Care Program: Year 2000 Comparison of Number of People Served and Medicaid Expenditure, Under Age 65 to Over Age 65						
	% age 64 and under	% age 65 and over	Total # served	% of \$ spent age 64 and under	% of \$ spent age 65 and over	Total dollars spent per county year 2000
Albany	34%	66%	425	40%	60%	\$2.5 M
Allegany	37%	63%	156	30%	70%	\$469,699
Broome	39%	61%	596	44%	56%	\$1.8M
Cattaraugus	45%	55%	246	49%	51%	\$760,309
Cayuga	25%	75%	160	37%	63%	\$435,527
Chautauqua	43%	57%	614	45%	55%	\$2.9M
Chemung	38%	62%	347	35%	65%	\$1.0 M
Chenango	24%	76%	128	25%	75%	\$299,366
Clinton	29%	71%	317	41%	59%	\$1.4 M
Columbia	46%	54%	78	66%	34%	\$392,365
Cortland	39%	61%	119	41%	59%	\$376,030
Delaware	34%	66%	153	46%	54%	\$632,176
Dutchess	44%	56%	445	41%	59%	\$3.3 M
Erie	41%	59%	2,142	44%	56%	\$19.9M
Essex	32%	68%	155	37%	63%	\$685,803
Franklin	27%	73%	309	26%	74%	\$1.7 M
Fulton	22%	78%	219	21%	79%	\$940,748
Genesee	40%	60%	108	48%	52%	\$335,249
Greene	29%	71%	58	69%	31%	\$314,961
Hamilton	38%	62%	32	33%	67%	\$85,402
Herkimer	32%	68%	176	49%	51%	\$258,533
Jefferson	33%	67%	216	42%	58%	\$273,173
Lewis	32%	68%	107	50%	50%	\$793,655
Livingston	26%	74%	50	22%	78%	\$175,062
Madison	52%	48%	21	71%	29%	\$52,377
Montgomery	28%	72%	145	24%	76%	\$716,827
Nassau	30%	70%	3,440	42%	58%	\$56.9 M
Niagara	38%	62%	439	39%	61%	\$2.9 M
Oneida	36%	64%	454	46%	54%	\$1.0 M
Onondaga	39%	61%	789	41%	59%	\$2.4M
Ontario	27%	73%	112	32%	68%	\$403,432

Orange	35%	65%	434	36%	64%	\$3.1 M
Orleans	59%	41%	29	66%	34%	\$46,963
Oswego	33%	67%	178	30%	70%	\$388,720
Otsego	28%	72%	93	41%	59%	\$291,953
Putnam	25%	75%	99	16%	84%	\$1.7 M
Rensselaer	45%	55%	259	47%	53%	\$1.2 M
Rockland	29%	71%	316	27%	73%	\$3.7 M
St. Lawrence	33%	67%	608	26%	74%	\$2.5 M
Saratoga	24%	76%	104	29%	71%	\$296,812
Schenectady	42%	58%	180	45%	55%	\$731,001
Schoharie	22%	78%	81	22%	78%	\$357,718
Schuyler	22%	78%	18	31%	69%	\$33,541
Suffolk	30%	70%	1,730	33%	67%	\$18.9M
Sullivan	41%	59%	129	51%	49%	\$616,817
Tioga	34%	66%	50	63%	37%	\$107,291
Tompkins	40%	60%	150	38%	62%	\$379,540
Ulster	41%	59%	494	32%	68%	\$4.5 M
Warren	32%	68%	161	37%	63%	\$395,335
Washington	32%	68%	115	41%	59%	\$313,265
Wayne	30%	70%	142	31%	69%	\$627,447
Westchester	32%	68%	1,903	32%	68%	\$28.2M
Wyoming	35%	65%	80	34%	66%	\$239,214
Yates	29%	71%	59	24%	76%	\$93,063
NYC	22%	78%	63,900	20%	80%	\$1.3 B
NYS Total	25%	75%	103,422	22%	78%	\$1.5 B

- In NYS overall 25% of the personal care caseload is less than 64 years old. This figure is heavily weighted by the fact that 22% of the PCA caseload in NYC is less than 64 years old.
- The majority of counties outside of NYC are serving caseloads in PCA where 30% or more of the clients are less than 64 years of age.
- Data on Monroe County has been purposely omitted as most of their clients are served by the Long Term Home Health Care Program, rather than personal care.

