The Faces
of Medicaid

The Complexities of Caring for People with
Chronic Illnesses and Disabilities

CHCS Center for
Health Care Strategies, Inc.

Acknowledgements

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Introduction

A complex question has persisted in our minds since the Center for Health Care Strategies (CHCS) opened its doors in 1995 to direct The Robert Wood Johnson Foundation's Medicaid Managed Care Program: why doesn't anyone know how many Medicaid recipients have what chronic illnesses and disabilities requiring what array of medical and social services? Without an answer to this question, it would seem self-evident that state Medicaid agencies, health plans, and consumer groups—the stakeholders—are severely limited in their efforts to design high quality managed care programs for a substantial number of beneficiaries—not only those eligible by virtue of SSI, but also many AFDC/TANF recipients with chronic, complex needs. Without data identifying these conditions, their comorbidities, and their prevalence, how could enrollment approaches be designed, provider networks be developed, rates be set (and risk adjusted), and quality be monitored? In short, how could contracts be written?

As an initial step toward helping states, managed care organizations and consumer groups to answer these questions, CHCS prepared *The Faces of Medicaid: The Complexities of Caring for People with Chronic Illnesses and Disabilities.* The goals of this report are to begin to identify populations with special health care needs in Medicaid and now State Children's Health Insurance Programs, describe the severity of some of their primary and secondary conditions, and highlight a subset of the clinical and fiscal policy issues faced by states and health plans enrolling these populations in managed care.

The CHCS team accomplished these goals through an analysis of claims data from four states, supplemented by other national data sources, exhaustive literature reviews, and interviews with consumers and other experts in the field. The report highlights best practices and policy implications for further discussion, including: adjusting covered benefits and rates, reimbursing family caregivers, providing adequate transportation for people with disabilities, and altering the definition of medical necessity to accommodate chronic conditions.

The Center for Health Care Strategies is a nonprofit, policy resource center that promotes high quality health care services for low-income populations and people with chronic illnesses and disabilities. Initiatives at CHCS are organized around four organizing principles: informed purchasing, consumer action, integrated systems of care, and managed care best practices. *The Faces of Medicaid* addresses all these issues.

The Basics of Medicaid Managed Care

I n the past decade, Medicaid managed care enrollment in the United States has increased from four million to 17 million. Further increases are estimated at over 20 million in the next five years.

While managed care was initially introduced to healthy Medicaid populations, primarily pregnant women and children, it is now being widely adopted as a means to cost-effectively deliver comprehensive health care to people with special health care needs.

The Role of SSI and SSDI in Medicaid

SSI is an income assistance program for disabled, blind, or aged individuals that is independent of individuals' employment status. In most states, SSI entitlement ensures eligibility for Medicaid benefits.

SSDI is an insurance program for those who have worked a specified amount of time, and have lost their source of income due to a physical or mental impairment. If recipients exhaust their Medicare benefits or exhaust their income, they then become eligible for SSI or Medicaid or both.

Medicaid Beneficiaries, 1997

Blind .26%
Disabled 17%
Other 2%
Elderly 12%
Children under age 21 48%
Adults 21%
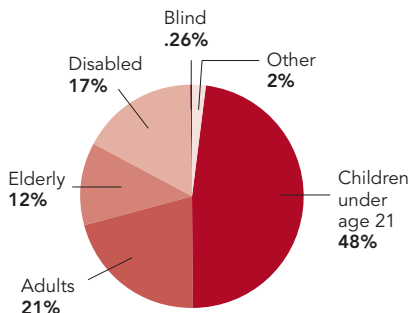
The Disabled percentage is the portion of the current Medicaid population considered to have special health care needs.

Source: HCFA, 1997.

What is Medicaid?

In response to the significant need for health care for the disabled and disenfranchised, the U.S. government in 1965 created Medicaid as Title XIX of the Social Security Act. Today, the federal government and 54 states and territories jointly administer this public health care financing program.

Who Qualifies for Medicaid?

State Medicaid programs must cover the following people:

- Recipients of Temporary Assistance to Needy Families (TANF)
- Recipients of Supplemental Security Income (SSI)
- Recipients of Supplemental Security Disability Insurance (SSDI)
- Children under age six and pregnant women whose family income is at or below 133 percent of federal poverty guidelines
- Infants born to Medicaid-eligible pregnant women
- Children who receive adoption assistance or foster care
- Children born after September 30, 1983, who are over age five and live in families with income up to the poverty level
- Medicare recipients with incomes below poverty
- Special Protected Groups

States may choose to cover other groups under their Medicaid and State Children's Health Insurance Programs (SCHIP), most notably additional children as well as pregnant women and those whose medical expenses reduce their income to the states' ceiling to qualify as medically needy.

What Services do People on Medicaid Use?

Mandatory Medicaid Services	Optional Medicaid Services
Inpatient hospital	Prenatal and delivery
Outpatient hospital	Ambulatory
Physician	Home health
Medical and surgical dental	Intermediate care facilities for
Home health	the mentally retarded
Nursing facility for people over 21	Clinic
Family planning and supplies	Nursing facilities for people under 21
Rural health clinic	Optometrist and eyeglasses
Laboratory and X-ray	Prescription drugs
Pediatric and family nurse practitioner	TB-related
Federally qualified health center	Prosthetic devices
Nurse midwife	Dental
EPSDT (Early and Periodic Screening, Diagnosis, and Treatment)	

Source: HCFA, 1998.

What Does Medicaid Cost?

Medicaid Expenditures, 1997

Other
1%

Children
under age 21
16%

Blind and
Disabled
40%

Adults
14%

Elderly
29%
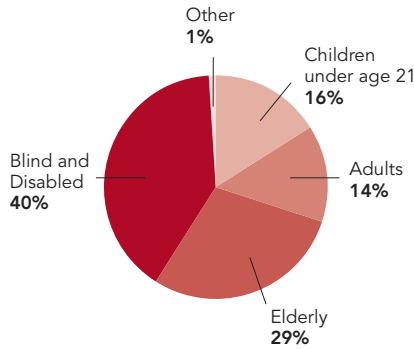
Source: HCFA, 1997.

Medicaid Beneficiaries and Expenditures by Enrollment Group, 1997

	Beneficiaries=40.6 million	Expenditures=$161.2 billion
Disproportionate Share Hospital Payments		10%
Elderly	10%	28%
Blind and Disabled	17%	38%
Adults	21%	10%
Children	52%	15%
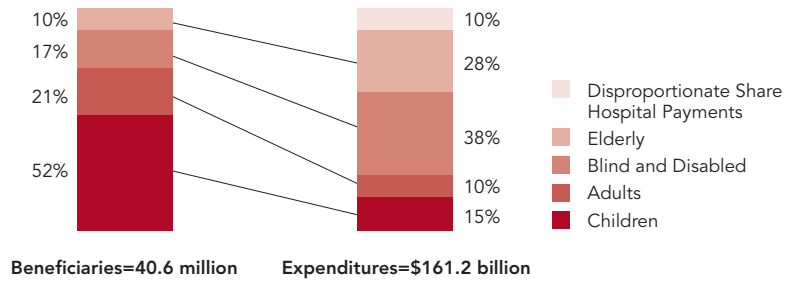
Source: Kaiser Commission on Medicaid and the Uninsured, 1999.

What is Managed Care?

Managed care is a prepaid form of health care delivery designed to manage the cost, quality, and accessibility of care. Most managed care organizations (MCOs) include a restricted panel of contracted care providers, certain limitations on benefits to subscribers, and some type of system to authorize services.

There are many kinds of MCOs, and the abbreviations for them add to the confusing "alphabet soup" of managed care. MCOs have been distinguished from traditional indemnity insurance companies (e.g., Blue Cross and Blue Shield) mainly by the degree of controls on cost and quality.

Continuum of Managed Care
Increasing Controls on Cost and Quality

Fee-for-service indemnity	Service Plans	PPOs	Point-of-service HMOs	Open panel HMOs	Closed panel HMOs
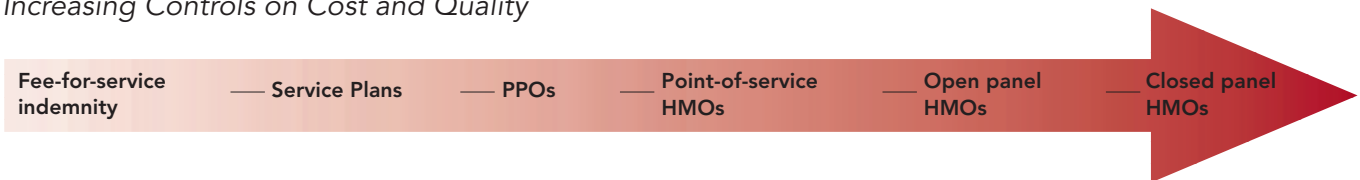
**Medicaid Managed Care
Enrollment in Millions, 1994–1998**
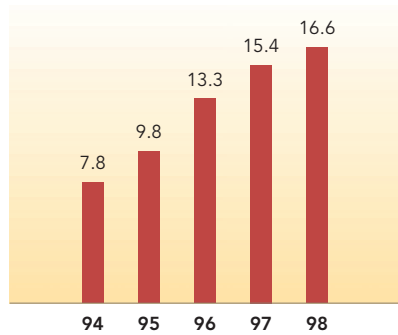
Source: HCFA, 1999.

Spotlight on the States:

Tennessee
In January 1994, Tennessee launched its Medicaid managed care initiative, TennCare, for virtually all of its Medicaid and uninsured populations. By the end of 1994, the state had enrolled 1.2 million people in one of the 12 MCOs under contract to TennCare. All MCOs are fully capitated, and many were formed specifically for TennCare.

Source: Kaiser Family Foundation, May 1999.

What is Medicaid Managed Care?

Medicaid managed care is designed to provide low-income beneficiaries with quality health care services comparable to those received by commercial populations. Managed care models have been seen as an antidote to the uncoordinated, episodic care typically provided under traditional Medicaid fee-for-service arrangements.

Medicaid laws have permitted enrollment in managed care since 1966. Yet by 1981, only about a quarter of a million people, out of the roughly 20 million with Medicaid coverage, had enrolled in Medicaid managed care.

With the expansion of the waiver-granting authority of the Health Care Financing Administration (HCFA) in 1981, states experimented with many new approaches to using alternative financing and delivery arrangements for Medicaid. By the end of the 1980s, Medicaid managed care enrollment grew to about two million.

In the past five years, enrollment in Medicaid managed care has grown rapidly. As Medicaid expenditures reached nearly 20 percent of the typical state budget, pursuit of cost control through managed care expansion increased dramatically. Currently, all but two states — Alaska and Wyoming — have a Medicaid managed care model in place.

Medicaid Managed Care: The Challenges for People with Special Health Care Needs

Since 1981, states have been obtaining waivers from the HCFA to set up voluntary or mandatory Medicaid managed care programs. Initially, states were enrolling just the AFDC (now TANF) portion of their Medicaid population. As states' Medicaid managed care initiatives mature, they are expanding enrollment to other populations, including individuals with special needs.

In addition to experimenting with program design, some states also have launched disease management initiatives around certain chronic illnesses, most notably asthma, diabetes, and HIV/AIDS. Chronic disease management coordinates the range of acute care, pharmacy, behavioral, and social services across the entire health system to respond more effectively to patients' needs.

Individuals receiving SSI benefits are typically those with special health care needs on Medicaid. Reference to people with "special health care needs on Medicaid" usually indicates recipients that qualify for SSI because of their disability status. The majority of SSI recipients have a primary diagnosis of a mental disorder (mental illness and mental retardation).

Currently 1.6 million (27.4 percent) of non-elderly disabled Medicaid beneficiaries, in 36 states, are in some form of managed care. As more states move Medicaid recipients with special health care needs into managed care, they must address new policy and operational concerns that either were not issues or were not relevant under fee-for-service programs.

SSI Recipients by Category

Blind
1%

Aged
21%

Disabled
78%
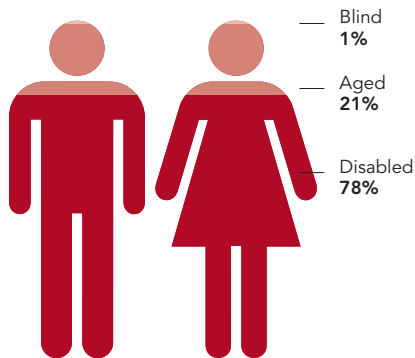
Source: SSA, 1996.

Diagnostic Breakdown of SSI Recipients

Physical Disability
42%

Mental Illness
30%

Mental Retardation
28%
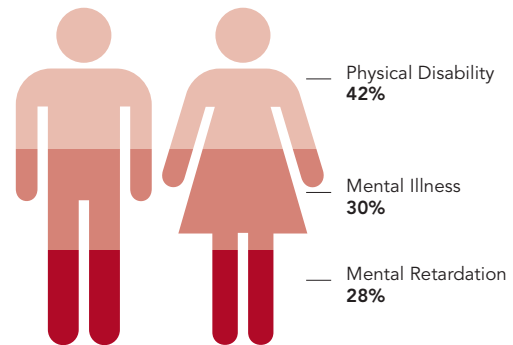
Source: SSA, 1996.

An Introduction to the Issues

Therefore, as more states move Medicaid recipients with special health care needs into managed care, they must address a series of challenges that were not as critical or relevant under fee-for-service programs. These challenges, which we will cover throughout this report, are to:

1. **Identify** the population on Medicaid with chronic illnesses and disabilities

2. **Reach and Serve** through improving outreach, enrollment and access

3. Redesign systems of **Care**

4. **Integrate** multiple service systems into a well-coordinated program

5. **Empower** people with special health care needs by promoting consumer independence

6. Successfully **Communicate** to this population by practicing culturally competent health care

7. **Monitor** the quality of care through effective accreditation and performance measures

8. **Finance** systems that minimize risk by predicting costs

Identify

What are Chronic conditions? Chronic conditions differ from acute conditions in that generally cure is not a possibility. Some of the most prevalent chronic conditions, such as hay fever or sinusitis, are not normally disabling; however, others, such as heart disease and diabetes, can cause significant limitations in a person's ability to perform certain basic activities of daily living, or ADLs, such as bathing, dressing, and eating.[1] Thus, in addition to long-term medical care, people with chronic conditions often need personal, social, or rehabilitative care over a prolonged period of time. These services are referred to as long-term care services and can be provided either in the home and community, or in institutions.

Chronic conditions are more prevalent and more complex among people with lower incomes, for example, those on Medicaid. Of the approximately 40 million Medicaid beneficiaries, 10 to 12 million have chronic conditions or illnesses.

Elderly Medicaid beneficiaries with significant disabilities and medical needs often reside in institutional settings. While younger individuals with disabling conditions may also live in a variety of institutional arrangements, the majority of this population resides in the community. This report focuses on the Medicaid population under age 65, and living in the community.

A Note on Methodology

Many states are gradually shifting medical coverage for the nonelderly Medicaid population with special health care needs to managed care. But the basic characteristics of this population have not been adequately studied, making it more difficult to ensure that managed care supports them. As we analyze the characteristics of nonelderly Medicaid beneficiaries with chronic or disabling conditions, we'll examine this population in four states:[2] California, Georgia, Kansas, and New Jersey. The data presented in this chapter is an average across these four states.

Our research is based on the HCFA's State Medicaid Research Files (SMRF) in those states. SMRF have a common data format and have been edited by the HCFA to increase the "user-friendliness" of the files for research purposes. States selected for this study are geographically diverse and have differences in type of Medicaid managed care programs and level of statewide managed care penetration. Medicaid special needs populations in other states may vary from this composite profile.

One reason that characteristics of the Medicaid population with special health care needs are not well known is that Medicaid claims files were not specifically designed to identify this population. Thus, deciding on a reasonable definition that would minimize, to the extent possible, both over- and under- identification of individuals, as having special health care needs was critical to this effort. Since only Medicaid beneficiaries under age 65 with health problems are eligible for SSI, inclusion of this subgroup was straightforward. However, not all Medicaid beneficiaries with special health care needs are eligible for SSI. We also identified individuals with special health care needs who qualified for Medicaid under other eligibility pathways (e.g., AFDC) using diagnostic criteria from the new Chronic Illness and Disability Payment System (CDPS) developed by Richard Kronick and his colleagues[3] at the University of California, San Diego. Finally, a small number of beneficiaries who were not identified through diagnostic criteria were captured through utilization and cost criteria, adapted from Brian Burwell and colleagues[4] at MEDSTAT (1997). More detail on our method of identifying beneficiaries with special health care needs can be found in the Technical Appendix.

It is also important to note that the following groups are excluded from this analysis:

- Beneficiaries in capitated managed care arrangements, since claims are no longer submitted for reimbursement, and thus information may be incomplete or missing;

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1   *Chronic Conditions: A Challenge for the 21st Century.* National Academy on an Aging Society, November 1999.

2   For this study, we use the terms "people with special health care needs" and "people with chronic illnesses or disabilities" interchangeably.

3   Kronick R., Gilmer T., Dreyfus T., Lee L. "Improving Health-based Payment for Medicaid Recipients: CDPS." *Health Care Financing Review/Spring 2000/Volume 21, Number 3: 1-36.*

4   Burwell, B., Crown, B. and Drabek, J. *Children with Severe and Chronic Conditions on Medicaid.* Washington DC: The MEDSTAT Group, November 1997.

- Dually eligible Medicaid/Medicare beneficiaries, since many of their claims are submitted to the Medicare, rather than Medicaid, program;

- Beneficiaries enrolled for fewer than three months in 1995, since their diagnostic, cost, and utilization profiles may be misleading over this short period of time;

- Women pregnant during the years of interest, since pregnancy-related office visits and hospitalizations would have biased comparisons between people with and without special health care needs.

Thus, the following charts present data on the "Medicaid-only" population in fee-for-service arrangements who were enrolled more than three months in 1995. We compare data between groups of beneficiaries with special health care needs by eligibility pathway, i.e., SSI versus other. We also compare all beneficiaries with special needs to those without special health care needs. Data in the following categories helps to characterize this population:

- Prevalence and types of chronic or disabling conditions

- Pathways of Medicaid eligibility

- Services used

- Medicaid expenses

The source for all figures in this chapter is: Mathematica Policy Research analysis of the HCFA data from the State Medicaid Research Files for California, Georgia, New Jersey, and Kansas, 1995. (See Technical Appendix for discussion of research methodology).

Prevalence and Types of Chronic or Disabling Conditions

Percentage of Adult Medicaid Beneficiaries with Chronic or Disabling Conditions

Other Medicaid Beneficiaries
39%

People with chronic or disabling conditions
61%
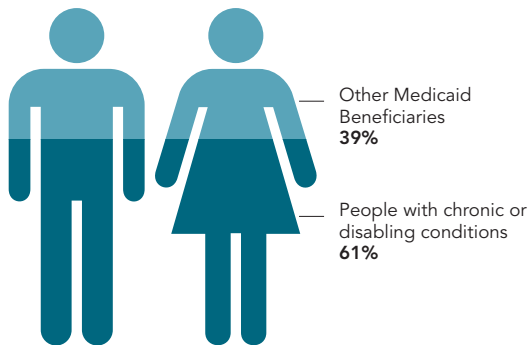
Most adult nonelderly Medicaid beneficiaries have chronic or disabling conditions

Percentage of Child Medicaid Beneficiaries with Chronic or Disabling Conditions

Other Medicaid Beneficiaries
69%

People with chronic or disabling conditions
31%
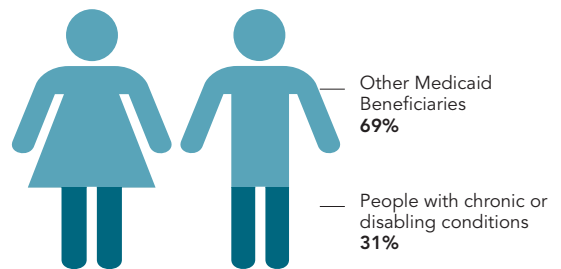
A substantial number of child Medicaid beneficiaries also have chronic or disabling conditions

Medicaid special needs beneficiaries have a range of physical and mental health-related diagnoses. In addition, many have less common conditions that require a range of specialized clinical expertise and support. Children with chronic or disabling conditions also have diverse diagnoses, different from those common among adult Medicaid beneficiaries. One major difference is the prevalence of congenital anomalies in children.

