

Forum Session Meeting Announcement

Friday, July 22, 2005

9:00am — Breakfast

9:30am–11:30am — Discussion

Understanding the Role of Medicaid in Assisting People with Disabilities

A Discussion Featuring:

Karen Tritz

Analyst in Social Legislation
Congressional Research Service

Brian Burwell

Vice President, Chronic Care and Disability
Medstat

Carol Tobias

Director
Health and Disability Working Group
Boston University School of Public Health

Estelle Richman

Secretary
Pennsylvania Department of Public Welfare

Location

**Reserve Officers Association
of the United States**
One Constitution Avenue, NE
Congressional Hall of Honor
Fifth Floor
(Across from the Dirksen Senate
Office Building)

Registration Required

Space is limited. Please respond
as soon as possible.

Send your contact information by
e-mail to: nhpfmeet@gwu.edu

THE GEORGE
WASHINGTON
UNIVERSITY
WASHINGTON DC

Understanding the Role of Medicaid in Assisting People with Disabilities

OVERVIEW

People with disabilities present Medicaid with an incredibly wide array of complex conditions and expectations that are not well identified or understood. Medicaid reform, on the table at both the federal and state level, could profoundly affect people with disabilities. This population generates a disproportionate share of Medicaid expenditures and will likely be a focal point of reform efforts. Therefore, a better understanding of Medicaid's beneficiaries with disabilities is critical to anticipate the effects from proposed reforms and to identify new opportunities for improving the delivery of cost-effective services. This Forum session will review how disability is defined, how Medicaid serves people with disabilities, and the systems that are in place to deliver care to this population.

For additional information – See Jeffrey S. Crowley and Risa Elias, Medicaid's Role for People with Disabilities, *The Kaiser Commission on Medicaid and the Uninsured*, August 2003; available at www.kff.org/medicaid/4027.cfm. ■

SESSION

Pressure to fundamentally reform the Medicaid program continues to mount. The President has proposed spending reductions, congressional committees are holding hearings, the Secretary of the Department of Health and Human Services has chartered a reform commission, and the nation's governors have issued a new policy outlining their priorities for Medicaid reform. Some states, such as Florida, are not waiting for Congress to act; instead, they are pursuing Medicaid reform through the use of waivers. This momentum for reform will generate myriad proposals that, if enacted, could greatly affect Medicaid's beneficiaries.

Because Medicaid is really a conglomeration of categorical programs serving distinct populations, predicting the potential effects of such reform on Medicaid beneficiaries with disabilities will be extremely difficult. For 25 million children and 14 million adults, Medicaid is a primary and acute care program.¹ For 5 million beneficiaries age 65 and older—particularly the 1.2 million who receive nursing home care—it is also a long-term care program.²

However, less well known is that Medicaid provides critical medical and supportive services to 8 million nonelderly beneficiaries with disabilities.³ Although they constitute just 16 percent of the Medicaid population, beneficiaries with disabilities generate 43 percent of the program's expenditures. In addition, traditional analysis does not account for the beneficiaries who are disabled but do not qualify for Medicaid under the

National Health Policy Forum
Facilitating dialogue.
Fostering understanding.

2131 K Street NW, Suite 500
Washington DC 20037

202/872-1390
202/862-9837 [fax]
nhpf@gwu.edu [e-mail]
www.nhpf.org [web]

Judith Miller Jones
Director

Sally Coberly
Deputy Director

Monique Martineau
Publications Director

Forum Session Manager
Randy Desonia
Senior Research Associate

Supplemental Security Income (SSI) program. Therefore, these figures both underestimate the total impact of people with disabilities on Medicaid and fail to convey the incredible diversity of their conditions and needs. To be successful, reform will have to be based on an understanding of the needs of this population that has such a dramatic effect on Medicaid expenditures. However, understanding these needs and crafting effective reforms will be challenging because of a lack of information on Medicaid's beneficiaries with disabilities.

The information that is available on these beneficiaries comes from a body of research that is confusing, categorical, inconsistent, and incomplete. There are more than 20 federal definitions of disability for determining program eligibility and for use in statistical analysis.⁴ Thus, projecting the number of people with disabilities and the severity of their condition varies widely depending on the definition used.

Even when a single definition is used within a program, it can result in misunderstandings. In Medicaid research, the term "disabled beneficiary" usually refers to a category of people aged 64 and younger who became eligible through the SSI program. Yet, there are many enrollees with disabilities who obtain eligibility under other Medicaid categories: children, non-SSI adults, and the aged.

Perhaps the biggest hindrance in understanding the difficulties people with disabilities face within Medicaid is the fact that the population is a heterogeneous one with differing medical and supportive needs. Individuals' conditions, which often vary in severity over time, include physical disabilities (such as quadriplegia and blindness), developmental disabilities (such as autism and mental retardation), disabilities due to mental health disorders (such as schizophrenia and bipolarism), and other disabling conditions (such as cerebral palsy, muscular dystrophy, spina bifida, and HIV / AIDS).⁵ Each condition and combination of conditions present their own service delivery challenges.