Medicaid Funded Home Care Programs in NYS for Children, Adults and Elders: Number of Recipients and Dollars Spent			
Program	Number of recipients statewide	Total dollars spent	Avg. annual cost per recipient
AIDS, Case Management	11,242	\$39,315,334	\$3,497
Assisted Living Program	2,830	\$38,020,342	\$13,434
Care at Home 1 & 2 (case management*)	585	\$1,551,333	\$2,652
Care at Home 3,4,5 (case management*)	451	\$1,559,029	\$3,457
CDPAP, NYC	1,189	\$43,170,561	\$36,308
Certified Home Health Care	90,999	\$605,087,137	\$6,649
Consumer Directed Personal Assistance Program	1,744	\$25,350,267	\$14,536
Early Intervention, Case Management	15,101	\$10,968,301	\$726
Early Intervention, except case management	15,789	\$111,730,811	\$7,076
HC BW	40,720	\$2,593,238,874	\$63,685
Hospice	3,936	\$29,547,287	\$7,507
Long Term Home Health Care Program	27,316	\$430,570,430	\$15,763
Medical Day Care	15,304	\$240,321,584	\$15,703
Mental Health	14,098	\$34,237,189	\$2,429
MSC (OMRDD)	48,459	\$94,105,558	\$1,942
Personal Care	84,044	\$1,503,080,718	\$17,884
Private Duty Nursing	2,808	\$152,052,502	\$54,150
Traumatic Brain Injury	779	\$30,000,759	\$38,512

• source NYS MA statistics for year 2000

* The figures for the CAH programs are for the case management only and do not include the cost of other services authorized within the program.

Summary of the Number of Recipients in Multiple Medicaid Funded Long Term Care Programs in New York State in 2000	
Number of Recipients	Number of Combined Programs
1	8
1	7
21	6
155	5
1,515	4
9,210	3
83,817	2
175,154	1
Total 269,864	

Programs are:

- AIDS Case Management
- Assisted Living
- Care At Home I & II (physically disabled)
- Care At Home III, IV, & VI (developmentally disabled)
- Certified Home Health Agency
- Consumer Directed Personal Assistance Program
- Early Intervention
- Home and Community Based Services Waiver
- Hospice
- Long Term Home Health Care
- Medical Day Care
- Mental Health Case Management
- OMRDD Medicaid Service Coordination
- Personal Care
- Private Duty Nursing
- Traumatic Brain Injury Waiver

Figure A State-by-State Comparisons of Medicaid Expenditures, Fiscal Year 1998

	Medicaid Expenditures	Federal Medical Assistance Percentage (FMAP)	Medicaid DSH Payments	Average \$ Payment per Person Served	Average \$ Payment per Person Served (w/out DSH)
All Jurisdictions	\$175,065,785,063	57%	\$14,961,830,000	\$4,307	\$3,939
Alabama	2,386,960,623	69.3%	393,725,550	4,529	3,782
Alaska	404,349,539	59.8%	15,359,184	5,427	5,221
Arizona	1,995,647,195	65.3%	123,400,100	3,931	3,688
Arkansas	1,503,143,348	72.8%	1,656,113	3,539	3,535
California	16,900,135,806	51.2%	2,450,659,581	2,386	2,040
Colorado	1,655,158,031	52.0%	139,080,856	4,799	4,395
Connecticut	2,984,090,391	50.0%	370,130,367	7,828	6,857
Delaware	450,384,207	50.0%	8,000,000	4,440	4,361
District of Columbia	776,545,565	70.0%	32,857,143	4,674	4,476
Florida	6,869,451,090	55.7%	370,501,877	3,607	3,412
Georgia	3,845,448,072	60.8%	409,567,607	3,147	2,812
Hawaii	624,947,036	50.0%	0	3,385	3,385
Idaho	505,050,782	69.6%	2,150,130	4,100	4,083
Illinois	6,693,269,901	61.4%	196,878,426	4,435	4,111
Indiana	1,516,260,653	63.8%	19,837,645	4,815	4,752
Iowa	7,050,809,934	50.0%	269,569,794	5,170	4,972
Kansas	1,131,055,936	59.7%	45,012,596	4,675	4,489
Kentucky	2,696,929,368	70.4%	194,685,201	4,185	3,883
Louisiana	3,298,850,530	70.0%	738,261,750	4,578	3,553
Maine	1,160,312,323	66.0%	122,431,837	6,807	6,089

Sources: FY 1998 HCFA Form 64, and FY 1998 HCFA Form 2082.