States' Diagnoses of Chronic or Disabling Conditions
Adult Medicaid Beneficiaries

Diagnosis	Number of states (of 4) in which this condition is a "Top Ten" Diagnosis for Medicaid beneficiaries
Hypertension	4
Psychoses (e.g., schizophrenia)	4
Asthma	4
Diabetes Mellitus	4
Other diseases of the central nervous system (e.g., multiple sclerosis, epilepsy)	4
Arthropothies and related disorders (e.g., rheumatoid arthritis)	4
Chronic Depression	4
Substance Abuse	3
Mycoses (e.g., fungal infections)	3
Disease of esophagus, stomach and duodenum (e.g., gastric ulcer)	2
Neurotic disorders (e.g., obsessive-compulsive disorders, agoraphobia)	2
Mental Retardation	1

States' Diagnoses of Chronic or Disabling Conditions
Child Medicaid Beneficiaries

Diagnosis	Number of states (of 4) in which this condition is a "Top Ten" Diagnosis for Medicaid beneficiaries
Asthma	4
Attention Deficit Disorder	4
Congenital anomalies (e.g., cleft palate, Downs Syndrome)	4
Chronic Depression	4
Intestinal infectious diseases (e.g., giardia)	4
Osteopathies, chondropathies, and acquired musculoskeletal deformities (e.g., acquired deformities of limbs, osteomyelitis)	4
Burns	4
Other disorders of the central nervous system (e.g., multiple sclerosis, epilepsy)	4
Psychoses (e.g., schizophrenia, affective psychosis)	2
Neurotic disorders (e.g., obsessive-compulsive disorders, agoraphobia)	2
Other diseases of the respiratory system (e.g., tracheostomy complication, abscess of lung)	1
Hernia of abdominal cavity	1

Note: For the above two analyses, diagnosis codes were grouped into 81 clinical categories as indicated in the ICD-9-CM, Fourth Edition 1994, Diseases: Tabular List Volume I. Salt Lake City, UT: Medicode, Inc., 1993. See Appendix for more detail.

Psychiatric and cardiovascular conditions are common in adults with chronic or disabling conditions. Pulmonary, psychiatric, nervous system, and gastrointestinal problems are common among children with chronic or disabling conditions.

Percentage of Adult Medicaid Beneficiaries with Special Needs in Each Major Group of Chronic or Disabling Diagnosis

Diagnosis Group	Percentage
Psychiatric	25
Cardiovascular	24
Skeletal and Connective	18
Pulmonary	16
Nervous System	15.5
Gastrointestinal	14
Diabetes	9
Substance Abuse	8.7
Genital	8
Renal	6.3
Skin	6
Developmental Disability	5
Infectious Disease	4.3
Eye	3.7
Cancer	3.6
Metabolic	3
Cerebrovascular	2
Hematological	1.4

Percentage of Special Needs Beneficiaries with Diagnosis in Group

Percentage of Child Medicaid Beneficiaries with Special Needs in Each Major Group of Chronic or Disabling Diagnosis

Diagnosis Group	Percentage
Pulmonary	29
Psychiatric	21
Nervous System	15.5
Gastrointestinal	15.4
Skeletal and Connective	10
Cardiovascular	7
Skin	6
Metabolic	5
Renal	4.4
Infectious Disease	4
Genital	1.7
Hematological	1.6
Developmental Disability	1.5
Eye	1.1
Diabetes	1.1
Substance Abuse	1
Cancer	0.9
Cerebrovascular	0.4

Percentage of Special Needs Beneficiaries with Diagnosis in Group

Many Medicaid special needs beneficiaries have conditions that require different types of services and providers. This is especially true for beneficiaries who have multiple conditions.

Percentage of Adult Medicaid Beneficiaries with Special Needs who Have Multiple Chronic or Disabling Diagnoses

Not classified
17%

Multiple chronic
or disabling diagnoses
46%

Single chronic
or disabling diagnosis
37%

Percentage of Child Medicaid Beneficiaries with Special Needs who Have Multiple Chronic or Disabling Diagnoses

Not classified
9%
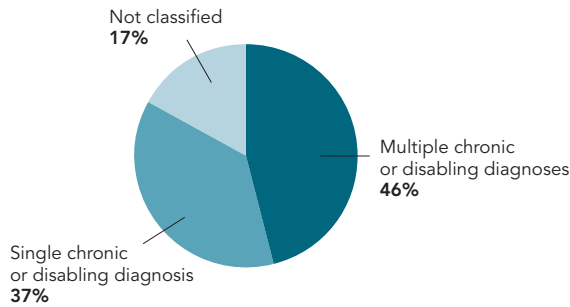
Multiple chronic
or disabling diagnoses
32%

Single chronic
or disabling diagnosis
59%
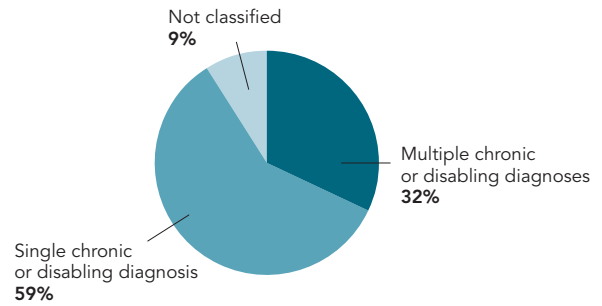
Medicaid special needs beneficiaries may have concurrent care needs related to mental and physical health. One in five adults and about one in ten children with special needs has a chronic or disabling physical diagnosis and a psychiatric, substance abuse, or developmental disability diagnosis.

Percentage of Adult Medicaid Beneficiaries with Special Needs who Have a Chronic or Disabling Physical Diagnosis as well as a Psychiatric, Substance Abuse, or Developmental Disability

Not classified
15%

Psychiatric, substance
abuse, or developmental
disability and physical
disability
20%

Psychiatric, substance
abuse, or developmental
disability only
14%

Physical only
51%

Percentage of Child Medicaid Beneficiaries with Special Needs who Have a Chronic or Disabling Physical Diagnosis as well as a Psychiatric, Substance Abuse, or Developmental Disability

Not classified
5%

Psychiatric, substance
abuse, or developmental
disability and physical
disability
9%

Psychiatric, substance
abuse, or developmental
disability only
14%

Physical only
72%
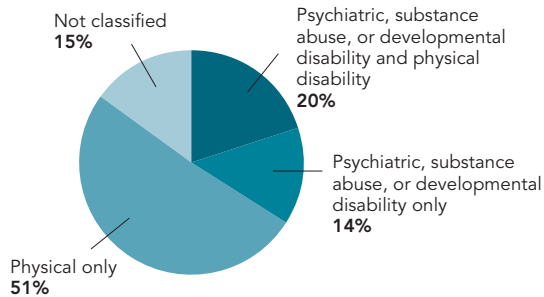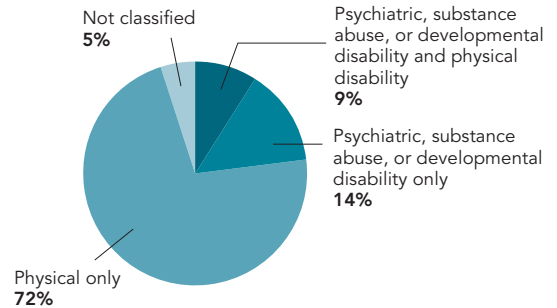
Pathways of Medicaid Eligibility

Medicaid managed care programs and policies must recognize that many beneficiaries with special needs enter Medicaid through eligibility pathways other than SSI. Children are more likely to enter through AFDC/TANF or other routes. Other eligibility includes beneficiaries who qualify for Medicaid through poverty-related eligibility provisions (including the Omnibus Budget Reconciliation Act), by being medically needy, by being in foster care, by having refugee status, or through any other eligibility other than cash AFDC or SSI.

Approximately half of adults with chronic or disabling conditions enter Medicaid through SSI, although the proportion entering through SSI varies somewhat by diagnostic category. The other half enter through AFDC or through another pathway. In contrast to adults, most children with chronic or disabling conditions enter Medicaid through AFDC or another pathway.

Eligibility Pathways for Adult Medicaid Beneficiaries with Chronic or Disabling Conditions, by Major Diagnostic Group

Diagnostic Group	Entered Medicaid through SSI eligibility	AFDC eligibility	Other eligibility
All	52	28	20
Infectious Disease	61	20	19
Cancer	58	20	22
Cardiovascular	59	25	16
Cerebrovascular	72	9	19
Nervous System	59	24	17
Diabetes	62	22	16
Developmental Disability	87	1	12
Eye	70	15	15
Genital	22	54	24
Gastrointestinal	50	32	18
Hematological	65	18	17
Metabolic	67	19	14
Psychiatric	56	28	16
Substance Abuse	52	35	14
Pulmonary	47	34	19
Renal	51	30	19
Skeletal and Connective	51	31	18
Skin	53	29	18

Percentage of Medicaid Beneficiaries with Special Needs

Eligibility Pathways for Child **Medicaid Beneficiaries with Chronic or Disabling Conditions, by Major Diagnostic Group**

Diagnostic Group	Entered Medicaid through SSI eligibility	AFDC eligibility	Other eligibility
All	15	45	40
Infectious Disease	9	48	43
Cancer	35	30	35
Cardiovascular	16	44	40
Cerebrovascular	45	24	31
Nervous System	27	37	36
Diabetes	14	49	37
Developmental Disability	65	9	26
Eye	19	38	43
Genital	7	47	46
Gastrointestinal	7	46	47
Hematological	24	40	36
Metabolic	30	33	37
Psychiatric	17	41	42
Substance Abuse	10	42	48
Pulmonary	8	52	40
Renal	14	44	42
Skeletal and Connective	14	44	42
Skin	7	54	39

Percentage of Medicaid Beneficiaries with Special Needs

Although the most common diagnoses are generally the same for both SSI and AFDC-eligible Medicaid beneficiaries with special needs, certain types of diagnoses are more likely for beneficiaries entering from one or the other of these pathways. For example, a greater percentage of SSI-eligible adult beneficiaries with special needs have cardiovascular diseases, while AFDC adult beneficiaries with special needs have a higher prevalence of asthma. Adults with developmental disabilities are the only group that enters Medicaid almost universally through one pathway (SSI).

Prevalence of Chronic or Disabling Conditions Among Eligibility Groups
(Notable Difference in Two or More States)

	Adults	Children
More common in the SSI Group:	Ischemic heart disease Hypertensive disease Diabetes Psychoses	Mental retardation Disorders of the blood and blood- forming organs (e.g., hemophilia) Attention deficit disorder Psychoses Congenital anomalies (cleft palate) Other diseases of central nervous system
More common in the AFDC/ Other Group:	Asthma Mycoses (fungal infections) Depression (two states)	Burns Intestinal infectious diseases Hernia of abdominal cavity Asthma

Services Used

Medicaid special needs beneficiaries use more of all types of health and health-related services than do other Medicaid beneficiaries, with the largest proportional difference in inpatient care, home health and long-term care. However, special needs beneficiaries also use services in a more predictable pattern than nondisabled individuals.

Health Services used by Adult Medicaid Beneficiaries
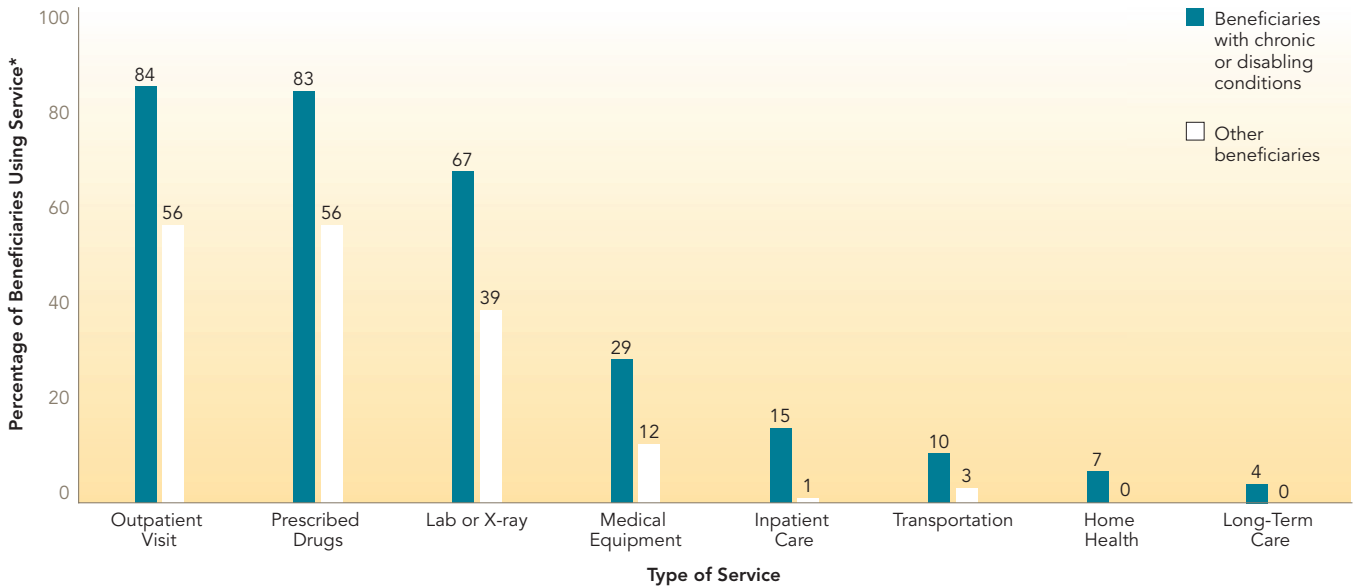
Percentage of Beneficiaries Using Service*

■ Beneficiaries with chronic or disabling conditions

□ Other beneficiaries

Type of Service	Beneficiaries with chronic or disabling conditions	Other beneficiaries
Outpatient Visit	84	56
Prescribed Drugs	83	56
Lab or X-ray	67	39
Medical Equipment	29	12
Inpatient Care	15	1
Transportation	10	3
Home Health	7	0
Long-Term Care	4	0

Type of Service

*Based on claims data, these figures indicate number of bills generated by visits for outpatient care per person-year.

Health Services used by Child Medicaid Beneficiaries
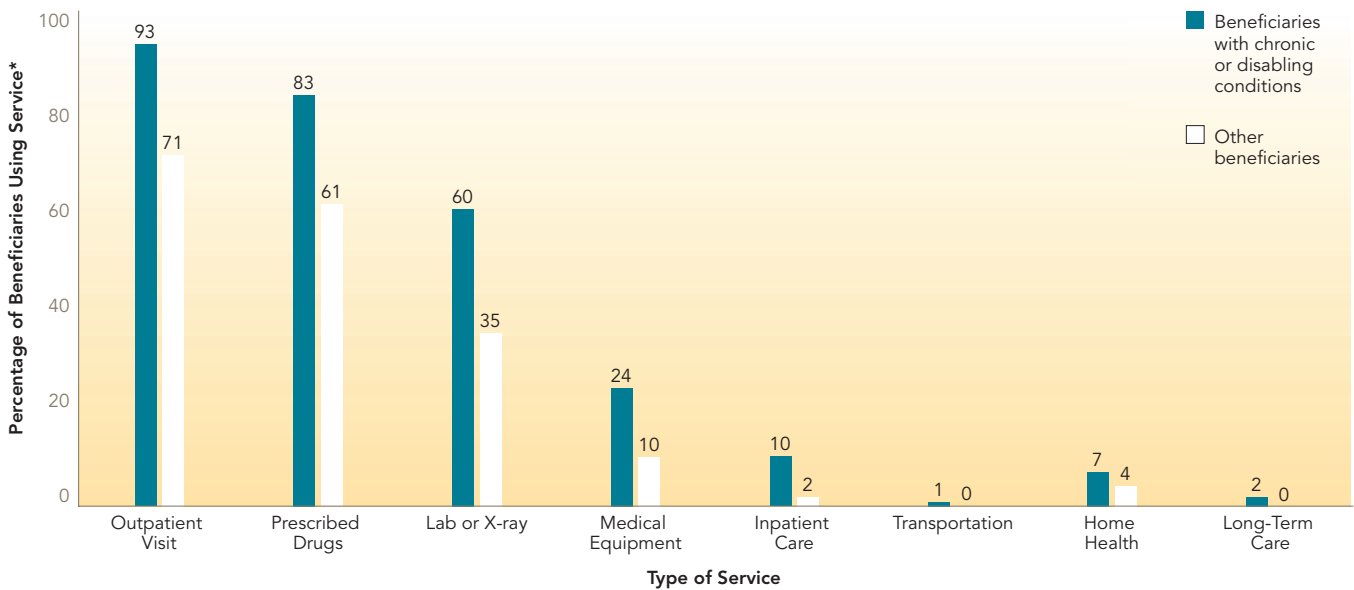
Percentage of Beneficiaries Using Service*

■ Beneficiaries with chronic or disabling conditions

□ Other beneficiaries

Type of Service	Beneficiaries with chronic or disabling conditions	Other beneficiaries
Outpatient Visit	93	71
Prescribed Drugs	83	61
Lab or X-ray	60	35
Medical Equipment	24	10
Inpatient Care	10	2
Transportation	1	0
Home Health	7	4
Long-Term Care	2	0

Type of Service

*Based on claims data, these figures indicate number of bills generated by visits for outpatient care per person-year.

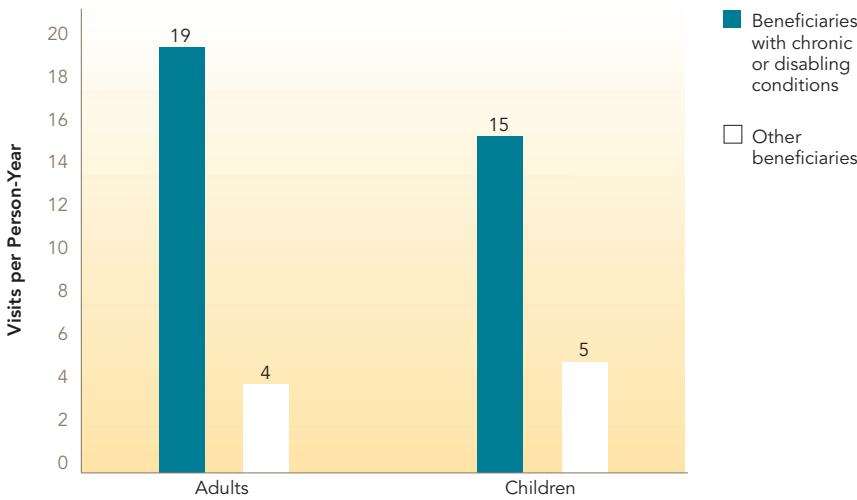Medicaid beneficiaries with chronic or disabling conditions visit the doctor more than other beneficiaries.

