

CAEAR Coalition

Spring 2011 Meeting

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Ryan White Program Appropriations: FY2011 and FY2012

Program	FY 2010 Conference Report	FY 2011 CAEAR Coalition Request	FY 2011 President's Budget Request	FY 2011 Highest Passed ¹ Level	CAEAR Coalition FY 2012 Request	President's FY 2012 Budget Request
Part A	\$679.1m (+\$16m)	\$905m (+225.9m)	\$679.1m (+\$0m)	\$694.1m (+\$15m)	\$751.9m	\$679.1m
Part B Base	\$418.8m (+\$10m)	\$474.7m (+55.9m)	\$428.8m (+\$10m)	\$428.8m (+\$10m)	\$495.0m	\$418.8m
Part B ADAP	\$860.0m ² (+\$45m)	\$1205.1m (+370.1m)	\$885.0m ³ (+\$25m)	\$895.0m (+\$35m)	\$991.0m	\$940.0m
Part C	\$206.8m (+\$4.9m)	\$337.8m (+131m)	\$211.9m (+\$5.1m)	\$211.9m (+\$5m)	\$272.2m	\$211.5m
Part D	\$77.8m (+\$0.9m)	\$84.8m (+7m)	\$77.8m (+\$0)	\$77.8m (\$+0)	TBD	\$77.8m
Part F AETC	\$34.8m (+\$0.4m)	\$50m (+15.2m)	\$37.4m (+\$2.6m)	\$37.4m (+\$2.6)	\$50.0m	\$34.8m
Part F Dental Reimb.	\$13.6m (+0.2m)	\$19m (+5.4m)	\$15.4m (+1.8m)	\$15.4m (+\$1.8m)	TBD	\$13.6m

1. Includes numbers from the FY2011 House Subcommittee bill, FY 2011 Senate Committee bill and the FY 2011 House Continuing Resolution.

2. Includes an additional \$25 million in FY2010 reprogrammed funding announced in July 2010.

3. The President submitted a budget amendment in August 2010 to increase this account by \$30 million.

AIDS Budget and Appropriations Coalition

(an affiliated workgroup of the Federal AIDS Policy Partnership)

March 25, 2011

The Honorable Harry Reid
Majority Leader
United States Senate
Washington, DC 20510

The Honorable Mitch McConnell
Minority Leader
United States Senate
Washington, DC 20510

The Honorable John Boehner
Speaker of the House
United States House of Representatives
Washington, DC 20515

The Honorable Nancy Pelosi
Democratic Leader
United States House of Representatives
Washington, DC 20515

Re: FY11 Funding Levels for Domestic HIV/AIDS Programs

Dear Majority Leader Reid, Minority Leader McConnell, Speaker Boehner, and Democratic Leader Pelosi:

On behalf of the undersigned HIV/AIDS service and advocacy organizations, we urge you to provide adequate increases for the domestic HIV/AIDS programs outlined below and protect them from any cuts as you finalize spending levels for fiscal year 2011. Additionally, we urge you to pass a continuing resolution that is free of any extraneous policy riders that would negate current law.

HIV/AIDS remains a significant and serious health concern in the United States with over 1.1 million people currently living with HIV and an estimated 56,000 new infections annually. HIV disproportionately impacts racial and ethnic minority communities and low income people who depend on public services for their life-saving health care and treatment. It is primarily the responsibility of the public health system to ensure that infectious diseases, such as HIV, are prevented. Early and reliable access to HIV care and treatment help patients with HIV live healthy and productive lives and is cost effective. Investing in HIV prevention today translates into less spending in the future on care and treatment.

Amidst rising infection rates and shrinking state and local budgets, increased federal funding for HIV/AIDS programs is more vital than ever. While we realize there are constraints within the federal budget, the programs outlined below help serve the most vulnerable in our society, many of whom are struggling to survive both physically and economically.

Ryan White Program

The Ryan White HIV/AIDS Program provides life-extending healthcare, drug treatment, and support services to approximately 529,000 low-income, uninsured and underinsured individuals and families affected by HIV/AIDS. Due to increased caseloads and budget cuts, Ryan White programs are hitting capacity limits and implementing service reductions. Patients are facing record wait times to access clinical care and life-saving therapy. Currently there are 7,553 people on AIDS Drug Assistance Program (ADAP) waiting lists in 11 states, and states are moving thousands of people off their programs onto

pharmaceutical company supported charities. Other states are reducing their drug formularies and eligibility levels.