Figure B State-by-State Comparisons of Medicaid Expenditures, Fiscal Year 1998 (continued)

	Medicaid Expenditures	Federal Medical Assistance Percentage (FMAP)	Medicaid DSH Payments	Average \$ Payment per Person Served	Average \$ Payment per Person Served (w/out DSH)
Maryland	2,858,399,994	50.0%	135,983,963	5,094	4,852
Massachusetts	6,240,026,597	50.0%	497,279,716	6,870	6,323
Michigan	6,124,381,104	53.6%	319,344,308	4,494	4,259
Minnesota	3,133,340,561	52.1%	56,255,876	5,820	5,715
Mississippi	1,748,939,562	77.1%	183,879,961	3,600	3,222
Missouri	3,441,932,848	60.7%	666,056,976	4,689	3,782
Montana	429,924,141	70.6%	220,049	4,267	4,265
Nebraska	897,652,159	61.2%	5,922,068	4,250	4,222
Nevada	557,205,936	50.0%	73,559,997	4,348	3,774
New Hampshire	898,041,296	50.0%	128,411,171	8,493	7,126
New Jersey	6,675,476,319	50.0%	1,020,399,407	6,856	5,601
New Mexico	1,077,359,070	72.6%	9,407,934	3,270	3,242
New York	27,539,936,152	50.0%	1,860,442,452	8,961	8,356
North Carolina	4,872,406,054	63.1%	354,104,750	4,172	3,868
North Dakota	356,138,657	70.4%	1,194,829	5,718	5,699
Ohio	6,900,675,153	58.1%	657,034,743	5,346	4,837
Oklahoma	1,458,029,874	70.5%	22,722,398	4,257	4,191
Oregon	1,866,822,080	61.5%	27,047,133	3,652	3,599
Pennsylvania	8,846,726,699	53.4%	546,328,751	5,808	5,450
Puerto Rico	334,000,000	50.0%	0	346	346

Sources: FY 1998 HCFA Form 64, and FY 1998 HCFA Form 2082.

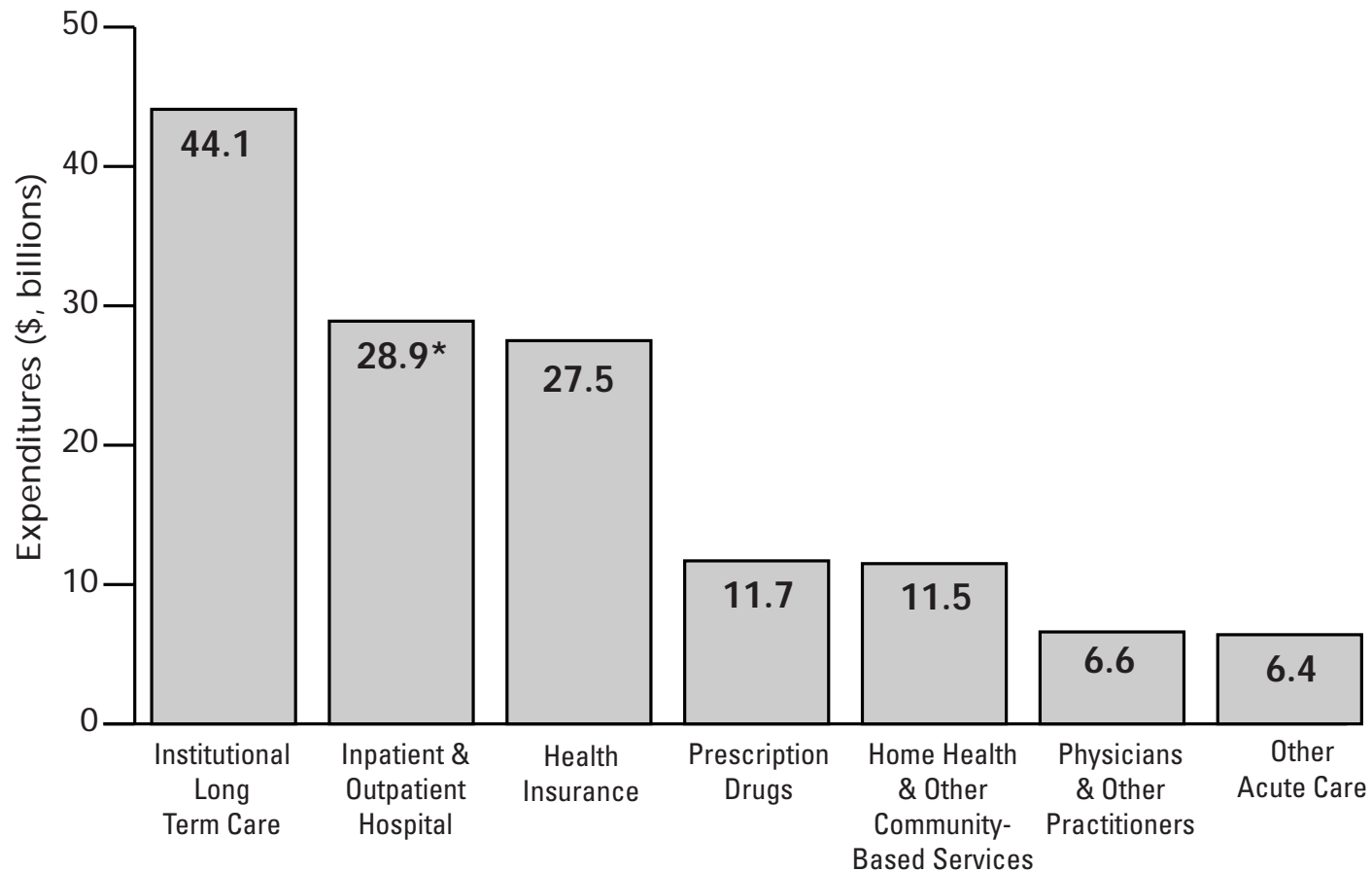
**Figure C State-by-State Comparisons of Medicaid Expenditures,
Fiscal Year 1998 (continued)**