Number of Outpatient Visits per Person-Year for Medicaid Beneficiaries with Chronic or Disabling Conditions

*Per enrolled month or person-year or per 1,000 person years.

For Medicaid beneficiaries, the frequency of hospitalization is much higher among adults than children and people with chronic illnesses or disabilities than other beneficiaries. Hospitalization is even more frequent for individuals with multiple chronic or disabling conditions.

Hospital Admissions per 1,000 Person-Years for Medicaid Beneficiaries
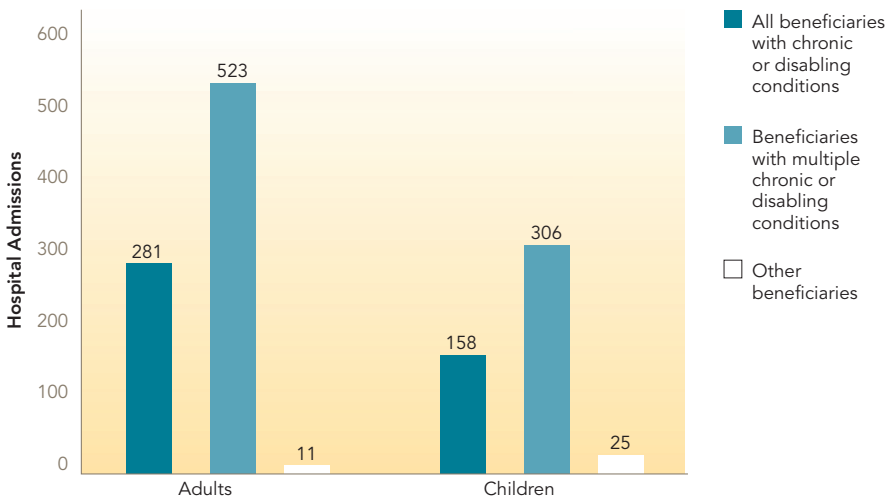
Although a relatively small portion of Medicaid special needs beneficiaries use home health and long-term care services, those who do use such services use them frequently and thus incur high expenses. Adult special needs Medicaid beneficiaries use home health and long-term care services more often than child special needs recipients.
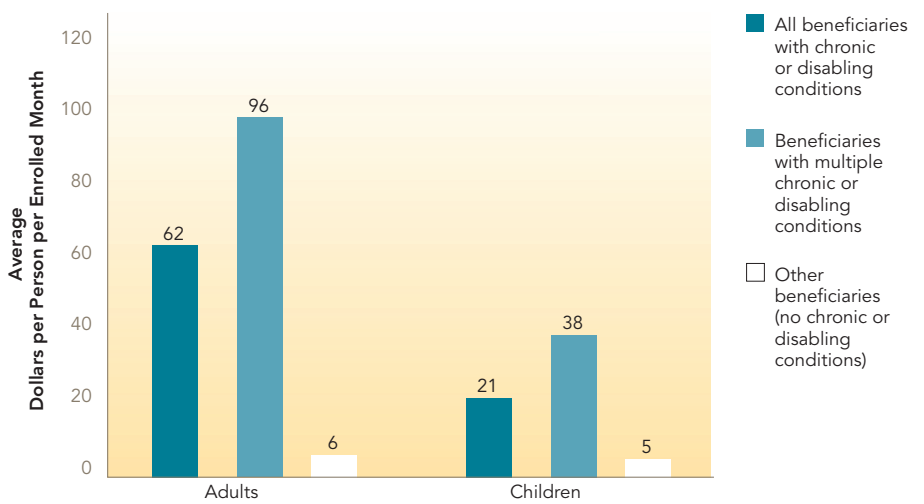
Medicaid Expenses per Chronically Ill or Disabled Beneficiary for Home Health and Institutional Long-Term Care

	Monthly Expenses Four State Average
Adults	
Home Health	$70
Institutional Long-Term Care	$134
Children	
Home Health	$9
Institutional Long-Term Care	$25

Note: The figures average the expenses of a small minority of frequent service users with those of a large majority of nonusers of these services.

Medicaid beneficiaries with chronic illnesses and disabilities, especially those with multiple conditions, use prescription medications more frequently. This leads to much higher drug expenses for these groups.

Expenses for Prescription Drugs for Medicaid Beneficiaries

Legend:
- All beneficiaries with chronic or disabling conditions
- Beneficiaries with multiple chronic or disabling conditions
- Other beneficiaries (no chronic or disabling conditions)

Y-axis: Average Dollars per Person per Enrolled Month

Adults: 62, 96, 6
Children: 21, 38, 5

Adults and children with chronic illnesses and disabilities, especially those with multiple conditions, use laboratory and X-ray services much more often than do other Medicaid beneficiaries.

Claims per Person-Year for Lab and X-Ray Services for Medicaid Beneficiaries with Chronic Conditions
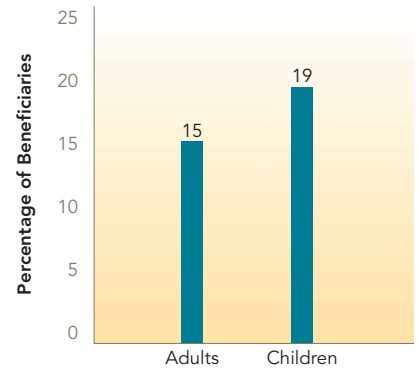
	Adults	Children
Beneficiaries without chronic illness or disability	3	2
All beneficiaries with chronic illness or disabling diagnoses	12	4
Beneficiaries with multiple chronic or disabling diagnoses	19	7

While many Medicaid special needs beneficiaries use a variety of services in a given year, other people in this group use few health services during that period. A substantial group does not use intensive services and uses outpatient services and prescriptions at a level below the average even for non-special needs beneficiaries. The existence of this group once again points to the diversity of health care use patterns among Medicaid special needs beneficiaries.

Medicaid Expenses

Special needs beneficiaries on Medicaid require more services from the health care system. As a result, their care is, on average, much more costly than care for other beneficiaries. These high average costs mean that this large segment of Medicaid beneficiaries represents a very high portion of total Medicaid program costs for the nonelderly population. Costs for people with disabilities are much more predictable than costs for a general population: among beneficiaries covered by Medicaid because of eligibility for SSI, high-cost people with disabilities this year are very likely to be high-cost next year, and low-cost individuals this year are likely to be low-cost next year.[5]

Medicaid Beneficiaries with Chronic or Disabling Conditions who are Low Users of Health Services
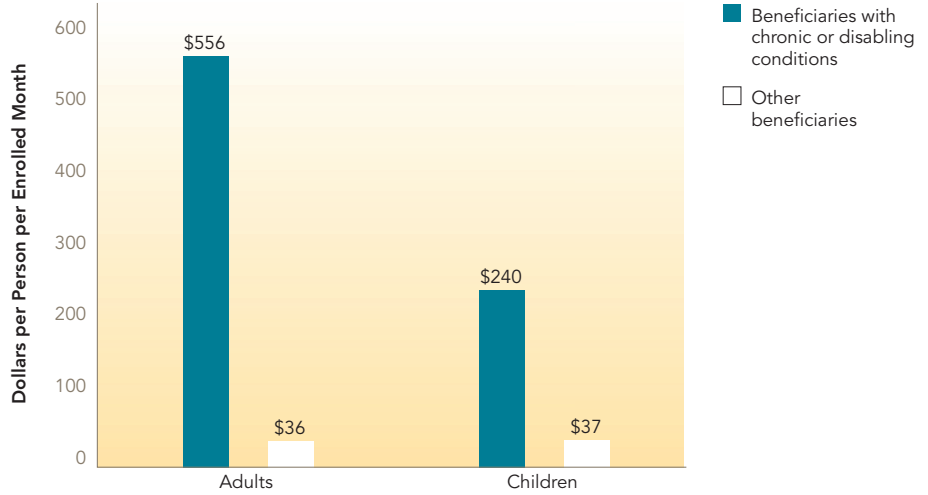

Note: "Low user" for adults is defined as having four or fewer outpatient claims (including lab and x-ray), one or no prescriptions, and no inpatient or long-term care or home health services in a year.

"Low user" for children is defined as having six or fewer outpatient claims (including lab and x-ray), two or fewer prescriptions, and no inpatient or long-term care or home health services in a year.

These definitions place the service use for these individuals at a level lower than the average for Medicaid beneficiaries without chronic or disabling conditions.

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5   Kronick, R. and Dreyfus, T. *The Challenge of Risk Adjustment for People with Disabilities: Health Based Payment for Medicaid Programs.* Center for Health Care Strategies, November 1997.

Average Monthly Medicaid Expenses for Beneficiaries with Chronic or Disabling Conditions, Compared with Other Beneficiaries

■ Beneficiaries with chronic or disabling conditions

☐ Other beneficiaries

Dollars per Person per Enrolled Month

- Adults: $556 (chronic or disabling), $36 (other)
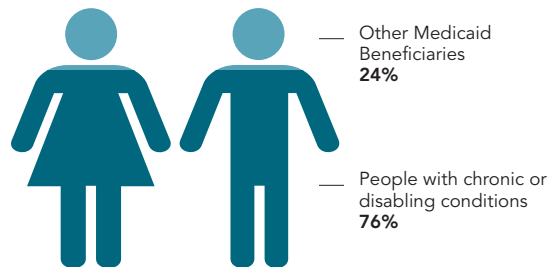- Children: $240 (chronic or disabling), $37 (other)

On average, monthly Medicaid costs are much higher for beneficiaries with chronic or disabling conditions.

Percentage of Total Medicaid Expenses Accounted for by Adult Beneficiaries with Chronic or Disabling Conditions

Other Medicaid Beneficiaries
4%

People with chronic or disabling conditions
96%
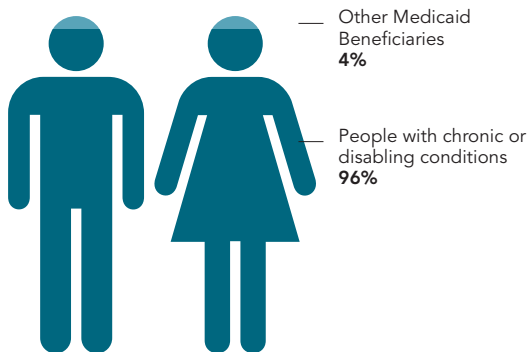
Beneficiaries with chronic or disabling conditions account for all but a small portion of total Medicaid expenses for nonelderly adults.

Percentage of Total Medicaid Expenses Accounted for by Child Beneficiaries with Chronic or Disabling Conditions

Other Medicaid Beneficiaries
24%

People with chronic or disabling conditions
76%

Beneficiaries with chronic or disabling conditions account for most Medicaid expenditures for children.

Among Medicaid special needs beneficiaries, those entering through SSI are more likely to have conditions for which it is especially expensive to provide health care. Even within specific diagnostic categories, the SSI group tends to have conditions that are more costly to treat. This suggests increased severity in the diagnosis of those entering Medicaid through SSI, when compared to those entering Medicaid through AFDC or another pathway.

**High-Cost Medicaid Beneficiaries,
Eligible through SSI or Other Pathway**
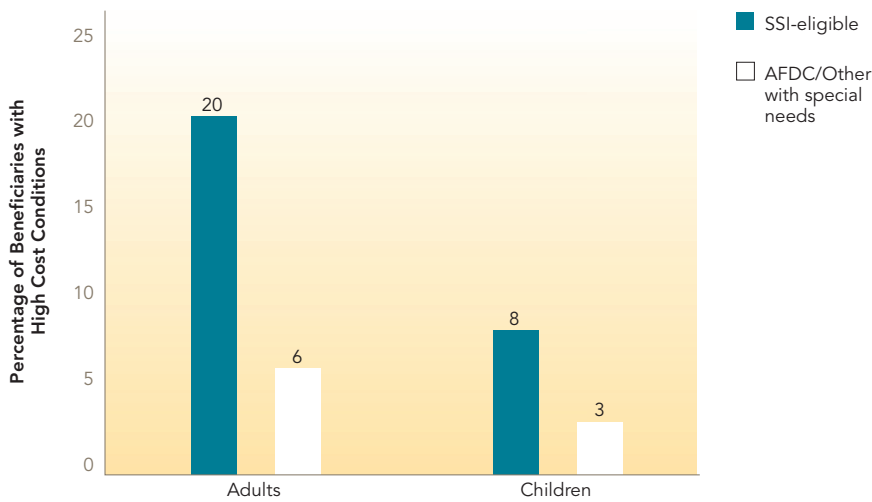
Note: "High-cost" were defined as those conditions the CDPS classifies as high-cost or very high-cost, including, AIDS, organ transplants, lung cancer, cystic fibrosis, schizophrenia, and quadriplegia, for example.

SSI-eligible Medicaid beneficiaries with chronic or disabling conditions are more likely to have high-cost conditions than beneficiaries entering Medicaid by other pathways.

Distribution of Beneficiaries with Chronic or Disabling Psychiatric Conditions by Costliness of Diagnosis

SSI-Eligible Adults

AFDC/Other Eligible Adults

Low Cost
53%

High Cost
41%

Medium Cost
6%

High Cost **9%**
Medium Cost **5%**
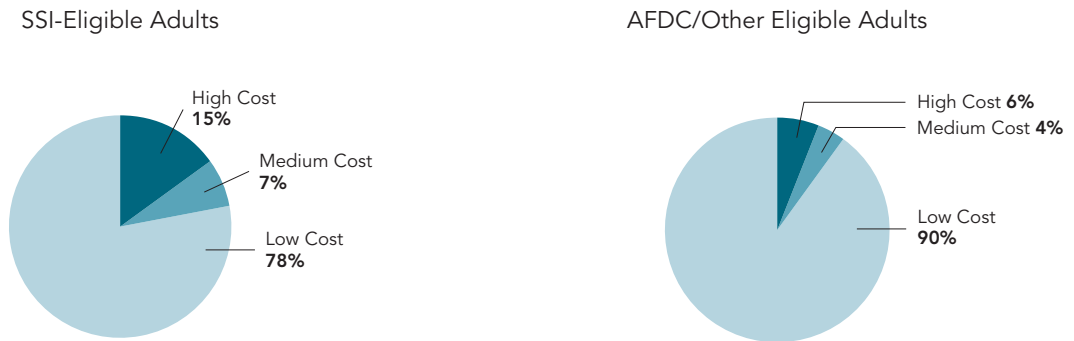
Low Cost
86%
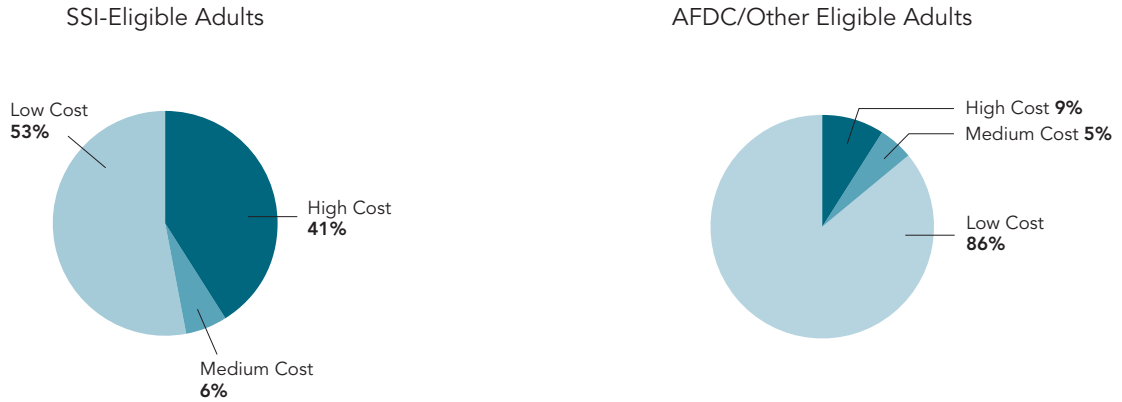
SSI-eligible Medicaid beneficiaries with chronic or disabling psychiatric conditions are more likely to have high-cost psychiatric conditions than beneficiaries entering Medicaid by other pathways.

Distribution of Beneficiaries with Chronic or Disabling Pulmonary Conditions by Costliness of Diagnosis

SSI-Eligible Adults

AFDC/Other Eligible Adults

High Cost
15%

Medium Cost
7%

Low Cost
78%

High Cost **6%**
Medium Cost **4%**

Low Cost
90%

SSI-eligible Medicaid beneficiaries with chronic or disabling pulmonary conditions are more likely to have high-cost pulmonary conditions than beneficiaries entering Medicaid by other pathways.

Policy Implications

1. *Chronic or disabling mental and physical conditions often co-exist in the same individuals. Therefore, the coordination of care for mental and physical conditions becomes a high priority.*

Effective coordination of medical care and mental health treatment reduces utilization and costs. However, mental health care often is provided through separate delivery systems, and due to confidentiality concerns, there may be little sharing of information about ongoing treatment. Coordination of such care seems especially challenging when mental health care is carved out under a managed care arrangement.

2. *Many beneficiaries with special health care needs enter Medicaid through eligibility pathways other than SSI.*

Managed care programs that enroll only the AFDC (now TANF) population must be structured to support individuals with special health care needs. These programs must include safeguards enabling such individuals to obtain needed services (such as care coordination).

3. *There is a lack of reliable encounter data for managed care populations to perform the types of analyses shown here.*

As more of the Medicaid population is enrolled in mandatory managed care programs, policymakers and program officials need to know whether they are purchasing services that meet the needs of the population and whether they are getting value for their investment. Utilization and expenditure data are required to provide policymakers with data on how well their programs are working, particularly for those with special needs, and whether payment changes are justified due to changes in case mix, costs and utilization patterns.

4. *Medicaid purchasing should meet the needs of people with special health care needs.*

As states enroll more Medicaid beneficiaries in mandatory Medicaid managed care programs, policymakers and program officials should determine whether they are purchasing services that meet the needs of beneficiaries with chronic and disabling conditions. They should judge how much value their state and beneficiaries are getting for their investment. Data on service use and expenditures are required to provide policymakers with useful information on how well their programs work.

Reach and Serve

The Livios, who reside in New Jersey, have five children. Jane is a high-school graduate who worked as a legal secretary until she quit in 1986 to raise her children. Her husband works third shift stocking shelves in a grocery store.

The Livio's son Casey, who is now three, was born with serious physical problems, including bowel decay and a heart defect. When he was only 48 hours old, he underwent an ileostomy (removal of the upper bowel) and a colostomy procedure. At two months of age, Casey had surgery to repair a heart defect. The heart operation and later removal of the colostomy bag both resulted in a build-up of fluid around the heart. When he was seven months old, his doctors placed a pericardial window in his heart to help drain the fluid.

The barrage of surgeries on his tiny torso and an unrecognized milk allergy kept Casey from gaining much-needed weight in his first year. When he weighed in at only nine pounds in his eighth month, a gastroenterologist was consulted and Casey was subsequently put on a feeding tube. He now weighs about 21 pounds, and he is just starting to eat adult food.

Through Casey's first year of multiple surgeries and doctors' visits, the Livios were receiving Medicaid through an expansion as part of the welfare-to-work transitional program. Jane says no one assisted her when she enrolled in Medicaid. "It was automatic because we were on welfare," she recalls. But to enroll, she had to go to her social services agency and apply. She was told that the HMO was mandatory at that time, and she had a choice of three. Jane does not feel she made an educated choice—she just picked one and no one helped her decide. She reviewed the handbooks and they all seemed similar.