For these reasons, we strongly urge you to support an increase in funding of at least \$116.7 million for the Ryan White Program. We support the funding be divided in the following ways: **\$15 million for Part A**, which will go to 52 metropolitan areas in 28 states, the District of Columbia and Puerto Rico; **\$10 million for Part B base**, which goes to all states; **\$78 million for ADAP**, which goes to all states; **\$5 million for Part C**, which funds 444 clinics in 49 states, DC and Puerto Rico; **\$2.5 million for Part D**, which funds 98 programs in 36 states for Women, Children and Youth; **\$ 2.6 million for Part F**, which funds the AIDS Educations and Training Centers; **and \$1.8 million for Part F Dental programs.** While these numbers do not represent the true need, in most instances, they represent what was proposed by Congress in earlier versions of FY11 spending bills.

The delay in passing a final spending bill for FY11 has created great uncertainty for the providers of care and treatment under the Ryan White Program. The fiscal constraints caused by the weak economy and increased caseloads are compounded with the receipt of only partial grant awards, which makes it extremely difficult to plan and budget year long operations and activities.

HIV Prevention at the CDC

We strongly support the President's FY2011 request to increase funding for HIV prevention at the CDC by \$66 million for activities to reduce new infections and increase HIV testing. In FY2010, \$30 million from the Prevention and Public Health Fund supported: comprehensive HIV prevention planning and implementation in the 12 highest impacted cities and counties; increased HIV testing and linkage to care; expanded HIV surveillance; and increased HIV, viral hepatitis, STD prevention, and sexual health promotion for Tribal Communities. To ensure that these critical activities continue, we urge you to support an increase of \$66 million in FY2011. We note that \$35 million of this amount is fully offset and would not represent additional federal funding.

Division of Adolescent and School Health

We urge you to continue investing dedicated funding for the Division of Adolescent and School Health (DASH) at the CDC as a separate and dedicated funding stream and include at least \$40.2 million for DASH's HIV prevention work. Young people ages 13-29 years old account for one-third of all new HIV infections, the largest share of any age group.

Teen Pregnancy Prevention Initiative

All young people should be provided with comprehensive, medically accurate, and age-appropriate sex education that helps them reduce their risk of unintended pregnancy, HIV/AIDS, and other STDs. Young people are at risk for a variety of negative health outcomes and educators on the ground know that they best serve young people when they address the inter-related health needs of young people. **We strongly oppose the elimination of the Teen Pregnancy Prevention Initiative as proposed by HR 1 and instead support the original House approved FY11 level of \$133.7 million.**

HIV/AIDS Research at the National Institutes of Health

We ask that you increase overall funding for the National Institutes of Health (NIH) in FY 2011, especially for the HIV portfolio and reject any funding cuts. If the United States is to remain the global leader in HIV/AIDS research for better drug therapies, evidence-based behavioral and biomedical prevention interventions, and vaccines, Congress must adequately invest in NIH. In recent years, there have been great strides in HIV research. With proper funding in 2011, exciting new scientific opportunities in HIV prevention, HIV therapeutics and cure research may be leveraged to turn the tide of the HIV epidemic worldwide.

Housing Opportunities for Persons with AIDS

For the more than 62,000 households coping with HIV/AIDS, the Housing Opportunities for Persons With AIDS program (HOPWA) is a critical source of housing and services that work to prevent the spread of the virus, facilitate improved health outcomes and save taxpayer dollars by reducing reliance on other systems such as hospitals, emergency rooms and shelters. The need for housing people living with HIV/AIDS has exploded as other housing options available have become strained. **We urge you to increase HOPWA by \$15 million for a total of \$350 million as was originally proposed by the House passed Transportation, Housing, and Urban Development Appropriations bill.**

National HIV/AIDS Strategy

The Office on National AIDS Policy (ONAP) is coordinating the implementation of the National HIV/AIDS Strategy. **Please support \$1.4 million for the work that ONAP is doing to implement the National HIV/AIDS Strategy as was proposed by both the House and Senate Financial Services and General Government Appropriations bills.**

HR 1

We also emphatically state our opposition to the substantial funding cuts and policy riders included in HR 1 and urge you to reject them. The draconian funding cuts, program terminations, and policy provisions contained in HR 1 would impose serious constraints on the ability to provide care and treatment to people who are currently living with HIV/AIDS, curtail effective programs and services that work to prevent future infections, and derail the discovery of medical research that help improve the treatment and prevention of HIV.