	Medicaid Expenditures	Federal Medical Assistance Percentage (FMAP)	Medicaid DSH Payments	Average \$ Payment per Person Served	Average \$ Payment per Person Served (w/out DSH)
Rhode Island	1,011,108,624	53.2%	55,985,976	6,603	6,237
South Carolina	2,429,333,787	70.2%	445,678,485	4,083	3,334
South Dakota	371,532,790	67.8%	1,074,213	4,149	4,137
Tennessee	3,826,379,693	63.4%	0	2,075	2,075
Texas	10,272,990,955	62.3%	1,438,878,261	4,419	3,800
Utah	740,413,343	72.6%	4,133,372	3,431	3,412
Vermont	434,561,127	62.2%	22,260,838	3,505	3,325
Virgin Islands	10,381,533	50.0%	0	525	525
Virginia	2,443,379,308	51.5%	160,677,775	3,740	3,494
Washington	3,622,166,158	52.2%	332,814,161	2,563	2,328
West Virginia	1,328,062,888	73.7%	21,883,410	3,876	3,812
Wisconsin	2,830,114,783	58.8%	11,177,687	5,457	5,436
Wyoming	213,767,800	63.0%	122,769	4,635	4,632

Note: (1) The Medicaid Expenditures cited above are fiscal year 1998 total computable current expenditures (including administrative costs) from the HCFA Form 64; (2) DSH refers to Disproportionate Share Hospitals which receive higher Medicaid reimbursement than other hospitals because they treat a disproportionate share of Medicaid patients.

Sources: FY 1998 HCFA Form 64, and FY 1998 HCFA Form 2082.