While her husband was without a job, they received Medicaid; when he gained employment again, they went on extended Medicaid. But now that he has been working for a while, they are no longer eligible for Medicaid. Casey's doctor bills are very high, and his father's job does not offer an adequate health insurance benefit. Despite his special health care needs, Casey is not eligible for Supplemental Security Income benefits. Jane applied and was denied.

◄

Jane and Casey Livio

Improving Outreach, Enrollment, and Access
Outreach and Enrollment

In many states, Medicaid beneficiaries with special health care needs are given the option of entering a managed care plan. Ideally, outreach and enrollment for these plans should be coordinated, but this has challenged states. Advocates for people with disabilities are concerned that the complexities of the managed care enrollment process inhibit access for individuals with special needs. There are a variety of steps states should take to improve outreach, access and ultimately, enrollment efforts.

States with Medicaid Managed Care Programs Enrolling Non-Elderly Persons with Chronic Illness and Disabilities[1]

Alabama	Kentucky	Ohio
Arizona	Louisiana	Oregon
Arkansas	Maryland	Pennsylvania
California	Massachusetts	South Carolina
Colorado	Michigan	South Dakota
Delaware	Mississippi	Tennessee
District of Columbia	Montana	Texas
Florida	Nebraska	Utah
Georgia	New Jersey	Vermont
Idaho	New Mexico	Virginia
Indiana	New York	West Virginia
Kansas	North Carolina	Wisconsin

Most states' Medicaid programs have low managed care enrollment rates. Increasing this level of enrollment will require more active consumer outreach and enrollment efforts and more of a collaborative relationship between states and managed care organizations.

When states enroll people with special health care needs in Medicaid, they must consider many issues. These individuals are often geographically or socially isolated. Many also are non-English speaking. States generally inform beneficiaries about their program through the mail. However, there are many additional mechanisms states can use to reach out to this group.

States with the highest enrollment tend to be more creative in reaching out to populations with special health care needs. The following table outlines a variety of approaches to outreach and enrollment.

[1]   Source: Kaiser Commission on Medicaid and the Uninsured, December 1998.

Approaches to Disseminating Medicaid Managed Care Enrollment Information to all Medicaid Recipients

Approach	# of States Using		Which States Do?
	Yes	No	
Group Orientation Sessions	18	6	Most, but not Hawaii, Ill., Mont., N.Mex., Okla., Oreg.
Health Fairs/Community Events	20	4	Most, but not Mass., Mont., Nev., Oreg.
Telephone Hotline Recordings	9	15	Ariz., Hawaii, Ind., Mass., N.Mex., Ohio, Okla., Vt., W.Va.
Video Presentations	15	9	Ariz., Conn., Ind., Mass., Mo., Mont., N.J., N.Mex., Ohio, Okla., Tex., Utah, Va., Vt., Wash.
Posters at:			
Eligibility Offices	20	4	Most, but not Hawaii, Ill., Utah, Va.
Provider Sites	12	12	Calif., Conn., Del., Ga., Ind., Maine, Mo., Mont., N.J., Oreg., Vt., W.Va.
Community Centers	12	12	Conn., Del., Ga., Maine, Mass., Mo., N.J., Ohio, Oreg., Tex., Vt., Wis.
Commercial Sites	3	21	Maine, Oreg., Vt.
Brochures at:			
Eligibility Offices	22	2	Most, but not Ill., W.Va.
Provider Sites	12	12	Calif., Conn., Del., Ga., Ind., Mo., Mont., N.J., Oreg., Pa., Vt., W.Va.
Community Centers	12	12	Calif., Del., Ga., Hawaii, Mass., Mo., N.J., Ohio, Oreg., Pa., Tex., Vt.
Broadcast Media			
Press	8	16	Calif., Conn., Ind., Mass., Mo., Tex., Vt., W.Va.
Radio	12	12	Calif., Conn., Ind., Maine, Mass., Mo., Mont., Ohio, Pa., Tex., Vt., W.Va.
Television	9	15	Calif., Conn., Ind., Maine, Mass., Mo., Mont., Tex., Vt.

Note: Among 24 respondent states

*States not responding about specific approaches are counted in the "No" column.

Source: Kenesson, M. Medicaid Managed Care Enrollment Study: Report of Findings from the Survey of State Medicaid Managed Care Programs. Center for Health Care Strategies, December 1997.

Policy Issue: *States' Medicaid managed care programs should adapt enrollment and outreach policies for people with special health care needs.*

In addition to outreach, there are enrollment issues related to people with special health care needs that states should consider:

- *Allow Family Members to Enroll in Different Plans.* Many states require all family members on Medicaid to enroll in the same health plan. Since some plans do not have experience serving people with special health care needs, states should provide exemptions to this requirement.

- *Extend the Window for Enrollment.* There are many factors that a person with special health care needs has to consider before selecting a plan, such as, provider network, office location, and physical accessibility. Obtaining all this information can take time. States should extend the enrollment period for people with special health care needs, and authorize extensions upon request.

- *Train Enrollment Brokers.* States should provide guidelines to enrollment brokers to facilitate plan selections for people with special health care needs.

- *Customize Orientation Activities.* States should redesign orientation tools. Steps taken might include producing documents in large typeface, in Braille, and translation for non-English populations; providing interpreters and TTY machines for the hearing impaired; and holding orientation meetings in handicap-accessible locations that can be reached by public transportation.

- *Incorporate Needs Assessment Survey During Enrollment.* States could design a needs assessment survey to evaluate a person's conditions during enrollment.

Policy Issue: *States, agencies, and plans should define "access" to help them determine whether Medicaid managed care is meeting the needs of people with chronic illnesses and disabilities.*

Accessing Care

Many consumers, advocates, and state officials express concern about the effect of Medicaid managed care on access for people with special health care needs. Access is a broad term, but in general, encompasses five characteristics:

- Availability
- Accessibility
- Accommodation
- Affordability
- Acceptability

People with special needs on Medicaid encounter many barriers to health care. They must overcome physical distances and sometimes contend with a small supply of physicians, especially primary care physicians, in rural and inner-city areas. Administrative impediments to access include long lines, busy phones, limited business hours, co-payments or deductibles, and complicated forms. States and plans also should make provider network information more readily available to beneficiaries.

Many states have developed special access strategies for this population, which address these issues at least in part. These strategies include:

- Requiring providers to offer care for special needs individuals.
- Allowing specialists to serve as primary care practitioners.
- Allowing standing referrals to specialists.

Number of People with Spinal Cord Injury*
Reporting Various Levels of Difficulty Getting Care
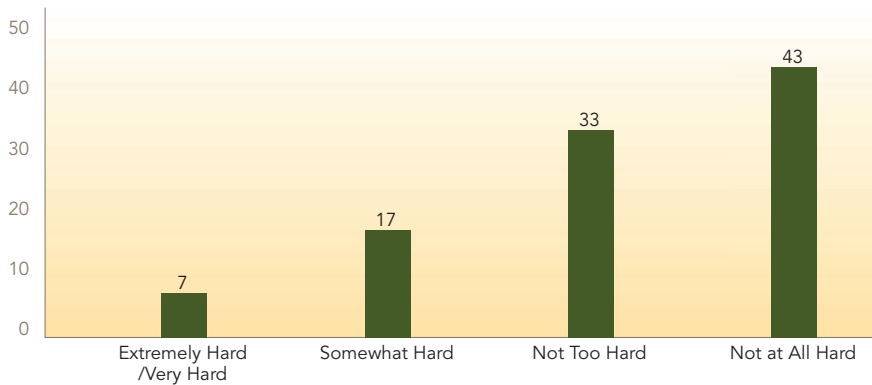
*Out of 100 people surveyed.
Source: Massachusetts Survey of Secondary Conditions, MDPH, 1997.

As demonstrated in the above graph, nearly a quarter of people with spinal cord injury in this sample experienced difficulty accessing care.

Care

Paula Connolly is a single mother of four children living in West Des Moines, Iowa. She has a 14-year-old, 11-year-old twins, and a nine-year-old son, Aaron. Early on, Aaron's doctors diagnosed him with significant developmental problems, including severe cognitive delay. They subsequently identified him as having Neuhauser Syndrome, an extremely rare genetic disorder characterized by distinctive abnormalities of the eyes, altered muscle tone, and mental retardation.

Aaron did not walk until he was six years old, his muscles are hypotonic (flaccid), and he receives feedings through a tube implanted in his stomach. He cannot speak, so he communicates with some signing and a voice-output device. He is prone to seizures and uses a wheelchair. At the age of nine, Aaron has the skill levels of a two-year-old.

Paula's major support system is her parents. They moved back to Des Moines to help out with Aaron. Short-term relief through respite care has been a significant help as well. "Aaron has had the same two respite providers for a long time," says Paula. "They are like family."

After Paula learned that Aaron had special needs, she began hearing about services from other parents of special needs children—but not from her case manager. She felt she needed to be proactive and find information for herself. Paula says that her case manager calls her four times a year "to see how things are going."

Because she owns a home and another property, Paula is not eligible for Supplemental Security Income. Aaron qualifies for Medicaid because of his special needs, and has been a recipient for about seven years.

Because Paula works for the state, she learns about most of the services for which she qualifies from her job. Paula feels lucky that her job is very flexible. She says the nine-to-five career track does not work when you have a child with special needs.

◄

Paula and
Aaron Connolly

Redesigning Health Care for People with Special Needs

With the emphasis of managed care on prevention, on having a medical home, and on using a primary care provider (PCP), people with chronic illnesses and disabilities tend to rely on fee-for-service arrangements to meet their special-ized health care needs. As states enroll these individuals in managed care, the basic premises of care must be redefined to meet these populations' needs.

Policy Issue: *States' Medicaid managed care programs should consider allowing specialists to serve as primary medical providers for people with special health care needs.*

For example, certain services that are not typically part of a managed care ben-efit package are essential for people with special health care needs. These serv-ices may include the use of home health aides, personal care attendants, adult day care, and direct access to specialty care. In addition, people with special health care needs often regard their specialist as their main medical provider, since PCPs are not always experienced with these medical conditions. This presents a challenge when they enter a managed care plan that does not allow direct access to specialty providers without referral from a PCP.

Specialty Physicians Usually Seen by People with Spinal Cord Injury as their Main Medical Provider
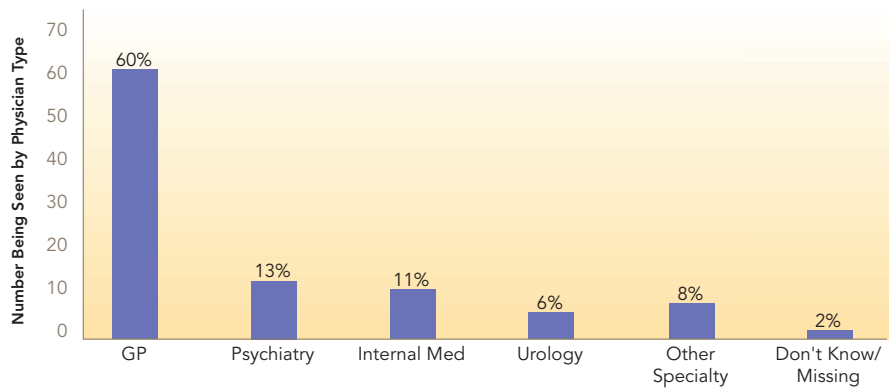
Note: Total out of 67 that listed an MD as their primary care provider.

An obvious solution to this problem would be for managed care organizations to allow people with chronic illnesses and disabilities to use their specialist as their main source of medical care, in effect as their PCP. By definition, most specialists do not provide primary care, including routine screenings and immunizations and general care coordination. Specialists' training could be enhanced to include general primary care elements. Alternatively, managed care organizations (MCOs) could recruit PCPs to their network who have experience with special health care needs.

A further challenge of enrolling people with special needs in managed care is its potential to interrupt existing provider-patient relationships. MCOs will want to create as large a provider network as possible to avoid this, or, in certain circumstances, allow individuals to use an out-of-network provider, without financial penalty.

MCOs may also want to consider flexible gatekeeping arrangements. These arrangements allow access to certain services (i.e., outpatient mental health or school-based services) on a limited basis without prior authorization from a PCP.[1]

Spotlight on the States:

New Jersey

The New Jersey Department of Human Services recently completed a three-year planning process for Medicaid managed care for people with developmental disabilities. The plan makes important special needs accommodations:

- Clients may opt out of managed care, if networks do not include necessary health care providers.

- Specialists may serve as primary medical providers.

Policy Issue: *Managed care should revise definitions of preventive care for people with special health care needs.*

Managed care emphasizes regular visits to a primary care provider and the practice of preventive medicine by PCPs. But prevention guidelines require modification for persons with special health care needs. Goals for this population include avoiding complications or exacerbation of existing conditions as well as basic disease prevention or management.

People with special health care needs frequently use ancillary services, such as rehabilitation therapy, durable medical equipment, pharmacy, infusion therapy, respite care, personal care attendants, adaptive equipment, and long-term mental health. Most MCO networks provide these services, but with a cap on the quantity of services per year. Chronic conditions may call for a level of services that exceed these limits.

As part of a preventive care package, MCOs might consider offering people with disabilities expanded access to these services. The continued and uninterrupted use of some of these services is often critical to maintaining a person's health status, and to avoiding the cost and suffering that comes with deteriorating illness and disability. Care coordination can serve as the MCO's method for monitoring service use for this higher risk group.

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1   McManus, M. and Fox, H. "Enhancing Preventive and Primary Care for Children with Chronic or Disabling Conditions Served in Health Maintenance Organizations." *Managed Care Quarterly,* 1996; 4(3): 19-29.

<div style="background:#f8f5d0">

Policy Issue: *States should consider ways to compensate family caregivers and provide them enhanced respite care packages.*

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A "caregiver" provides assistance to someone with a medical condition. Caregivers can be volunteers or paid and are associated with a service system. However, family members, friends, and others often serve as caregivers as well. As of 1997, there were roughly 25 million family caregivers in the United States, providing about 85 percent of all home care services, at a value of $300 billion annually.[2]

For people with disabilities and chronic illnesses who need assistance with activities of daily living, having a family member provide care is often a welcome alternative. But for the caregiver, who may work a full- or part-time job in addition to caring for their relative, this added responsibility can be quite burdensome.

Community-Based Living Arrangements Among Adults with Chronic Conditions on Medicaid, Ages 18-64

Lives alone
Lives with spouse
Lives with relatives
Lives with non relatives

15.5%
2.4%
50.9%
31.2%
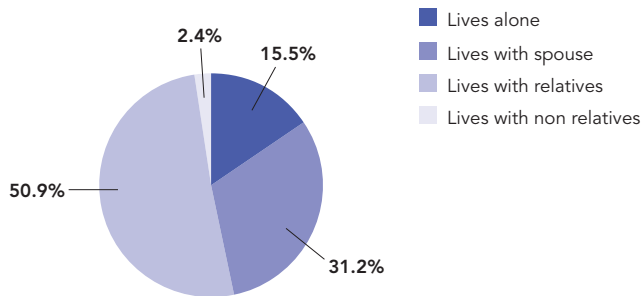
Source: 1994/95 NHIS-D. Adult Followback Survey. Weighted data.

Community-Dwelling Adults with Special Needs on Medicaid with Unmet Need for Help with Personal Care Activities

Walking	Transferring	Bathing	Toileting	Dressing	Managing Medication
19%	18%	16%	16%	13%	10%
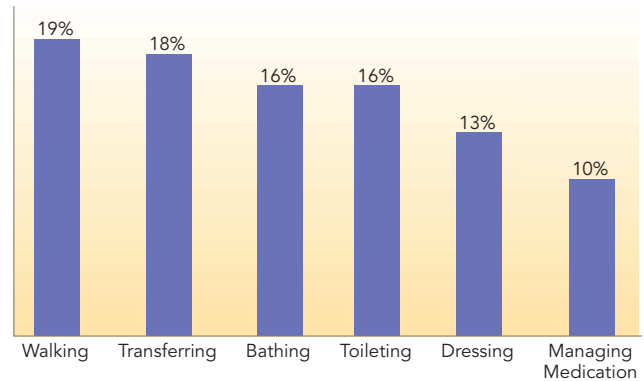
Source: 1994/95 NHIS-D. Adult Followback Survey. Weighted data.

In order to alleviate part of this burden, some state Medicaid programs, including those in Michigan and California, allow the hiring of family members as formal, paid service providers. Other states, including Maryland and New York, prohibit this practice. The issue remains controversial. Critics claim that paying family caregivers could undermine traditional societal expectations that families provide care informally. Most states currently permit—albeit in varying degrees—family members to be paid providers in at least one public program.[3]

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2   Family Caregiver Alliance Newsletter, Summer 1997.

3   Doty, P., Kasper, J., and Litvak, S. "Consumer-Directed Models of Personal Care: Lessons from Medicaid." *The Milbank Quarterly*, 1996: 74(3): 377-409.

Family caregivers are typically dedicated to caring for their relative. However, they are usually not trained health care practitioners, and many are unpaid. As a result, some personal care activities may not be satisfied. Medicaid agencies could consider developing a training and reimbursement program for family members who are willing to be primary caregivers for relatives with chronic illnesses and disabilities.

Policy Issue: *States should guarantee adequate transportation for Medicaid beneficiaries with special health care needs.*

Federal Medicaid regulations require states to "ensure necessary transportation for recipients to and from providers." Transportation is one of the activities-of-living categories that can most directly affect health, because it is necessary to access care outside the home. Most states meet the transportation requirement by enlisting transportation providers—usually taxis and private medical vans—and paying them whenever they transport Medicaid recipients. But, despite these steps and the federal mandate, many Medicaid beneficiaries report transportation as an area of unmet need.

A recent survey by the Community Transportation Association of America reports that almost 50 percent of states with Medicaid managed care programs do not include nonemergency transportation services under Medicaid managed care plans. These 23 states rely on non-monitored fee-for-service arrangements to fulfill their federal obligations to ensure access to care. The remaining states have developed newer approaches that can be grouped into three general categories:

- Transportation Brokerage—Verifies eligibility of plan enrollees who need transportation, and arranges and pays for transportation (programs in Ark., Fla., Ga., Ky., Md., Mass., Mich., Oreg., Vt., and Wash.)

- Administrative Manager—State Medicaid agency staff (as opposed to a private entity) assumes the gatekeeper's role or contracts out some administrative responsibilities (programs in Ala., Id., La., Md., Mich., Mont., N.Mex., N.Y., and Oreg.)

- Capitated Transport Services—Responsibility for transporting Medicaid enrollees is transferred to a managed care provider (experience in Ariz., Mo., R.I. and Tenn.)

Selected Family Caregiver Statistics, 1999

- Family members and friends provide 85 percent of all home care. The average age of caregivers is 57.

- Adult children make up about 75 percent of caregivers in African-American and Latino families, and 40 to 60 percent of caregivers in Caucasian families.

- An estimated 14.4 million full-and part-time workers are balancing caregiving and job responsibilities.

- Some 80 percent of caregivers provide unpaid assistance seven days a week.