Specifically, we oppose the following:

- Completely defunding Title X family planning programs and prohibiting any funding for Planned Parenthood Federation of America, Inc. and its clinics;
- Completely defunding the Teen Pregnancy Prevention Program;
- Banning any federal funding of syringe exchange programs and prohibiting the District of Columbia from spending any of its own local funds on syringe exchange programs;
- Defunding implementation of important elements of the Patient Protection and Affordable Care Act;
- Eliminating all funding of the Prevention and Public Health Fund;
- Cutting CDC Prevention funds by nearly \$900 million;
- Cutting NIH research by \$2.5 billion; and
- Cutting Community Health Centers by \$1 billion.

In conclusion, we urge the Congress to work with the President on finalizing a continuing resolution that he can sign so that we can quickly come to a conclusion on FY11 spending levels. In such a continuing resolution we hope it will ensure adequate funding to respond to the nation's HIV/AIDS epidemic and irresponsible funding cuts and policy riders will be rejected.

Thank you for your consideration of our requests. If you have any questions, please contact the ABAC co-chairs Donna Crews at dcrews@aidsunited.org, Jen Heitel Yakush at jyakush@siecus.org, or Carl Schmid at cschmid@theaidsinstitute.org.

Sincerely,

Acadiana C.A.R.E.S
ActionAIDS
ADAP Advocacy Association (aaa+)
Advocates for Youth
African American Health Alliance

AIDS Action Baltimore
AIDS Action Committee of Massachusetts
AIDS Alabama
AIDS Alliance for Children, Youth & Families
AIDS Foundation of Chicago
AIDS/HIV Health Alternatives
The AIDS Institute
AIDS Legal Referral Panel of the San Francisco Bay Area
AIDS Project Los Angeles
AIDS Taskforce of Greater Cleveland
AIDS United
Alaskan AIDS Assistance Association
American Academy of HIV Medicine
amfAR, the Foundation for AIDS Research
Association of Nurses in AIDS Care
Association of Nutrition Services Agencies
AVAC
BIENESTAR
CAEAR Coalition
CANN - Community Access National Network
Cascades AIDS Project
Central City Community Health Clinics
Colorado AIDS Project
Community Education Group
CT AIDS Resource Coalition
Georgia Equality
Harlem United
Harm Reduction Coalition
HealthHIV
HIV Dental Alliance
HIV Prevention Justice
HIV Medicine Association
HIVictorious, Inc.
Housing Works
Human Rights Campaign
Hyacinth AIDS Foundation
LA Gay & Lesbian Center
Latino Commission on AIDS
LIGHT Health & Wellness Comprehensive Services Inc
Lower East Side Harm Reduction Center
Mendocino County AIDS/Viral Hepatitis Network
Menlo House
Metropolitan Latino AIDS Coalition (MLAC)
Minnesota AIDS Project
Nashville CARES
National AIDS Housing Coalition
National Alliance of State & Territorial AIDS Directors (NASTAD)
The National Association of People with AIDS (NAPWA)
National Coalition for LGBT Health
National Coalition of STD Directors
National Council of Jewish Women (NCJW)
National Latino AIDS Action Network (NLAAN)

National Minority AIDS Council (NMAC)
North Central Texas HIV Planning Council
Okaloosa AIDS Support and Informational Services, Inc. (OASIS)
Our House
Pan Pacific Consulting
Project Inform
Racial and Ethnic Health Disparities Coalition (REHDC)
Ryan White Medical Providers Coalition
Sadler Healthcare
Sexuality Information and Education Council of the U.S. (SIECUS)
National Black Leadership Commission on AIDS
Treatment Access Expansion Project
Treatment Action Group (TAG)
Urban Coalition for HIV/AIDS Prevention Services (UCHAPS)
VillageCare
Western Pacific Med/Corp
Women Together For Change

cc: Members, United States Senate
Members, United States House of Representatives

Increased Ryan White Program Resources Needed in 2011 and 2012 to Respond to Growing Need for Care