Figure D Total Medicaid Expenditures by Type of Service, Fiscal Year 1998



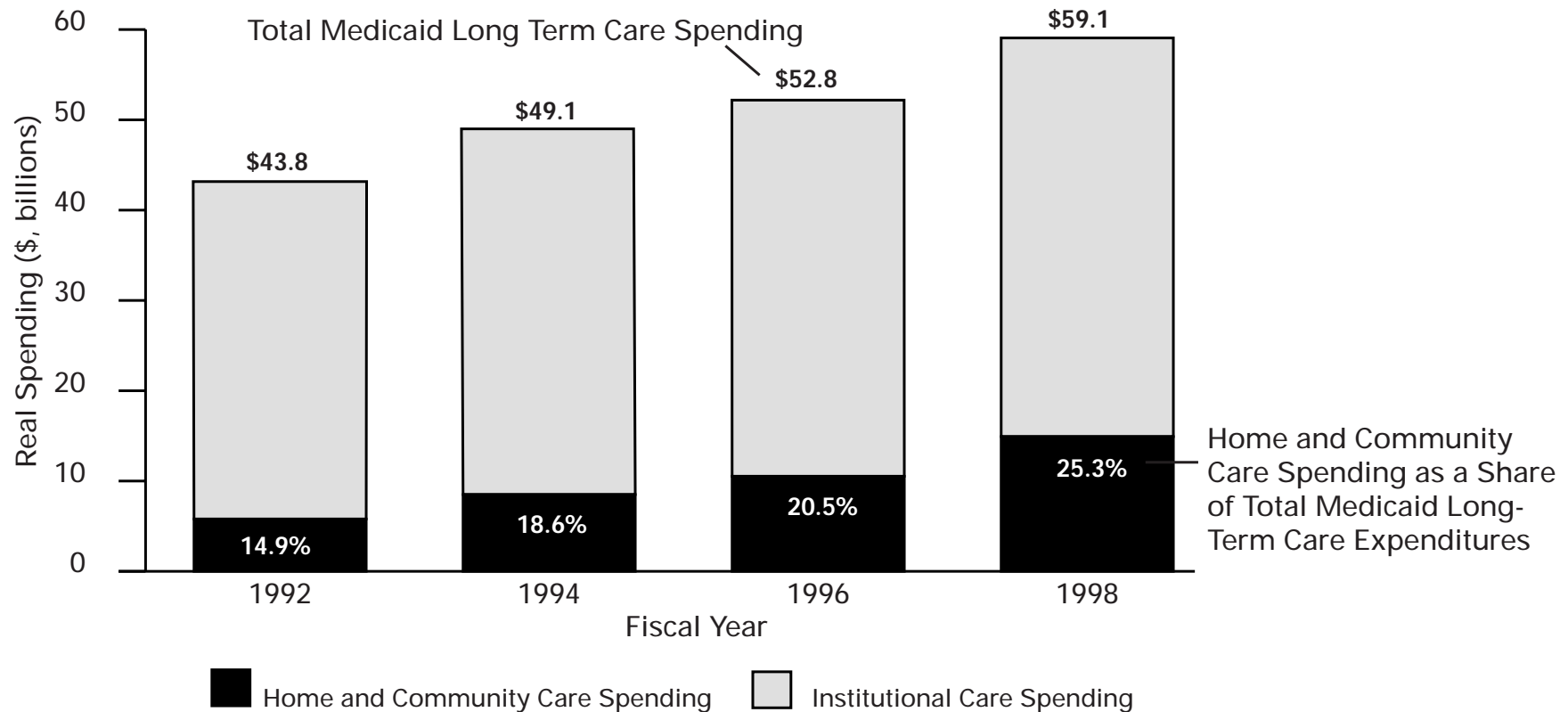
*DSH expenditures are not included; \$22.4 billion inpatient hospital expenditures, \$6.5 billion outpatient hospital expenditures.

Note: (1) "Health Insurance" refers to Medicaid program expenditures for Medicare premiums (on behalf of dual beneficiaries), as well as Medicaid premiums paid to primary care case management groups, HMOs and pre-paid health plans; (2) "Home Health & Other Community-Based Services" includes four categories found on the HCFA Form 64 (home health, personal care, home and community, and home and community-based disabled-elderly); (3) "Other Acute Care" includes clinics, Federally Qualified Health Centers, lab & x-ray and Early and Periodic Screening, Diagnosis and Treatment services.

Source: HCFA Form 64, total computable expenditures.

Figure E Medicaid Spending for Institutional Long Term Care and Home and Community Care

Spending on home and community care as a share of total Medicaid long term care expenditures has increased over time.