- Between 20 and 40 percent of caregivers have children under age 18 to care for in addition to their disabled relative.
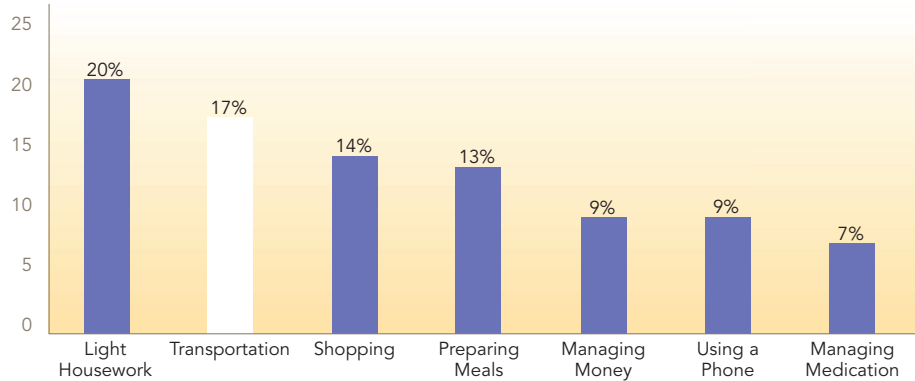
Source: Family Caregiver Alliance Clearinghouse, 1999.

Community-Dwelling Adults with Special Needs on Medicaid with Unmet Need for Help with Instrumental Activities of Daily Living

Source: 1994/95 NHIS-D. Adult Followback Survey. Weighted data.

Redefining Medical Necessity

Medical necessity criteria are used by all managed care organizations to authorize or deny medical treatments. Every day, MCOs make decisions about whether to authorize payment for medical benefits, ranging from surgeries to prescription drugs. If the recommended service is a covered benefit, the next consideration used to authorize payment is whether the benefit is medically necessary.

There is currently no federal definition of medical necessity, so it is the prerogative of each plan or state to establish its own definition. Contractual definitions generally require that services apply to illness, injury or pregnancy; are consistent with generally accepted medical practice; are not primarily for the providers' or patient's convenience; and are the most efficient way to safely treat the problem.[4]

Policy Issue: *When designing medical necessity criteria for Medicaid, states and plans should be flexible to accommodate individuals with special health care needs.*

As states implement Medicaid managed care programs, definitions of medical necessity are being written or revised in state Medicaid statutes, regulations, and contracts with managed care organizations.[5]

4   Medicare Part B: Definition of Medical Necessity, December 1989.
5   National Health Law Program, August 1998.

In drafting medical necessity criteria, states must pay particular attention to the special needs of people with chronic illnesses and disabilities. Definitions should be comprehensive and allow for coverage of services that will not necessarily cure or correct a physical or mental condition. However, services that improve independent living and prevent institutionalization should be positioned as medically necessary.

For states revising medical necessity criteria, the National Health Law Program—a public-interest law firm that seeks to improve health care for America's working and unemployed poor, minorities, elderly, and people with disabilities—offers a comprehensive model definition. This definition is noteworthy because it includes those routine services that people with disabilities require in order to maintain their current level of functioning.

> The health plan must provide all medically necessary care, including services, equipment, and pharmaceutical supplies. Medically necessary care is the care which, in the opinion of the treating physician, is reasonably needed:
>
> - To prevent the onset or worsening of an illness, condition, or disability;
>
> - To establish a diagnosis;
>
> - To provide palliative, curative, or restorative treatment for physical and/or mental health conditions;
>
> - To assist the individual to achieve or maintain maximum functional capacity in performing daily activities, taking into account both the functional capacity of the individual and those functional capacities that are appropriate for individuals of the same age.
>
> Each service must be performed in accordance with national standards of medical practice generally accepted at the time the services are rendered. Each service must be sufficient in amount, duration, and scope to reasonably achieve its purpose; and the amount, duration, and scope may not arbitrarily be denied or reduced solely because of the diagnosis.

Defining medical necessity is an attempt to apply collective norms to medical treatment. This is much more difficult for persons with chronic illnesses or disabilities.

Definition of Medically Necessary Services (or Medical Necessity)

An Example:
Horizon Mercy HMO of New Jersey

Services or supplies necessary to prevent, diagnose, correct, prevent the worsening of, alleviate, ameliorate, or cure a physical or mental illness or condition; to maintain health; to prevent the onset of an illness, condition, or disability; to prevent or treat a condition that endangers life or causes suffering or pain or results in illness or infirmity; to prevent the deterioration of a condition; to promote the development or maintenance of maximal functioning capacity in performing daily activities, taking into account both the functional capacity of the individual and those functional capacities that are appropriate for individuals of the same age; to prevent or treat a condition that threatens to cause or aggravate a handicap or cause physical deformity or malfunction, and there is no other equally effective, more conservative or substantially less costly course of treatment available or suitable for the enrollee. The services provided, as well as the type of provider and setting, must be reflective of the level of services that can be safely provided, must be consistent with the diagnosis of the condition and appropriate to the specific medical needs of the enrollee and not solely for the convenience of the enrollee or provider of service and in accordance with standards of good medical practice and generally recognized by the medical scientific community as effective. Course of treatment may include more observation or, where appropriate, no treatment at all. Experimental services or services generally regarded by the medical profession as unacceptable treatment are not medically necessary for purposes of this contract.

Source: NJ Physical Health Contract with Horizon Mercy, 1999.

Integrate

Robert Benvenuti and Fernando Garcia have been partners for many years. Fernando discovered that he was HIV positive in 1990. When his condition rapidly deteriorated into AIDS, he developed severe dementia, leaving him unable to care for himself.

For the past ten years Robert has stood by Fernando's side, sharing care-giving duties with home health aides and helping Fernando obtain Medicaid benefits. When he is not taking care of Fernando, Robert attends nursing school and works in a hospital near Boston.

Fernando first enrolled in Medicaid while he and Robert were living in New York. A hospital social worker helped him apply for SSI/SSDI and Medicaid. When the pair moved to Massachusetts, it took a long time to figure out what services, other than Medicaid, they qualified for — there was no central place for them to find information. Even now, Robert is sure there are services they could be receiving, but he doesn't know how to find out what is available and how to apply. If they were to move to a new state, he says it would be "a maze" to figure out.

Other than home health aides, Robert has no relief from his daily routine of caring for Fernando. AIDS Action provided a respite worker when Fernando and Robert first moved to Boston, but they lost touch and the agency cannot find a replacement. Most of Fernando's family members live in Texas, too far to offer day-to-day assistance.

Robert tries to take Fernando's illness progression one day at a time. He doesn't worry about the little things much anymore. Everything else seems trivial.

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Robert Benvenuti and
Fernando Garcia

Integrating Multiple Service Systems
Reducing Fragmentation

People on Medicaid—in particular, those with special health care needs—are vulnerable: Many are not only in need of medical coverage, but a substantial number require social services. Almost all are poor.

Policy Issue: *Sources of services and care for individuals with special health care needs on Medicaid are fragmented. Managed care has the potential to coordinate care across multiple services and systems.*

Although state government is the largest purchaser of services for people with chronic illnesses and disabilities, there are myriad additional public and private agencies paying for services, or providing them directly, to support these individuals in the community. Thanks to a variety of federal legislation, many public services exist for people with special health care needs, including:

- Special Child and Adult Health Services
- Supplemental Nutrition Program for Women, Infants and Children (WIC)
- Early Intervention Services
- Department of Education
- Department of Labor, Division of Vocational Rehabilitation
- Division of Developmental Disabilities
- Department of Juvenile Justice
- Division of Youth and Family Services
- Division of Mental Health Services

While there are many sources of assistance for people with special health care needs on Medicaid, most states manage these services separately from one another, creating a fragmented system. The following graph depicts the broad range of services used by people with special health care needs. All these services are reimbursed by Medicaid and can potentially be coordinated through case managers in managed care organizations. These public and private entities are often disconnected and may have different eligibility criteria, making care coordination difficult.

Adults (Ages 18-64) with Chronic Conditions on Medicaid who received Community-Based Services within a 12-Month Period
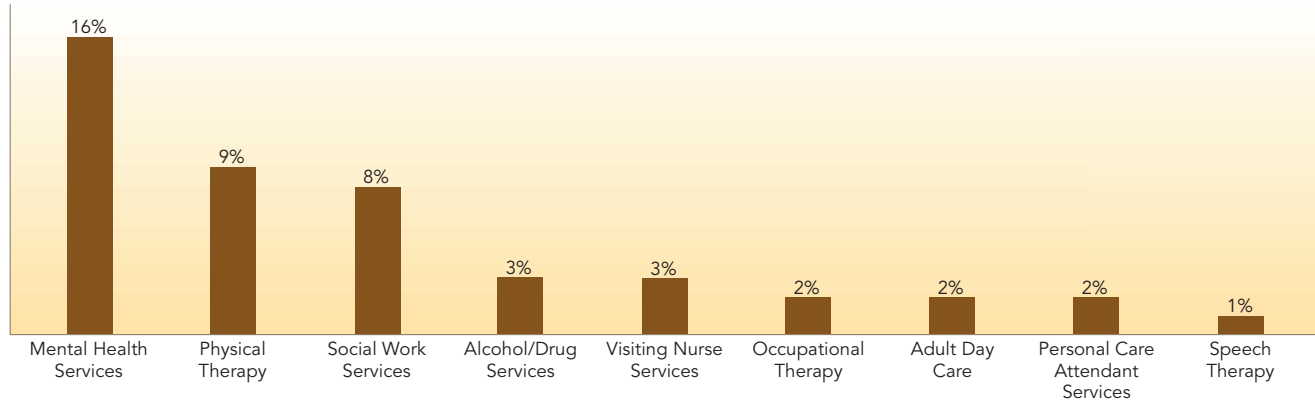
Source: 1994/95 NHIS-D. Adult Followback Survey. Weighted data.

Policy Issue: *States could house social and health services programs used by people with special health care needs under the umbrella of a single state agency (i.e., Medicaid agency). Integrating multiple social service agencies, thereby blending services, funding, and case management, is another option.*

The technical, bureaucratic, and political obstacles to integrate funding streams are formidable. These obstacles include turf battles that invariably exist between agencies, complicated by the need for funding continuity for the services they provide.[1] Despite the challenges, some states have integrated services for certain vulnerable groups.

Additional forms of coordination between state Medicaid agencies and other state agencies include:

- formal interagency agreements;
- joint requests for proposals;
- coordinated requests for proposals;
- contract between the Medicaid agency and another state agency to assign respective purchasing and monitoring responsibilities;
- shared administration;
- fund pooling, under a capitated or fee-for-service payment system;
- shared data;
- advisory group to other agency;
- regularly scheduled meetings.

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1   Interview with Lisa Clements, Ph.D., Director of the Interdepartmental Initiative for Children with Severe Needs, State of Missouri.

While some states are starting to integrate multiple service systems for children, there is very little corresponding activity for adults with special health care needs.[2] This is due in part to the variable levels of coverage available to adults with chronic illnesses and disabilities (especially those with a compounding diagnosis of substance abuse) across the country.

Case Management/Care Coordination

Policy Issue: *Case management and care coordination can ease the transition of Medicaid beneficiaries with special health care needs from fee-for-service to managed care. However, case management alone isn't always the answer—some case managers have too many clients. A balance among resources is needed.*

Medicaid agencies nationwide have practiced both case management and care coordination. These efforts address the need to integrate multiple service systems. When a state contracts with a managed care organization to deliver services, they expect the managed care organization to be responsible for case management/care coordination activities.

Case management may be formal or informal, and can occur at the state or plan level. Case management is the function of coordinating health, substance abuse, mental health, and social services, by linking clients with appropriate services to address specific needs and achieve stated goals.[3]

A case manager:

- provides the client with a single point of contact for multiple health and social services systems (with social services addressing a range of issues including physical limitations to housing, mental health, pregnancy, speech therapy, and nutritional assistance);

- advocates for the client;

- is flexible, community-based, and client-oriented;

- assists the client with needs generally thought to be outside the realm of health care.

Case managers in states typically transcend interagency boundaries. This function helps agencies complement one another, enabling them to provide more complete services to clients.

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2 Interview with Charlotte McCullough, Child Welfare League of America.

3 Substance Abuse and Mental Health Services Administration. *Comprehensive Case Management for Substance Abuse Treatment.* 1998.

A state may provide optional, targeted case management services to recipients under its Medicaid State plan. The Medicaid statute enables states to reach out beyond the Medicaid program to coordinate a broad range of activities and services necessary to improve the health of a Medicaid client. States desiring to provide these case management services may do so by amending their state plans.

There are currently 13 states that use targeted case management. Eleven of these states use the approach for their SSI population. Nineteen states conduct administrative case management (case management not targeted to a particular group); of these, 13 states practice case management with their SSI population.

States with Targeted Case Management	Ariz., Colo., D.C., Fla., Iowa, Ind., Ky., Mass., Mont., Okla., Pa., Tenn., Wis.
States with Targeted Case Management of SSI Population	Ariz., Colo., D.C., Fla., Iowa, Ind., Ky., Mass., Mont., Pa., Wis.

The Impact of Case Manager Contact: Reducing Unmet Need for Services Among HIV-Infected Persons on Medicaid

Legend:
- Unmet Need for Emotional Counseling
- Unmet Need for Home Health Care

Case Manager Contacts	Unmet Need for Emotional Counseling	Unmet Need for Home Health Care
0	33%	24%
1-5	29%	22%
6-11	28%	10%
12 or more	17%	12%
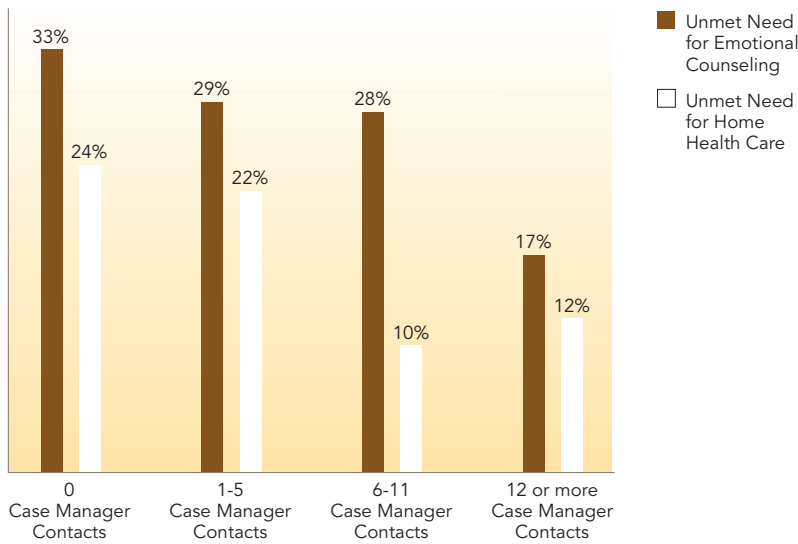
Source: HIV Cost and Services Utilization Study. Weighted data, 1999.

Spotlight on the States:

Maryland
The HealthChoice Program in Maryland requires all participating health plans to designate Special Needs Coordinators to serve as the plans' points of contact for persons with special health care needs.

Oregon
Oregon requires plans participating in the Oregon Health Plan to designate Exceptional Needs Care Coordinators to serve as advocates and points of contact for SSI-eligible enrollees and others with special needs.

Policy Issue: *Sources of services and care for individuals with special health care needs on Medicaid are fragmented. Managed care has the potential to coordinate care across multiple services and systems.*

Like case management, care coordination is used by states to ease the transition of Medicaid beneficiaries from fee-for-service to managed care. Case management and care coordination are similar activities, but can be distinguished by their scope. Typically, a case manager has a clinical background and focuses foremost on the medical needs of high-cost/high-risk patients. Care coordinators typically have backgrounds in social work and concentrate on the spectrum of medical and social services required by people with special health care needs.[4]

Features of Case Management vs. Care Coordination in Medicaid Managed Care

Features	Case Management	Care Coordination
Objective	Contain costs	Facilitate access
Target Population	High-cost/high-use patients	High-risk populations
Organizational Location	Utilization management	Quality assurance
Functional Orientation	Prior authorization	Problem solving
Model	Medical model	Social service model
Context	Health care context	Psychosocial context
Services	Covered services	Covered and noncovered services
Nature of coordination	Promote coordination and communication across disciplines within the organization delivering medical care	Promote coordination of social support and medical services across different organizations and providers

4   From an interview with Neva Kaye, National Academy for State Health Policy, June 1999.

Some states require managed care organizations to provide care coordinators for their Medicaid special needs populations. Other states have at least one managed care organization that provides care coordinators.[5]

Care Coordination Arrangements in States

Plans must provide care coordinators	Ala., Calif., Conn., D.C., Fla., Hawaii, Ind., Ky., Mass., Maine, Minn., Mont., N.Y., Ohio, Okla., Oreg., Pa., R.I., S.C., Tex., Utah, Vt., Wis.
At least one plan provides care coordinators	Del., D.C., Iowa, Ill., Kans., Mo., N.C., N.Dak., Nebr., N.H., N.Mex., N.Y., Tex., Va., Wis., W.V.
Plans must provide care coordinators for SSI population	Ala., Calif., Fla., Conn. (children only), Ind., Ky., Mass. (children only), Mont., N.Y., Oreg., Pa., S.C., Tex., Utah, Vt., Wis.
At least one plan provides care coordinators for SSI population	Del., Iowa, N.C., Nebr., N.Mex., Va.

Managed care organizations vary widely in their care coordination models. There are three most common approaches:

- **Centralized Team Model.** The care coordinator is the central contact for all Medicaid beneficiaries and screens members before assigning them to a nurse-social worker case management team. The team coordinates beneficiaries' medical and psychosocial service needs.

- **Regionalized Model.** The care coordinator screens beneficiaries and assigns a nurse case manager based in the member's geographic region. The nurse case managers coordinate care across various providers in that region.

- **Provider-Based Model.** The MCO assigns provider groups to identify, assess, and monitor members, and to plan and coordinate their care. A provider group physician determines which enrollees are eligible for care coordination. The nurse case manager, who is employed by the medical group, monitors beneficiaries' progress and facilitates access to medical and social services. The health plan care coordinator may provide referral or administrative support as needed.[6]

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5   National Academy for State Health Policy. *Medicaid Managed Care: A Guide for States.* March 1999.

6   Rosenbach, M. and Young, C. *Care Coordination in Medicaid Managed Care: A Primer for States, Managed Care Organizations, Providers, and Advocates.* Center for Health Care Strategies. July 2000.

E m p o w e r

John Kelly suffered a severe spinal cord injury in an automobile accident in January 1984, leaving him paralyzed from the neck down. He had insurance at the time, but was advised to enroll in Medicaid as soon as possible.

Individuals like John who become paralyzed are susceptible to a variety of complicating conditions that typically increase care needs and costs exponentially. John has a number of these secondary conditions: He is prone to urinary tract infections, irregular bowel and bladder, ulcers, breathing problems, hypothermia, and osteoporosis. In addition, he occasionally experiences skin breakdowns and low blood pressure.

John nevertheless manages to live on his own and maintain an active social life, with friends that he visits and vice versa. He regularly sees his girlfriend who lives nearby in western Massachusetts.

To facilitate his care needs, John participates in the Medicaid-sponsored Personal Care Attendant (PCA) program. He works out his own schedule and hires people. Medicaid funds him for 78 hours of care per week. He feels he gets enough hours of care, but not enough to pay for them adequately.

"The PCA program is very oppressive, but it's better than living in a nursing home or with parents," says John. "It's hard to find people. The solution is higher wages for attendants and less prejudice toward people with disabilities." He has fired his attendants before, but never received training in how to hire, fire, or manage these assistants. He wants to find people who understand their role as an employee, but who are still caring.