Moreover, the expectations regarding what each beneficiary may achieve in terms of employment, living arrangements, and other activities, as well as the supportive services necessary to realize these expectations, can differ even among people who have the same condition. For example, services for disabled children may aim to enable a child to live with his or her parents and focus on education. For working age disabled adults, however, services may enable them to be employed. And for the aged disabled, supportive services can enable them to continue residing in their homes.

This Forum session will begin with an overview of disability, some of the criteria used to determine eligibility for federally funded health programs, and the general roles played by federal health financing programs in covering people with disabilities. A more detailed description of the role Medicaid plays in serving people with disabilities will follow. The speakers will describe the Medicaid beneficiaries who have physical and cognitive impairments, including a discussion of their health needs, the services they receive, and the systems that deliver their care. The meeting will conclude with a description and discussion of the unique health

needs and delivery systems of Medicaid beneficiaries with disabilities due to mental disorders. Throughout the briefing, opportunities to enhance the understanding of the disabled population and improve the delivery of services will be noted.

KEY QUESTIONS

- How does the federal government define disability, and how do the differing definitions hinder a better understanding of the needs and numbers of people with disabilities?
- What are the most prevalent disabling conditions, and have there been new trends in recent years?
- What major federal health programs assist people with disabilities?
- How do people with disabilities become eligible for public assistance?
- Which disabled populations are enrolled in Medicaid, and how do they affect the program?
- What are the primary Medicaid delivery systems for people with physical, developmental, and mental disabilities?
- What are the numbers and characteristics of Medicaid's "hidden disabled," that is, the disabled who qualify for Medicaid under nondisabled categories? Do the hidden disabled encounter greater difficulties in receiving specialty services and coordinated care?
- What management techniques are used to ensure timely service referrals and to coordinate service delivery? How are services coordinated for people with multiple impairments?
- What are the roles of managed care plans and home- and community-based service Medicaid waiver programs in delivering services to people with disabilities?
- What data and management changes should be considered to ensure a smoother transition of benefit coverage and service delivery as a disabled person ages?

SPEAKERS

Karen Tritz is an analyst in social legislation for the Congressional Research Service (CRS), where she assists Congress on issues related to people with disabilities, Medicaid, and long-term care. Before joining CRS in 2002, Ms. Tritz worked at the Centers for Medicare & Medicaid and the Wisconsin Department of Health and Family Services, where she developed programs and policies in Medicaid long-term care and return-to-work efforts for adults with disabilities.

Brian Burwell is vice president at Medstat, where he oversees research and evaluations on chronic care and disability issues for state and federal governments. At Medstat, he has worked on dozens of studies and authored numerous publications on such issues as Medicaid managed

care for people with disabilities, case management, nursing home litigation, Medicaid estate planning, and informal home care. Recently he has been publishing reports on Medicaid home- and community-based service expenditures. Before joining Medstat in 1984, Mr. Burwell worked at Urban Systems Research and Engineering, where he specialized in Medicaid and long-term care studies.

Carol Tobias is an assistant professor at the Boston University School of Public Health and is director of its Health and Disability Working Group. Since 1996, she has conducted program evaluations and provided technical assistance on innovative health care delivery systems for a broad spectrum of disability issues including physical disability, developmental disability, psychiatric disability, substance abuse, children with special health care needs, frail elders, and people with multiple chronic conditions. Ms. Tobias previously directed Boston's Public Health AIDS Program. At the Massachusetts Medicaid agency, she was responsible for managed care programs and services for people with disabilities.

Estelle Richman is secretary of the Pennsylvania Department of Public Welfare, where she oversees the Medicaid, mental health and substance abuse, mental retardation, Temporary Assistance for Needy Families, and child welfare programs. Ms. Richman is a nationally recognized expert on behavioral health and children's services and has served as Philadelphia's deputy commissioner for Mental Health and the southeast area director for Pennsylvania's Office of Mental Health. Her work has been honored by several national organizations, including the Alliance for the Mentally Ill, the American Psychiatric Association, and the Ford Foundation.

ENDNOTES

1. The Kaiser Commission on Medicaid and the Uninsured, "Key Facts: Medicaid Program at a Glance," updated January 26, 2005; available at www.kff.org/medicaid/7235.cfm.
2. The figure of 1.2 Medicaid aged disabled was taken from the *Health Care Financing Review Medicare and Medicaid Statistical Supplement, 2003*, Centers for Medicare & Medicaid Services, Department of Health and Human Services, table 92; available at www.cms.hhs.gov/review/supp/2003/table92.pdf.
3. Kaiser, "Key Facts."
4. Program on Employment and Disability, "Disability Statistics," Cornell University School of Industrial and Labor Relations; available at www.ilr.cornell.edu/ped/disabilitystatistics/issues.cfm#DefiningDisability.
5. Nikki Highsmith and Stephen Somers, "Adults with Disabilities in Medi-Cal Managed Care: Lessons from Other States," Center for Health Care Strategies, September 2003, 8; available at www.chcf.org/documents/policy/MediCalDisabilitiesLessons.pdf.



The National Health Policy Forum is a nonpartisan research and public policy organization at The George Washington University. All of its publications since 1998 are available online at www.nhpf.org.