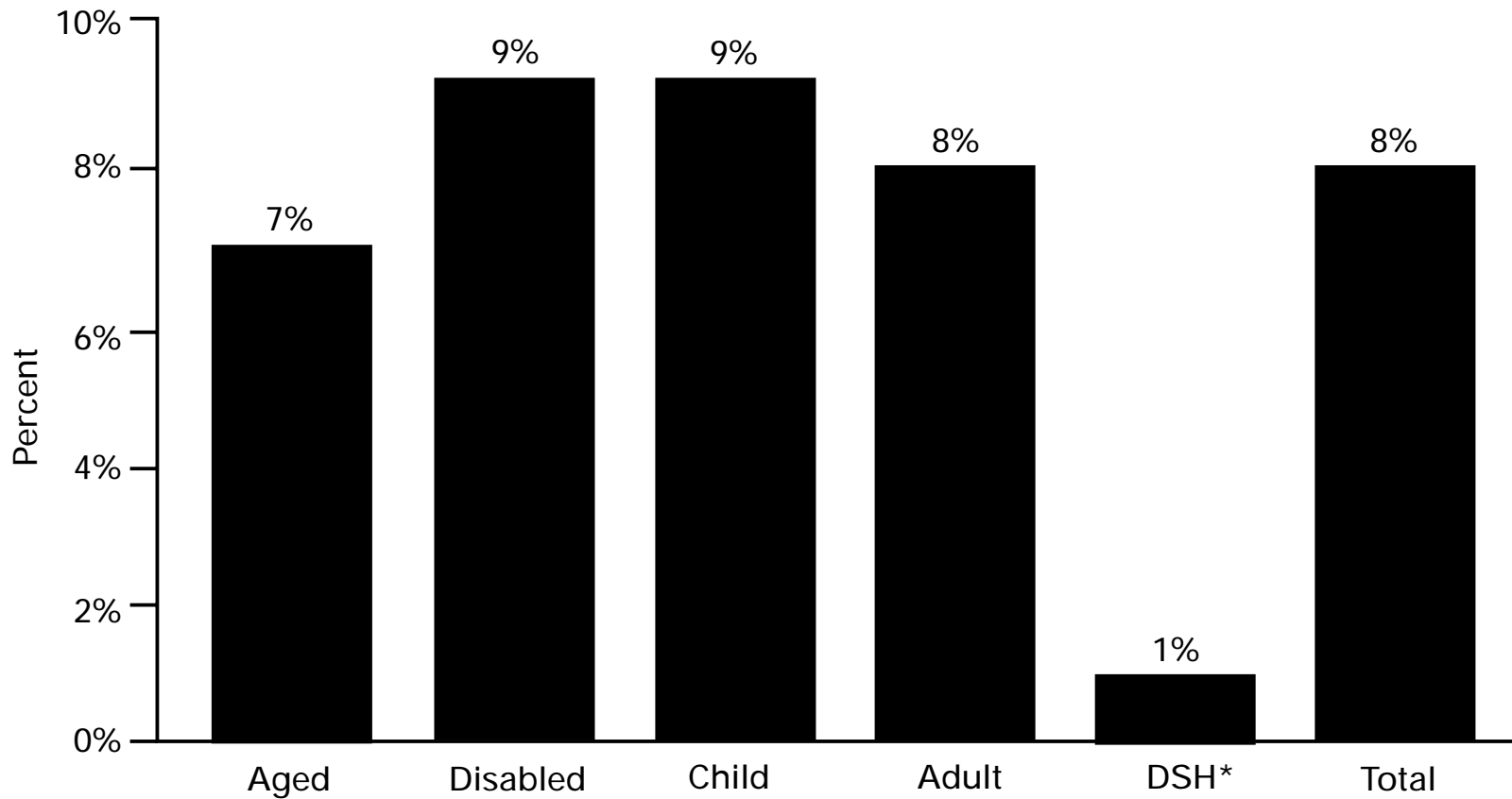


Note: (1) The data shown above are expressed in 1998 dollars; (2) Total Medicaid long-term care expenditures consists of spending on institutional long-term care and home and community care. Institutional long-term care spending includes expenditures for nursing facilities, and public and private ICF/MR facilities. Home and community-care spending consists of expenditures for personal care, home health, and home and community-based waivers.

Source: HCFA Form 64.

Figure F **Projected Average Annual Expenditure Growth Rates,
Fiscal Years 1998-2010**

People with disabilities and children are projected to have the highest increase in Medicaid expenditures.



*DSH refers to Disproportionate Share Hospitals which receive higher Medicaid reimbursement than other hospitals because they treat a disproportionate share of low-income individuals.

Note: Data shown above are expressed in nominal terms.

Source: HCFA/Office of the Actuary, President's Fiscal Year 2001 baseline budget.

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