John is determined to maintain his independence. He worked from 1986 to 1989 as a peer counselor at Boston Self-Help and the Boston Center for Independent Living and is currently a Ph.D. candidate at Brandeis University.

◀

John Kelly

Consumer Independence

Independent Living

Independent living is about self-determination: the right to choose and pursue one's own course of action.

The independent living movement emerged in the late Sixties and early Seventies as a reaction by some people with disabilities to a service system dominated by medical, vocational, and other professionals. With it came a strong push by the disability community to "demedicalize" support services.[1] There is no clear-cut definition of independent living, but the Texas Institute for Rehabilitation offers this generally accepted description:

> *Independent Living for a person with disabilities is living just like everyone else—having opportunities to make decisions that affect one's life, able to pursue activities of one's own choosing—limited only in the same ways that one's nondisabled neighbors are limited.*[2]

The Self-Determination Movement

The independent living movement inspired the push for self-determination. Self-determination is the ability of individuals to make the choices that allow them to exercise control over their lives, to achieve the goals to which they aspire, and to acquire the skills and resources necessary to participate fully in society. Self-determination traditionally has been out of reach or, at best, difficult to achieve for people with severe disabilities and health problems.[3]

Self-determination is based on four principles:

- **Freedom:** exercising the same rights as all citizens. People with disabilities will—with assistance, when necessary—establish where they want to live, with whom they want to live, and how they will occupy their time.

- **Authority:** controlling the sums of money needed for their own support, including reprioritizing these funds when necessary.

- **Support:** supervising their own support services, contracting for any number of discrete tasks for which they need assistance, and seeking companionship for personal support.

- **Responsibility:** spending public dollars wisely. People with disabilities have responsibility to view public support dollars as an investment in the overall quality of their lives, and not just as a resource or mandate to purchase services or care.

1   Smith, et.al. *Report of a Study Group on Health Care Reform, People with Disabilities, and Independent Living.* Independent Living Resource Utilization Program.

2   "An American Definition of Independent Living." ILRU at Texas Institute for Rehabilitation.

3   Center on Self-Determination. Oregon Health Sciences University. http://www.ohsu.edu/selfdetermination/selfdet.shtml

Policy Issue: *Self-determined care has the potential to save money for the state and managed care organizations by decreasing the amount spent on unnecessary or unwanted services.*

As states seek more cost-effective ways to deliver care to people with special needs, managed care has become a popular mechanism to accomplish this objective. People with special needs in Medicaid managed care enrolled in a predetermined program, are sometimes limited in their choice of providers, and often have no meaningful control over the dollars spent on their care. In a reform theory proposed by Donald Shumway and Thomas Nerney, co-directors of the University of New Hampshire Institute on Disability, self-determination would fundamentally reform the financing mechanisms and basic structure of the current service-delivery system.

The first step of this reform would be to allow individuals, with the help of friends and family, to develop an individualized budget plan for support dollars, usually based on some percentage of current service costs or capitation methods. With such a budget, patients can avoid purchasing what they do not need.

The second part of the reform concerns fiscal intermediaries. This function allows people with disabilities to serve as the employer of record for any staff hired to provide support, and enables them to designate a support organization or individual to manage all filings and payments to these staff. This step permits the person with a disability to avoid paperwork, and individuals can choose a provider or type of service (i.e., home health nurse, personal care attendant, physical therapist, etc.) to serve as the intermediary.

Therefore, restructuring service delivery for self-determination promotes individual and family decision-making. There is a shift in control of monetary resources directly to individuals with disabilities, their families where appropriate, and social support networks. These self-determination strategies can be offered in tandem with other managed care principles to meet the states' needs to control costs.

Preliminary findings from each state project suggest that effective promotion of self-determination requires:

- public policies that provide opportunities and incentives for individuals and their families to express self-determination;

- leadership development among consumers, policymakers, and service providers;

- case managers with strong personal skills.[4]

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4 The Alliance for Self-Determination. http://www.ohsu.edu/selfdetermination/overview.shtml

Policy Issue: *Assistive technology helps people with special needs overcome what might otherwise be "barriers" in their immediate environment. With these devices, they enjoy a greater degree of inclusion and integration in their communities.[5]*

Spotlight on the States:
Oregon

The Oregon self-determination project began in 1997, and since then has assisted 1,250 consumers with developmental disabilities in Multnomah County in choosing and directing their own services and supports. Oregon established a community organization called Self-Determination Resources, Inc. that helps consumers:

- determine services they want and develop budgets to pay for them;
- find the desired services and supports;
- develop support networks;
- select, train, and pay support providers;
- manage their budgets.

Wisconsin [6]

The Wisconsin self-determinition project was launched in 1997 and assists people with developmental disabilities in three counties. The goals of the project are to:

- keep choice and control as close to the consumer as possible;
- create individualized budgets;
- shift from the use of case managers to "support brokers."

Assistive Technology

In order to live independently, many disabled people use mechanical, orthopedic, electronic, and other types of devices—and services for obtaining them. After it appeared in the Technology Related Assistance for Individuals with Disabilities Act in 1988, "assistive technology" (AT) became the popular term for referring to these devices and services.

Many persons with disabilities benefit greatly from AT, including those with physical, visual, and hearing impairments. AT helps people not just see, hear, and move about, but to understand, organize, effect, and participate in their environment. Some AT devices are low-cost, but other more technical products are very expensive.

Medicaid is currently the largest funding source for assistive technology. An individual who seeks Medicaid funding for AT must generally meet a three-part test:

- the individual must be eligible for Medicaid;
- the specific device requested must be one that can be funded by Medicaid;
- the individual must establish that the device requested is medically necessary.

Examples of Assistive Technology Devices

- Motorized and custom-made wheelchairs
- Augmentative communication devices, including talking computers
- Vehicle modifications, including wheelchair lifts and hand controls
- Computer equipment and adaptations, including Braille printers, voice input and output, touch screens, and switches that allow computer access through voluntary movements such as eye blinks or head movements
- Assistive listening devices, including hearing aids
- Home modifications, including ramps, lifts, and stair glides
- Work-site modifications, including adapted office equipment and environmental control devices
- Classroom modifications, including adaptive seating systems

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5 National Center for the Dissemination of Disability Research, 1997. http://www.ncddr.org

6 Source: Phone interview with Roy Froemming, Project Facilitator. October 1999.

Consumer-Directed Care in the Home and Community

Policy Issue: *Consumer-directed care is an emerging issue that states need to consider when designing Medicaid managed programs for people with chronic illnesses and disabilities.*

An important trend emerging from the independent living movement is the concept of consumer-directed care. Part of the self-determination theme, consumer-directed care implies that Medicaid consumers prefer, and should be able to make decisions about their home and community service needs—and that they play a more active role in managing these services.

When given the choice, most people with chronic illnesses and disabilities choose to live in a community rather than in an institution. Medicaid has an optional home- and community-based waiver program that enables states to request waivers from Federal rules that limit the development of Medicaid-financed community-based treatment alternatives. States with Home- and Community-Based Waivers (HCBW) can provide seven services: case management, homemaker, home health, personal care, adult day health, habilitation (acclimating to environment), and respite care.[7]

However, HCBWs tend to be limited in scope and offer predetermined slots in the community for people with disabilities. HCBW services may be provided statewide or may be limited to specific geographic locations, further restricting access to home health care. In addition, there are often long waiting lists to fill these slots, resulting in extended institutional stays for many people with special health care needs who could be living in the community. To receive approval to implement HCBW programs, state Medicaid agencies must assure HCFA that the cost of providing home- and community-based services, even by contracting with MCOs, will not exceed the cost of care for the identical population in an institution.

Policy Issue: *States may face increasing demand for consumer-directed policies for key services such as personal care attendants.*

Personal care is the service most commonly used by people with disabilities. This service pays for a certain amount of care from a paid personal care attendant (PCA) to help perform daily activities such as eating and bathing. Currently, personal care services must be prescribed by a physician, supervised by a registered nurse, and (depending on the state) provided by a qualified individual who may not be a member of the recipient's family. Many individuals with special needs find these requirements restrictive, because decision-making remains with the medical community, and not with the person who has the disability.

7 Source: HCFA, 1999.

Two significant national initiatives are attempting to advance consumer-directed care. The first is federal legislation, The Medicaid Community Attendant Services and Supports Act (MiCASSA) and the second is a project called The Cash and Counseling Demonstration Program.

The Medicaid Community Attendant Services and Supports Act

(MiCASSA) is a bill currently being debated in the U.S. Congress. MiCASSA proposes to establish a national program of community-based attendant services and supports for people with disabilities. This bill would "allow the dollars to follow the person," meaning allowing them or their representatives, to choose the location where services and support would take place.

Source: http://www.adapt.org

The Cash and Counseling Demonstration Program

This program is a large-scale public policy initiative, funded by The Robert Wood Johnson Foundation. The program is designed to test the feasibility, and assess the advantages and disadvantages of, a consumer-directed approach to financing and delivering personal assistance services (PAS). The intent is to give Medicaid-eligible persons with disabilities more choice about and control over the PAS they require. The experimental intervention provides cash benefits that allow recipients to make decisions about and arrangements for their personal attendant and related personal assistance services. Arkansas, New Jersey, New York, and Florida are participating in this intervention.

Source: RWJF Cash and Counseling Program

People with Spinal Cord Injury Requiring Various Levels of Daily PCA Service

Number of Hours/Day Needed
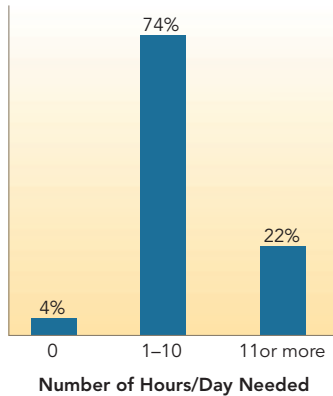
Source: Massachusetts Survey of Secondary Condition, MDPH, 1997.

Significant obstacles hinder the implementation of consumer-directed care in Medicaid:

- Institutional services are often mandatory, and personal care and HCBW programs are at the discretion of the states.

- Financial eligibility requirements for personal care and HCBW programs may be more restrictive than for institutional care.

- The amount and scope of personal care and HCBW benefits may be so limited that individuals with severe disabilities may be unable to live in the community while depending on them.

- Criteria established by states may restrict personal care and HCBW services.

- Consumer choice and information about personal care and HCBW may not be readily available to people with disabilities.[8]

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8   Powers, L. and Sowers, J. A *Cross-Disability Analysis of Consumer-Directed Long-Term Services.* Oregon Institute on Disability and Development, 1999.

Policy Issue: *Developments such as the Ticket to Work Act and the 1999 Olmstead v. L.C. decision may change the landscape for people with chronic illnesses and disabilities by providing them new opportunities for work and other forms of independence.*

The Ticket to Work Act

For people with chronic illnesses and disabilities, many of whom live below the federal poverty line and are enrolled in Medicaid managed care plans, the amount of effort required to navigate a complex managed health care system becomes so tiresome that it puts the goal of independent living out of reach.[9] However, recent federal legislation is altering that. The Ticket to Work Act, passed by Congress in late 1999, enables states to allow:
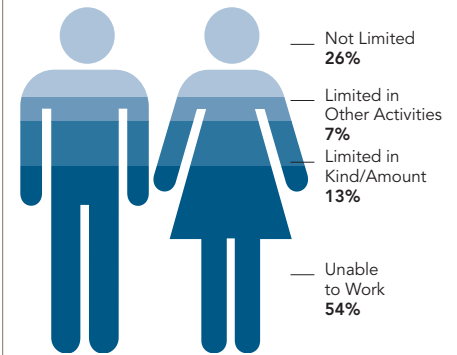
- workers with incomes above 250 percent of the poverty level to purchase Medicaid coverage;

- workers who show medical improvement to retain coverage;

- workers who are at risk of losing their ability to work, but who have never been on Medicaid, to have Medicaid coverage benefits extended to them.

Prior to this act, chronically ill and disabled Medicaid beneficiaries who returned to work could keep Medicaid only as long as they showed no medical improvement and their earnings remained under 250 percent of the poverty level.

The *Olmstead v. L.C.* Decision

A recent landmark decision by the Supreme Court may relieve many of these barriers to community-based and consumer-directed care. On June 22, 1999, the U.S. Supreme Court held in *Olmstead v. L.C.* that the unnecessary segregation of individuals with disabilities in institutions may constitute discrimination based on disability. The court ruled that the Americans with Disabilities Act might require states to offer community-based services rather than institutional placements for individuals with disabilities who so desire.

Limitation in Ability to Work Among Community-Dwelling Adults with Chronic Conditions on Medicaid, Ages 18-64

Not Limited **26%**

Limited in Other Activities **7%**

Limited in Kind/Amount **13%**

Unable to Work **54%**

Source: 1994/95 NHIS-D. Adult Followback Survey. Weighted data.

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9   From a phone interview with Dennis Fitzgibbons, Director of Operations at Alpha One.

Communicate

Pam Wiley, the mother of five children, has spent her whole life in New Jersey, where she has held a variety of jobs including working in casinos and in school cafeterias. Separated from her husband and raising her five children as a single mother, she has been off and on Medicaid and welfare for many years, and has been denied Supplemental Security Income benefits.

Pam, age 37, was recently diagnosed with diabetic neuropathy, which causes her severe pain in her legs and feet. Her diabetes also contributes to wasting of her muscles, nerves, circulatory vessels, and other tissue in her legs. Pam has a 19-year-old son with diabetes and another son with asthma. She also suffers from mild asthma herself. She and her son with asthma use inhalers when necessary.

Pam lives in a single home with her children, and her grandson, of whom she has custody. Because of the pain resulting from her diabetes, Pam is only able to work intermittently. She is currently in a Medicaid managed care plan.

Pam has seen a pain specialist for her diabetic neuropathy, but was only able to visit him once because she does not have access to transportation necessary for return visits. Pam notes "being on Medicaid is terrible because the doctors treat you like you're a welfare case, and don't really care about you as a person."

She admits that at one time she had problems with alcohol and drug abuse, but says that she stopped on her own. She feels that doctors sometimes assume that because she is black, she is a substance abuser. During one hospital visit, her white cells dropped significantly. As a result, the hospital staff put her on the AIDS floor. She knew she didn't have AIDS, and they did an HIV test, which indeed came back negative. She feels that the hospital staff assume that black people have AIDS.

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Pam Wiley
and children

Practicing Culturally Competent Health Care

Cultural competency, health literacy, and Medicaid are inextricably linked because large proportions of ethnic and racial minorities, as well as immigrants, are typically poor, under educated, and insured only by Medicaid. As Medicaid managed care becomes mandatory in many parts of the country, states and plans need to improve their approaches to relating to and communicating with people in these groups.

Policy Issue: *Demographics indicate that the need for cultural competency in Medicaid managed care will only increase.*
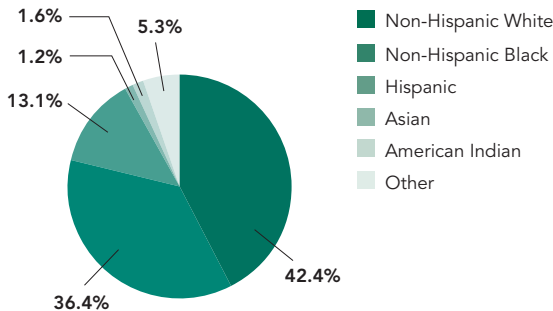
Approximately one-quarter of Americans are members of racial or ethnic minority groups. By the year 2050, this will increase to 50 percent. A disproportionate percentage of this population receives their health care through Medicaid. Thus, growth in the U.S. population of non-English speaking Americans (both Caucasian and non-Caucasian) makes the issue of cultural competency increasingly important.

Racial/Ethnic Composite of the Total U.S. Population and Percent Using Medicaid

Race/Ethnicity	Total Population in Thousands		Percent in Medicaid	
	1996	1987	1996	1987
Hispanic	23,384	18,752	21.0	16.9
Black	32,975	28,356	25.3	23.0
White and Other	202,157	190,783	8.4	4.1

Source: Medical Expenditure Panel Survey, Research Findings #9. August 1999.

Racial Distribution of Children with Special Health Care Needs on Medicaid, Ages 17 and Under

- Non-Hispanic White — 42.4%
- Non-Hispanic Black — 36.4%
- Hispanic — 13.1%
- Asian — 1.2%
- American Indian — 1.6%
- Other — 5.3%

Source: 1994/95 NHIS-D. Child Followback Survey. Weighted data.

Racial Distribution of Community-Dwelling Adults with Chronic Conditions on Medicaid, Ages 18-64

- Non-Hispanic White — 52.8%
- Non-Hispanic Black — 28%
- Hispanic — 9.6%
- Asian — 2.4%
- American Indian — 2.5%
- Other — 4.7%
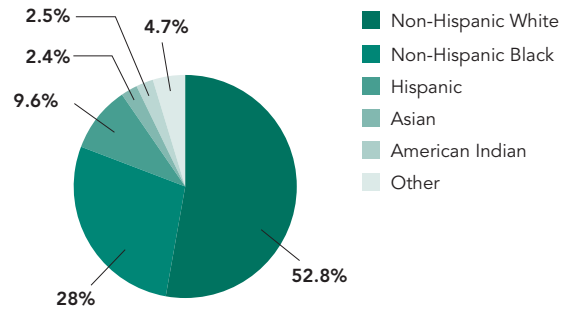
Source: 1994/95 NHIS-D. Adult Followback Survey. Weighted data.

In the health care setting, cultural competency can represent the capacity of providers to improve health outcomes by working with patients' cultural beliefs and primary language to customize treatment and services.

Applied to people with special health care needs, cultural competence involves recognizing and respecting differences among patients in values, expectations, and experiences (including those which relate to health care). At the same time, cultural competence recognizes the culture-based practices and dictates of organized medicine and the values, expectations, and experiences of the providers who practice it. A culturally competent health care organization promotes:

- understanding the cultural basis of certain chronic illnesses and how they are expressed in various racial and ethnic groups, e.g., sickle cell disease among African Americans;

- appreciating the role of language and its relationship to culture;

- acknowledging the boundaries of the organization's and providers' perspectives as well as their biases.

Policy Issue: *While many states already have cultural competency provisions in their contracts with Medicaid managed care organizations, others need to develop or improve these requirements, particularly for people with special health care needs.*

Certain federal and state guidelines require linguistic access and culturally competent care for people on Medicaid, including those with special health care needs. For example, federal Medicaid laws are designed to ensure that consumers have linguistic access to information about the Medicaid program, long-term care services, and childhood preventive care. The Health Care Financing Administration, in its primary guidance document to the states, mandates that states must:

- communicate orally and in writing in a language understood by the beneficiary;

- provide interpreters at Medicaid hearings.[1]

Provisions in the contracts of many states with managed care organizations seek to establish a culturally and linguistically competent system of care that acknowledges differences in peoples' backgrounds and beliefs and incorporates effective communication at all levels.

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1   *Ensuring Linguistic Access in Health Care Settings.* Henry J. Kaiser Foundation, 1998.

Cultural Competency Provisions in State Medicaid Managed Care Contracts [2]

State	Cultural Competence Provision
Arizona	
California	•
Colorado	
Connecticut	•
Delaware	
Florida	• (mental health only)
Georgia	
Hawaii	•
Illinois	
Iowa	•
Kansas	•
Kentucky	
Maine	•
Maryland	•
Massachusetts	
Michigan	
Minnesota	•
Missouri	•
Montana	
Nebraska	•
New Hampshire	
New Jersey	•
New York	• (mental health only)
North Carolina	•
Ohio	• (mental health only)
Oregon	•
Pennsylvania	•
Rhode Island	
Tennessee	
Texas	•
Utah	• (mental health only)
Vermont	
Virginia	
Washington	
West Virginia	•
Wisconsin	•

Of the 36 states with Medicaid managed care for people with special health care needs, 21 have cultural competency provisions in their state contracts, although a handful address the issue only in mental health services. Three-fourths of all states require written materials to be translated, and approximately half of all states require interpreter services for clinical and administrative encounters. California and Pennsylvania have included threshold and concentration standards for services delivered under their Medicaid programs to non-English speaking populations. For example, in California, linguistic services must be provided in areas that meet either the threshold standard of 3,000 beneficiaries per language group or the concentrations standard of at least 1,000 beneficiaries in a single zip code. Nebraska and Texas explicitly require professional interpreters when technical, medical, or treatment information is discussed.[3]

The Cultural Competence Continuum[4]

Cultural Destructiveness | Cultural Incapacity | Cultural Blindness | Cultural Precompetence | Cultural Competency | Cultural Proficiency

For managed care organizations, cultural competence is a developmental process that occurs along a continuum. A number of organizational abilities and activities contribute to a health plan's position and movement along this continuum:[5]

- Cross-Cultural Behavior
  Health plans should:
  - understand their Medicaid population's ethnically- and racially-linked risk factors for certain diseases;
  - improve access by locations, services and providers in areas accessible to neighborhoods of ethnic and racial concentration;
  - offer a comprehensive interpretation and translation system;
  - provide and support bilingualism and multiculturalism on the staff.

- Cross-Cultural Relations
  Staff members should endeavor, to the extent possible, to use interpersonal and patient-professional relationships expected by and acceptable to the members, their families, and their communities (i.e., acknowledging the family role in decision-making, appropriate touching, and verbal cues).

2 Ibid, Rosenbaum.

3 The Lewin Group. *The Impact of Culturally and Linguistically Appropriate Services on Access to Care in a Managed Behavioral Health Care Environment.* Prepared for SAMHSA. December 1998.

4 Source: King, M.; Sims, A.; and Osher, D. *How is Cultural Competence Integrated in Education?* American Institutes for Research. August 1999.

5 Source: Lonner, Thomas D. *Constructing Middle Ground: Cultural Competence in Medicaid Managed Care.* Center for Health Care Strategies, in press.

- Cross-Cultural Communications
  The staff should be able to create an atmosphere in which they and patients and family members can express their beliefs, find a common ground of understanding, and agree on a plan of action (i.e., develop a care plan for a minority disabled person).

- Cross-Cultural Inclusion
  The managed care organization should use skills, knowledge, and other resources to discover the beliefs, values, practices, traditions, and resources of patients and incorporate these into acceptable and effective services (i.e., as when designing the appropriate amount of drug treatment for a person with special needs from a culture that does not believe in the use of prescription drugs).

- Cross-Culturally Driven Clinical Work
  The health plan staff can adjust clinical care to compensate for differences in culture or belief systems, including prescribing shorter-term allocations of medications to increase patient-provider visits and interaction, and acknowledging the patient's use of alternative medicine.

Policy Issue: *Cultural background, literacy, and health needs have critical interplay in determining appropriate approaches to care.*

Toward Health Literacy

Health literacy is a concept related to cultural competency. Health literacy is the ability to apply reading and numerical skills in a health care setting. Patients enrolled in Medicaid managed care need to be able to comprehend the concepts and tasks necessary to meet their health care needs. These include being able to:

- read consent forms, medicine labels and inserts, and other written health care information;

- understand written and oral information given by physicians, nurses, pharmacists, and insurers;

- act on necessary procedures and directions, such as medication and appointment schedules;

- understand key policies and procedures of the managed care organization, such as the grievance and appeals processes.
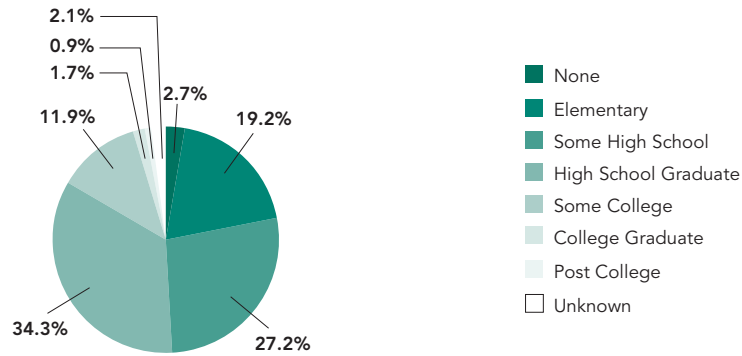
The results from the 1993 National Adult Literacy Survey revealed that nearly three-quarters of Medicaid recipients read below an eighth grade level. Among many repercussions, this translates into serious difficulties among the Medicaid population in understanding health and health care issues. As Susan Stableford of the University of New England indicates, "Managed care is very conceptually complex, so that even if people can read, they often have a hard time grasping the meaning."[6] Because of their conditions, people with special needs may have even more difficulty understanding and utilizing information.

Educational Distribution of Community-Dwelling Adults with Chronic Conditions on Medicaid, Ages 18-64

Legend:
- None
- Elementary
- Some High School
- High School Graduate
- Some College
- College Graduate
- Post College
- Unknown

Values: 2.1%, 0.9%, 1.7%, 2.7%, 19.2%, 11.9%, 27.2%, 34.3%

Source: 1994/95 NHIS-D. Adult Followback Survey. Weighted data.

Policy Issue: *States and plans should design materials at a fifth grade reading level or below, and consider translating all information related to health care.*

The average Medicaid consumer is living below the poverty line and reads at a fifth grade level or below. These consumers may have difficulty understanding the different procedures and protocols contained in member handbooks provided by most Medicaid managed care organizations. This difficulty is multiplied when dealing with Medicaid consumers with special needs. Health plans' and states' educational materials should be tailored to Medicaid consumers by writing in plain language and avoiding technical explanations. The example below illustrates how this could be done.

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6   From an interview with Sue Stableford, University of New England, 1999.

Before	After
"In order to be responsive to Member problems and concerns about [the HMO's] policies, programs, procedures, personnel, or benefits and services (their coverage, provision, or omission), the following grievance procedures have been established."	"If you have a problem or complaint, here's what to do."

Therefore, issues of cultural competence and health literacy play critical roles in determining the most effective approach to providing services to people with special health care needs on Medicaid.

Monitor

Scott Bennett was diagnosed with muscular dystrophy during childhood. Respiratory failure is his main condition, but he also experiences muscular weakness. Educators at his high school helped Scott apply for Medicaid and, in the summer before his senior year, he started to receive Supplemental Security Income and Medicaid benefits. In 1990, he became dependent on a ventilator.

Today, Scott works Monday through Friday for six-and-a-half hours a day as a computer supporter/programmer. He has a personal care attendant at home and at work, and a driver who takes him to and from work. Scott lived in Boston for 16 years, but recently moved to Taunton, Massachusetts, to be closer to his workplace.

Scott is convinced that without the new Medicaid laws, it would be impossible for anyone with a disability to work, and retain the necessary level of health care benefits. The recent implementation of laws like the Americans with Disabilities Act and the Work Incentives Improvement Act, or Supreme Court decisions like *Olmstead v. L.C.*, allow Scott to be a productive member of society and earn a living, while still receiving his Medicaid benefit package. Scott is grateful that he can keep his job and maintain his Medicaid and SSI coverage.

Even with Medicaid benefits, Scott often meets with obstacles when coordinating his care requirements. When he applied for a much-needed electric wheelchair, he received a denial letter from his managed care organization. He appealed the decision and a hearing was scheduled within 30 days. During the hearing, Scott suggested a compromise, and the decision was in his favor. The plan gave him part of the cost of the chair, and he obtained the remainder of the funding from the Muscular Dystrophy Association. Scott also appealed the denial of a partial dental plate that was eventually approved. He strongly believes that educating himself about treatment options and the grievance process helped him win his appeals.

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Scott Bennett

Measuring, Rating, and Safeguarding Care

A managed care delivery system aims to ensure quality by setting standards, and then gathering data to determine if those standards are met. Monitoring care steps and outcomes is especially important in the areas of chronic illnesses and disabilities, by virtue—among other things—of the shear amount of services needed by people in these categories. Many approaches to assessing and assuring quality of care are practiced today.

Accreditation, Licensing and Certification, Report Cards, and Credentialing

Policy Issue: *Measures to assess the quality of care provided by MCOs, as well as complaint and grievance processes, help safeguard the delivery of care for people with special needs on Medicaid.*

Many managed care organizations apply for accreditation from the National Committee on Quality Assurance (NCQA). NCQA evaluates these entities—which may be providers, insurers, or both—in a variety of areas, including members' rights and responsibilities, as well as quality management and improvement. The Joint Commission on the Accreditation of Healthcare Organizations (JCAHO), originally created to accredit hospitals, has recently expanded to accredit managed care organizations and provider networks that contract with managed care organizations for care delivery. The Accreditation Association for Ambulatory Health Care also accredits managed care organizations, though its main emphasis is accrediting ambulatory health providers.[1]

States also use the licensing and certification process to gauge the quality of newer managed care organizations. Many states have strict requirements (for cash reserves and data collection) for a Medicaid MCO to receive its license and certification to operate as a business in the state. Report cards are a relatively new tool that states employ to measure quality in health plans. Report cards rank health plans in different categories, such as provider network and clinic locations. These rankings are posted on web sites or mailed to consumers to assist them in selecting plans.

States may also require their health plans to credential participating providers. Credentialing refers to obtaining and reviewing primary source documentation on professional providers' licenses, malpractice history, and malpractice insurance. States may look at credentials for private medical practitioners, hospital staff, and ancillary providers.

Managed care consumers have various options for appealing a decision made by a physician or an MCO about their health care services. Each state Medicaid agency must allow recipients to receive a fair hearing if they are denied medical treatment.[2]

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1 Felt-Lisk, S. "Tools for Monitoring Quality for Vulnerable Populations." *Access to Health Care: Promises and Prospects for Low-Income Americans.* The Kaiser Commission on Medicaid and the Uninsured, 1998.

2 United States Code §1396a (a)(3)

A complaint process also exists for managed care organizations. According to law, each Medicaid MCO must establish an internal grievance procedure, under which an enrollee can challenge a denial of coverage or payment.[3] Plans also must report information on grievances to the state. When an MCO denies, reduces, suspends, terminates, or delays a service, it must provide written notice to the enrollee, and include information on how to obtain a fair hearing. The fair hearing system is an additional avenue of recourse for Medicaid managed care enrollees, and is not meant as a replacement for an MCO's internal grievance process.[4]

Ombudsprograms also can assist in dispute resolution, filing complaints or appeals, assisting in plan selection, and matching providers with patients. An increasing number of states use ombudsprograms to assist enrollees in Medicaid managed care programs and to monitor the quality of care delivered in managed care settings. As of 1998, nine states had passed legislation authorizing ombudsprograms to serve Medicaid managed care enrollees.[5]

Policy Issue: *Existing performance measures do not adequately address the full spectrum of delivery system activities. However, quality of care measurements for people with special needs are improving.*

Performance Measurement Tools

The Balanced Budget Act of 1997 requires Medicaid managed care organizations to measure performance. This is the process of using formal, scientifically grounded tools and methods to observe and record data on the services of a health care delivery system.[6] These measures are designed to assess how a system of care is serving a specific population, such as the chronically ill and disabled on Medicaid. Medicaid state agencies use performance measures to:

- guide decisions to purchase Medicaid-sponsored health care from providers;
- encourage improvement in Medicaid managed care programs;
- establish and apply benchmarks;
- introduce sanctions;
- provide qualitative information to Medicaid recipients who are trying to select a health plan.

Measuring MCO performance for people with special health care needs on Medicaid is difficult because of the heterogeneity of the population. Some measures for these individuals would be more useful if they were developed separately from those applied to other populations. Outcome measures for

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3 United States Code §1396u-2 (b)(4)

4 Perkins, J. and Olson, K. *Complaint and Grievance Procedures: Model Medicaid Contract Provisions.* National Health Law Program, 1998.

5 Ibid.

6 Source: Sofaer, S., et al. *Meeting the Challenges of Serving People with Disabilities: A Resource Guide for Accessing the Performance of Managed Care Organizations.* Center for Health Outcomes Research, Center for Health Care Policy Research, July 1998.

HEDIS Measures Used by 13 or More State Medicaid Agencies

Measure	Number of States
Childhood immunization status	24
Well-child visits in the first 15 months	24
Adolescent immunization status	14
Well-child visits in the 3rd, 4th, and 6th years of life	19
Prenatal care in the first trimester	22
Adolescent well-care visits	17
Incidence of low birth-weight babies	13
Discharge and average length of stay–maternity care	22
Children's access to primary care providers	16
C-section and vaginal birth after C-section	18
Availability of primary care providers	15
Birth condition and average length of stay, newborns	18
Initiation of prenatal care	13

Source: The National Association of Child Advocates. Health Plan Performance Measurement: What It Is, How it Impacts CHIP and Medicaid, and Why Child Advocates Should Care. November 1999.

people with chronic illnesses and disabilities should focus more on preventing adverse outcomes (i.e., falls or avoidable infections) or changes in functional health status, rather than a lack of disease/condition or improvement of condition. For many people with special health care needs, decreasing nonroutine specialist physician visits or maintaining stable health with a lifelong condition are some of the most sought-after outcomes.

Health Plan Employer Data Information Set

Few performance measures have been developed specifically for the Medicaid population. The Health Plan Employer Data Information Set (HEDIS) is the most common performance measurement tool used in Medicaid managed care. Originally developed for employer-based managed care organizations, HEDIS introduced Medicaid components with its 3.0 version. The current version is HEDIS 2000. Twenty-eight states use or were planning to use HEDIS measures to monitor Medicaid MCO plan performance as of July 1998.

HEDIS has many strengths, including its precision and validity, but it also has weaknesses. As revealed in the table, few of its most-used measures address people with chronic illnesses or disabilities. The majority of indicators are directed toward Medicaid recipients who are children and pregnant mothers. In addition, frequent turnover of Medicaid beneficiaries in health plan enrollment often results in continuity that is insufficient to accurately measure outcomes (i.e., HEDIS requires six-month continuous enrollment for inclusion in the data set). Furthermore, the complexity and cost of collecting and reporting HEDIS data limits the number of measures that Medicaid MCOs can report.[7]

Other Measurement Tools

The Consumer Assessment of Health Plans (CAHPS) is a survey that measures the level of satisfaction consumers have with their health plan. This tool has a Medicaid version and a recent version for people with chronic illnesses and disabilities. Twenty states are now using CAHPS.

The increased demand for information on quality in healthcare led to the creation of the Foundation for Accountability. This foundation has developed a framework for performance measurements in the areas of adult asthma, diabetes, depression, and substance abuse.

The federal government also has created a performance measurement tool—the Quality Assurance Reform Initiative (QARI). A group of medical directors from MCOs and state Medicaid agencies collaborated to create this tool. QARI has guidelines for states that recommend a systematic approach to quality assurance, consisting of internal program standards, focused studies, and external review. States were first encouraged to implement QARI, and more recently its successor, the Quality Improvement System for Managed Care. This recent initiative places more emphasis on requiring MCOs to demonstrate improvement than did QARI.

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7 *Health Plan Performance Measurement: What It Is, How it Impacts CHIP and Medicaid, and Why Child Advocates Should Care.* The National Association of Child Advocates. November 1999.

Policy Issue: *Improvements in measuring quality should start with input and consensus from all concerned parties. The utility of the resulting tools is paramount for state offices and managed care plans that have limited assessment resources.*

Measurement Concerns

The goal of measuring quality in Medicaid managed care remains a challenge. None of the existing tools for this task are sophisticated enough to monitor an entire Medicaid program's quality. However, states, health plans, and researchers continue to work together to develop better approaches. Finding a sound and commonly accepted quality-assessment strategy for Medicaid managed care will mean considering these factors:

- Many existing measures address access to needed services and interactions between members and providers. A number of tools also assess use of preventive services and modern treatments. But measures of care coordination—an issue with particular relevance for people with special needs—are scarce.

- Many performance measurement tools are surveys. Larger sample sizes always give surveys greater validity. However, the population of people with special health care needs is always smaller than the Medicaid population as a whole. Performance measures should be developed that offer qualitative feedback when sample size is small.

- Sophisticated performance measurements for tracking quality of care may exceed states' and plans' capacities to process the data—due in part to the status of their statistical and information technology capabilities.

- The intermittent nature of Medicaid enrollment and the frequent turnover in plan enrollment often causes problems for states trying to track quality in MCOs. However, people with special health care needs are more often long-term beneficiaries of Medicaid, and therefore provide states with a natural experiment to track performance in and across plans that serve them.

- States may want to convene focus groups of consumers, plans, and providers to determine a best method of performance measurement. This balance of perspectives will aid in developing measures that are comprehensive and realistic.

Spotlight on the States:

Oregon

"Oregon Shines II" is a strategic plan for the state of Oregon. The plan includes the following benchmark that is related to people with disabilities:

"Percentage of Oregonians with a lasting developmental, mental and/or physical disability who are living in the community with adequate supports"

The following performance measures are included:

- *percentage of seniors living independently;*

- *percentage of Oregonians with a lasting developmental, mental and/or physical disability who work;*

- *percentage of Oregonians with a lasting developmental, mental and/or physical disability living in households with incomes below the federal poverty level.*

Source: http://www.econ.state.or.us

Finance

When Joann Facenda was 22 weeks pregnant, her water broke and she gave birth to twin boys. One boy was one pound, eight ounces; the other was one pound, 10 ounces. The medical team gave Louie and Philip a one percent chance of survival.

Both boys were born with cerebral palsy, and had surgery just after birth for hydrocephalus and to perform a colostomy. The infants were in intensive care for four months. Medical bills were very high.

Today, the twins are seven years old. Philip is able to walk, mostly on his own, but Louie is in a wheelchair and is legally blind.

Just before the boys started attending elementary school, Joann moved her family from Philadelphia to West Des Moines, Iowa, because she found the Iowa school system to be more accommodating to special needs children. The boys live there with her and their older brother in a rented house. The boys go to school three days a week, and are involved with the local Easter Seals chapter.

Louis and Philip have fairly typical health care needs for children with special needs. They see a pediatrician on a regular basis, an ear, nose and throat specialist occasionally, and an ophthalmologist, general surgeon, and orthopedic surgeon twice a year. They also receive physical therapy once a week. Their hospital stays have all been for predictable visits for scheduled surgeries and they have not had to use emergency services very often.

Joann is happy with the school system in Des Moines, and enjoys the supportive community of other parents of special needs children. She is grateful for the benefits and support she receives from Medicaid.

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Joann Facenda with
Louie and Philip Facenda

Minimizing Risk by Predicting Costs

Rapid technological advances, increased marketplace turbulence, and growth in population have made Medicaid financing an increasing source of frustration for many states. States adopted Medicaid managed care to help ensure quality and appropriate care to beneficiaries, but also to save on costs. Since 30 percent of the Medicaid population—primarily individuals with special health care needs—is responsible for 70 percent of the expenditures, increased service use by this group is a challenge for states.

Policy Issue: *States have limited experience in setting capitated rates for people with chronic illnesses and disabilities, and plans have little experience in serving this population. To set rates that promote innovative managed care products for the special needs group, states should consider multiple rate setting options, including risk adjustment, risk sharing, and stop-loss options.*

Medicaid managed care programs for people with special needs have historically been voluntary, resulting in low enrollment. This low volume tends to increase the adverse selection and risk to health plans, because the plan would not have a large enough "healthy" base to balance the cost of the individuals with chronic illnesses and disabilities. States that would like to attract health plans to serve this population may benefit from a variety of risk-sharing strategies, including risk adjustment of rates, reinsurance, stop-loss, and risk corridors. These steps serve to:

- ensure adequate reimbursement to plans;

- provide incentives to plans that serve patients with greater needs;

- elevate the special needs market so that plans are willing to promote programs for this population (e.g., as a plan might if it had an exemplary AIDS program).

Policy Issue: *Using alternative methods to adjust rates (rather than age, gender, and eligibility categories) can assist in setting more appropriate reimbursement rates for managed care plans. Risk adjustment based on health status is a more accurate way to forecast cost for the chronically ill and disabled population.*

Risk Adjustment

Capitated payment is one of the most fundamental aspects of a managed care delivery system. Capitation is a risk-sharing strategy that refers to a set amount of money received (by the MCO) or paid out (by the state) per individual on a prospective basis to cover health care. Traditionally, capitation rates for managed care plans have been set at a percentage of the fee-for-service average payment, adjusted in most states for gender, eligibility category, age, and region. This method of estimation does not address high-service users such as Medicaid beneficiaries with special health care needs. Medicaid payment rates need adjustments to take into account the utilization patterns associated with some chronic conditions, and to ensure that MCOs will avoid losing money when enrolling this population. This approach to payment is called "health-based payment."

Health-based payment sets rates using measures of health status such as diagnoses, prior health care use or expenditures, functional status, and self-reported health status. The approach adjusts health plan payments according to predictions of health care needs. Proponents argue for health-based risk adjustment for people with special needs, because this population uses more services and also because its needs are, in many ways, more predictable. This predictability results from the much larger proportion of cost among the disabled that are for chronic health care needs, which are, by definition, more consistent over time.

Three publicly available classification systems have received the most attention as the basis for diagnostic risk adjustment:

- Disability Payment System (DPS)[1]– This diagnosis-based approach sets rates based on expenditure patterns for Medicaid beneficiaries with special needs. DPS was developed from several years of claims data for approximately 120,000 individuals in Ohio and Missouri. The system divides diagnoses into 18 major categories corresponding to body systems or to specific types of illness or disability. DPS then organizes most of these major categories by degree of elevated future costs.

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1   Kronick R., Gilmer T., Dreyfus T., Lee L. "Improving Health-based Payment for Medicaid Recipients: CDPS." *Health Care Financing Review*/Spring 2000/Volume 21, Number 3: 1-36.

- Ambulatory Care Groups Approach (ACG)[2]–This method predicts ambulatory care needs among a general population. The approach incorporates diagnoses from both ambulatory and inpatient claims, and uses them to predict total expenditures among Medicare beneficiaries. The ACG classification system begins by mapping diagnoses into ambulatory diagnostic groups.

- Diagnostic Cost Group Model (DCG)[3]– This family of models was developed to allow the Health Care Financing Administration to adjust capitated payments for Medicare beneficiaries. The DCG models use a large number of diagnostic groups, narrowly defining many of them to help better fit the conditions of the over-65 population. The approach divides major conditions into categories by degree of severity; for example, cancers, gastrointestinal conditions, pneumonia, and diabetes are each divided into two or three categories according to cost level. The models have recently been modified to predict expenditures for people under age 65, including commercial and Medicaid populations.

Policy Issue: *Plans that serve individuals with chronic illnesses and disabilities risk large financial losses. Risk adjusted payments help protect these plans.*

One of the reasons health plans favor risk-adjusted payments is to compensate for a phenomenon called adverse selection. A plan that serves high-risk, high-cost patients will often develop a positive reputation among these individuals. This can result in a disproportionate share of these high-risk beneficiaries enrolling in one particular plan over another, thereby increasing risk within the plan.

But spending is not a liability if a plan is paid adequately. Plans must receive a capitated rate based on the diagnosis or diagnoses of each individual. (States may also impose marketing restrictions on plans to control for plans that might have otherwise discouraged people with special health care needs from selecting their plan).

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2   Developed by Jonathan Weiner, Barbara Starfield, and colleagues at Johns Hopkins University.

3   Developed by Arlene Ash, Randy Ellis, Greg Pope, and colleagues at the Center for Health Economics Research.

Reinsurance, Stop-Loss, and Risk Corridors

Policy Issue: *States can share in a plan's profits or losses.*

To protect plans serving individuals with special health care needs, states can also use reinsurance—a form of insurance that financially protects them from extremely high-cost cases. Stop-loss is a reinsurance mechanism that shields plans from medical expenses above a predetermined threshold, generally on an annual basis. For example, a health plan may have stop-loss reinsurance for cases that exceed $100,000. After a case reaches $100,000, the plan receives 80 percent of expenses in excess of $100,000 back from the reinsurance company for the remainder of the year. [4]

Risk corridors are another risk-sharing arrangement designed to limit the degree of risk accepted by MCOs—in this case by having states share in a plan's profits or losses. The state would establish a "corridor" with a floor and a ceiling. If a plan experiences profits greater than the limit, then the state would share in those profits. If a plan experiences significant losses, then the state would cover a portion of the losses. [5]

Policy Issue: *States need flexibility to set rates based on a combination of fee-for-service historical information and MCO encounter data.*

Current Medicaid requirements under the Medicaid upper payment limit (UPL) hinder states' abilities to reset rates based on known service and cost data. Early experiments in a few states, such as Colorado, Maryland, and Minnesota, reveal that considerable resources are necessary to implement a risk-adjusted methodology. States need a sufficient amount of time to develop the rates and MCOs need sufficient time to thoroughly review them. The experience to date also reinforces the need for reliable cost and utilization information from fee-for-service claims or encounter data.

Efforts by states to set fair and predictable rates are worthwhile. Longer-term rate setting strategies can offer stability in an often-turbulent managed care marketplace. The goal of health-based payment is to set rates so that plans compete on value and not on risk selection. Health-based payment systems "level the playing field" for all plans enrolling people with special health care needs.

4 Kongstvedt, Peter R. *Essentials of Managed Health Care,* 2nd ed., (Gaithersburg, MD: Aspen, 1997).

5 Jacobs, A. *A Primer on Capitation Rate Setting for Medicaid.* Center for Health Care Strategies, October 2000.

Conclusion

The Faces of Medicaid presents many issues that affect people with chronic illnesses and disabilities and their transition from Medicaid fee-for-service to Medicaid managed care. These issues address identifying, caring for, communicating with, financing, monitoring, empowering, integrating, reaching and serving people with special health care needs.

The report highlights key policy implications related to these issues:

- States' Medicaid managed care programs should adapt enrollment policies to serve people with special health care needs, e.g., allowing family members to enroll in different plans.

- The health care needs of people with chronic illnesses and disabilities are often complicated by multiple problems requiring multiple types of services and providers from non-chronic or non-disabled populations.

- Sources of services and care for individuals with special health care needs on Medicaid are fragmented. Managed care offers the potential of coordinated care across multiple systems.

- Managed care programs should revise definitions of preventive care for people with special needs to allow for additional services this group may need to maintain good health.

- Measures to assess the quality of care provided by MCOs, as well as complaint and grievance processes, help safeguard and improve the delivery of managed care for people with special needs on Medicaid.

- Risk-adjusted capitation rates based on health status are a more accurate way to forecast and reimburse costs for the disabled population, which are more predictable than costs for a non-disabled population.

- While many states already have cultural competency provisions in their Medicaid MCO contracts, others need to develop or improve these requirements, particularly for people with special health care needs.

- Self-determined care has the potential to save money for the state and managed care organizations by decreasing the amount spent on unnecessary or unwanted services.

The Center for Health Care Strategies (CHCS) has developed projects to address these policy issues. In the area of informed purchasing, the *State Medicaid/CHIP Purchasing Institute* convenes biannually to work with dozens of states in the area of purchasing health care for chronically ill and disabled Medicaid beneficiaries. The *Best Clinical and Administrative Practices* project organizes medical directors of Medicaid and SCHIP health plans into workgroups to develop best practices around specific topics, such as improving birth outcomes and pediatric asthma. *Consumer Action,* a third CHCS special project, aims to institutionalize the role of consumers in every aspect of Medicaid managed care, ranging from grievance and appeals to medical necessity definitions. *Consumer Action* also is funding seed grants to community- and family-based organizations to improve consumer navigation of the health care delivery system.

It is our hope that *The Faces of Medicaid* provides state and federal policy-makers, state purchasers, health plans, and consumers with timely information to design and implement successful Medicaid managed care programs for people with special health care needs.

Technical Appendix

The four data sources used in *The Faces of Medicaid* were the Health Care Financing Administration's State Medicaid Research Files, the HIV Costs and Service Utilization Study, the National Health Interview Survey (NHIS) Disability Follow-back for Adults and Children, and the Massachusetts Department of Public Health and Boston University School of Public Health Massachusetts Survey of Secondary Conditions among Independently Living Adults with Disabilities.

State Medicaid Research Files (SMRF)

The "Identify" chapter in *The Faces of Medicaid* incorporates data from one source, the HCFA's SMRF, to examine the characteristics of the Medicaid population with special health care needs[1]. SMRF data from the states surveyed in the chapter include several linked data files. For each state, there are several files containing outpatient, inpatient, prescription, and long-term care bills (called claims) for Medicaid beneficiaries for a given year. There also is a person summary file that contains both Medicaid utilization and cost data, and eligibility data such as age, basis of eligibility, and dates of enrollment in Medicaid. SMRF data files have a common format and have undergone basic edits before they were released by the HCFA for research purposes.

Not all states submit SMRF data. Further, when beneficiaries enroll in capitated managed care arrangements, a claim no longer needs to be submitted to receive payment for a service, and thus the claims for these individuals are incomplete or missing altogether. Therefore, we selected four geographically diverse states that had SMRF data for 1994 and 1995 (the most recent years available) within the selected states, we excluded people in capitated managed care arrangements from this analysis.[2]

As we indicated in Identify, certain other Medicaid beneficiaries were excluded from the study for the following reasons:

- *Elderly and nonelderly dually eligible Medicaid/Medicare beneficiaries.* They were excluded because the claims data files do not include all of their claims, many of which would have been submitted to the Medicare program rather than to Medicaid. Therefore, we could not provide a reasonably complete picture of utilization and costs for this group using the SMRF data. This is a particularly vulnerable group who will be important to study using alternative data sources.

- *Medicaid beneficiaries who were enrolled in Medicaid for fewer than three continuous months during 1995.* They were excluded because we believed such a short time period would not accurately reveal their diagnostic, utilization, and cost profiles. We considered excluding beneficiaries with fewer than six months of continuous enrollment but were uncomfortable excluding such a substantial proportion of the population.

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1 All data analyses of SMRF were conducted by Mathematica Policy Research, Inc.

2 We excluded some whole counties in California that had high managed care penetration in 1995.

- *Women who were pregnant during 1994 or 1995.* They were excluded because we believed that the frequency of their office visits and hospitalizations related to childbirth would have confused the comparisons between people with and without chronic or disabling conditions.

Since the goal of the report is to describe the Medicaid population with special health care needs, the definition of "people with special health care needs" is critical. We could not find any single, existing claims-based operational definition of the Medicaid "special needs" population that would suffice for our analysis. However, we were able to build on existing tools to create a definition that—while not without limitations—is valid on its face and appropriate for the analyses we performed. Our definition, presented in Definition of Medicaid Special Needs, page 80, relies heavily on the new Chronic Illness and Disability Payment System (CDPS)[3] developed by Richard Kronick and others at The University of California, San Diego with funding from The Robert Wood Johnson Foundation and HCFA. While we believed it was important to supplement the CDPS diagnostic criteria for identifying our special needs population with utilization and cost criteria, the number of beneficiaries who met our special needs population definition only through the utilization and cost criteria was actually very small.[4]

To analyze the characteristics of the Medicaid special needs population, we compared data for the following groups, state by state, separately for children and adults:[5]

- The SSI-eligible Medicaid population, all of whom are considered to have special needs, as noted above.

- Medicaid beneficiaries eligible through AFDC[6] or eligibility pathways other than SSI or AFDC who have special needs based on our definition (see Definition of Medicaid Special Needs on page 80). "Other" eligibility pathways include qualifying for Medicaid through state-only funding, by being medically needy, by being in foster care or having refugee status, or through any other eligibility other than cash AFDC or SSI. In our charts and tables, this group is labeled "AFDC/Other with special needs."

- Medicaid beneficiaries without special needs. In our charts and tables, this group is labeled "AFDC/Other without special needs," or "Other Medicaid beneficiaries" when the two special needs groups above are combined.

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3 Kronick R., Gilmer T., Dreyfus T., Lee L. "Improving Health-based Payment for Medicaid Recipients: CDPS." *Health Care Financing Review*/Spring 2000/Volume 21, Number 3: 1-36.

4 In each state, fewer than two percent of the AFDC/Other population with special needs were identified only through the utilization and cost criteria.

5 Not all analyses were comparative. Our description of the most common types of conditions and eligibility pathways for people with special health care needs focused only on beneficiaries with special needs.

6 Since our data analysis, AFDC was renamed TANF (Temporary Assistance for Needy Families).

Definition of Medicaid Special Needs
Population used in Data Analysis

General Criteria
The following inclusions and exclusions apply to all enrollees regardless of whether they have special health care needs.

Included
Enrolled in California, New Jersey, Georgia, or Kansas Medicaid programs in 1995 unless excluded under specific criteria listed below.

Excluded
Dually eligible for Medicare and Medicaid

Age 65 and older

In capitated HMOs (except capitated plans for dental services only)

Fewer than three months of continuous enrollment during 1995

Pregnant during 1994 or 1995

Criteria used to Identify Enrollees as Having Special Health Care Needs
Any one or more of the following:

Had a claim during 1994 or 1995 showing a diagnosis that is included in the Chronic Illness and Disability Payment System (Kronick, et al., 2000), except pneumonia, thrush or other candidiasis, or cellulitis;

Is a Medicaid beneficiary receiving SSI;

Basis of eligibility is blindness or disability;

Met utilization or cost criteria during 1995, as follows (adapted from Burwell, et al., 1997):

- If enrolled six months or less, had either two or more hospitalizations, or ten or more days of inpatient care, or Medicaid outpatient payment of $2,500 or more, or total Medicaid payment of $10,000 or more.

- If enrolled seven to nine months, had two or more hospitalizations, or 13 or more days of inpatient care, or total Medicaid payment outpatient payment of $3,300 or more in 1995, or total Medicaid payment of $13,200 or more.

- If enrolled ten or 11 months, had three or more hospitalizations, or 18 or more days of inpatient care, or total Medicaid outpatient payment of $4,600, or total Medicaid payment of $18,400.

- If enrolled for 12 months, had three or more hospitalizations in 1995, or 20 or more days of inpatient care in 1995, or total Medicaid outpatient payment of $5,000 or more, or total Medicaid payment of $20,000 or more.

To illustrate many of the major points, we present graphics that combine the two special needs groups and compare the special needs population as a whole with the other Medicaid beneficiaries. However, we also point out the differences we found between the SSI-eligible special needs group, and the AFDC/Other special needs group. All charts and tables present averages across the four states. These averages are unweighted, so that each state's data counts equally toward the average, regardless of the number of enrollees in the state's program.

Several caveats should be stated at the outset. To provide timely information on the nonelderly special needs population in Medicaid, we have built upon existing tools for identifying and describing this population. However, we recognize that existing tools and data are far from perfect. For example, available data do not permit us to identify functional status, so that we may miss individuals with low functional status who did not have a claim with a diagnosis indicating chronic illness or disability during 1994 or 1995, and we may include individuals who had such a claim but who have mild cases and only minimal functional limitations. Chronic illnesses vary widely in type and severity, and other researchers—particularly those with more detailed clinical data—might argue for a different definition of special needs. Further, our analysis of four states cannot be assumed to be representative of all the states. However, the four states were highly consistent on the major patterns we report.[7] A final caveat concerns the age of the data (1994 and 1995). Disease prevalence and service use and cost patterns shift over time, and may particularly shift under managed care. However, given increasing enrollment in managed care and the lack of accurate encounter data for managed care enrollees, we chose to use data for states and time periods with a reasonably low level of managed care enrollment.

HIV Costs and Service Utilization Study

Within the "Integrate" chapter, the graph titled "Reducing Unmet Need for Services Among HIV-Infected People on Medicaid: The Influence of Case Manager Contact" illustrates unpublished data from the HIV Costs and Service Utilization Study (HCSUS)[8]. HCSUS was conducted by RAND under a cooperative agreement with the Agency for Healthcare Research and Quality (AHRQ). Martin F. Shapiro, M.D., Ph.D. and Samuel A. Bozzette, M.D., Ph.D. were Principal Investigators of the study. These analyses of HCSUS respondents on Medicaid are based on previously published data from analyses conducted on the full study sample[9].

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7   For a more detailed discussion of analytic issues, contact the Center for Health Care Strategies at (609) 279-0700.

8   These data were analyzed by John Fleishman, Ph.D., Senior Social Scientist at the Agency for Healthcare Research and Quality.

9   Katz, M.H., Cunningham, W.E., Mor, V., Andersen, R.M., Kellogg, T., Zierler, S., Crystal, S.C., Stein, M.D., Cylar, K., Bozzette, S.A., Shapiro, M.F. "Prevalence and Predictors of Unmet Need for Supportive Services among HIV-Infected Persons: Impact of Case Management." *Medical Care* 38 (1): 58-69, 2000.

National Health Interview Survey (NHIS) Disability Follow-back for Adults and Children

All data presented are unpublished data from Phase II of the Disability Survey conducted as a supplement to the 1994-95 National Health Interview Survey, also referred to as the Adult and Child Follow-back Surveys. Charts from this survey are presented in the "Care", "Communicate", "Empower", and "Integrate" chapters[10]. Analyses are confined to all children identified as Medicaid beneficiaries who participated in the Child Follow-Back Survey, and adult respondents to the Adult Follow-Back Survey, ages 18-64, who report Medicaid, but not Medicare, health insurance coverage. Data are weighted to be nationally representative of children and non-elderly adults who meet these insurance criteria, as well as one or more (two or more for children) disability-related criteria that satisfied eligibility for participation in the Follow-Back Surveys.

Massachusetts Survey of Secondary Conditions among Independently Living Adults with Disabilities

The Massachusetts Survey of Secondary Conditions among Independently Living Adults with Disabilities (MSSC) is a longitudinal study. The data presented in the "Empower" and "Reach and Serve" chapters are from the baseline interviews (conducted 1996-1997), with persons with disabilities. The opportunistic sampling frame consists of members of six Independent Living Centers serving communities across Massachusetts, members of a specialized Boston prepaid managed care organization providing comprehensive care for persons with disabilities, and SSI/Medicaid beneficiaries from an HMO serving Eastern and Central Massachusetts (this does not represent all Massachusetts' residents with spinal cord injury who have Medicaid). From each of the providers, individuals were drawn systematically for the sample.

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10 Data analyses for all charts were conducted by the Center for Gerontology and Health Care Research, Brown University.