The Need for HIV/AIDS Care and Treatment is Growing

- CDC has significantly increased efforts to **expand HIV testing in hard-hit communities** to help people living with HIV learn their status and enter care.
- **Researchers estimate that CDC's expanded HIV testing guidelines will bring an additional 46,000 people into care over five years** and reduce the 21% of people living with HIV but not in care. Bringing these individuals into care will save money in the long run, but requires an initial investment now—caring for individuals early in their disease will **increase the cost of care by \$2.7 billion over five years and the majority of those costs will fall to federal discretionary programs like the Ryan White Program** and will not be offset by entitlement programs.¹
- **45% of HIV-infected people in the U.S. for whom antiretroviral therapy would likely be recommended are not-accessing treatment**—together, primary medical care and medications are key to helping people living with HIV maintain their health.²

The Ryan White Program Works

- The OMB's Program Assessment Rating Tool (PART) found that the Ryan White Program has contributed to the **decline in the number of new AIDS cases and deaths due to HIV/AIDS**.
- The PART assessment gave the program a score of **100% in Program Results and Accountability**, making it **one of only seven out of 1,016 federal programs** to receive that score.
- The program **addresses disparities in access to HIV treatment and care**, serving women and racial and ethnic minorities in significantly higher proportions than their representation among reported AIDS cases.

Ryan White-Funded Programs are Economic Engines in their Communities

- Ryan White-funded programs, including many community health centers, bring jobs and economic development to low-income urban communities and sparsely populated rural areas, serving as anchors for existing and new businesses and investments. These organizations employ people in their communities, providing critical entry-level jobs and community-based training and career building.
- A large, urban community health center brings an estimated economic impact of \$21.6 million, employing 281 people, and a small, rural health center has an estimated economic impact of \$3.9 million, employing 52 people.³

State Budget Cuts Have Created an Immediate Funding Crisis

- The AIDS Drug Assistance Programs (ADAPs) in many states are on the brink of the worst funding shortfall in many years and there is a record number of people in need of ADAP services due to the economic downturn. Adjustments have been made to Medicaid reimbursement rates to address economic conditions but no similar steps have been taken for ADAP.

¹ Martin, E. G., Paltiel, A. D., Walensky, R. P. and Schackman, B. R. (2010), Expanded HIV Screening in the United States: What Will It Cost Government Discretionary and Entitlement Programs? A Budget Impact Analysis. *Value in Health*, 13: 893–902. <http://www.ncbi.nlm.nih.gov/pubmed/20950323>

² Kates J. Insurance Coverage and Access to HIV Testing and Treatment: Considerations for Individuals at Risk for Infection and for Those with Undiagnosed Infection. *Clinical Infectious Diseases*, 2007;45 (Suppl 4). http://cid.oxfordjournals.org/content/45/Supplement_4/S255.full

³ National Association of Community Health Centers, Access Granted, August 2007. <http://www.nachc.com/research>

- **7,558 people in 11 states are on waiting lists for the program. 18 states have cost-containment strategies that limit access.** Two states removed people from their ADAP after reducing financial eligibility. Some states have been forced to remove vital drugs from their ADAP formulary and/or institute annual expenditure caps and cost-sharing.
- Community is also engaged in cost-containment measures with industry, including rebates, price reductions, and patient assistance programs.

Requested Increases Authorized in Legislation

Program Component		FY 2011 Authorization	FY 2011 Current Request	FY 2012 Authorization	FY 2012 Request	Estimated Need
Part A		\$716.1 M	\$694.1M (+\$15M)	\$759.1M	\$759.1M	\$1,018M
Part B	Base	\$1,417M	\$428.8M (+\$10M)	\$1,489M	\$495M	
	ADAP		\$913M (+78M)		\$991.0 m	
Part C		\$259.2M	\$211.9M (+\$5M)	\$272.2M	\$272.2M	\$406.8M
Part F: AETCs		\$38.3M	\$37.4 (+\$2.6M)	\$40.2M	\$50M	

Part A—Cities and Communities

More than 70% of all people living with HIV/AIDS in the U.S. reside in a Part A community. Part A serves an estimated 300,000 people living with HIV/AIDS per year. **\$694.1 million in 2011 and \$759.1 million in 2012** will partially address the current unmet need for medical care and some support services for uninsured and underinsured people living with HIV/AIDS in these hard-hit communities. The rising cost of care due to **health care inflation** and the **complexity of care as the population ages** are affecting the amount of services provided—the number of visits for health-related care decreased from 3.18 million visits in 2005 to 2.6 million in 2009.

Part B—AIDS Drug Assistance Program

\$913 million in 2011 and \$991 million in 2012 are needed to reduce and prevent waiting lists, formulary reductions and other cost containment measures and to allow all state ADAPs to provide the full range of antiviral medications and treatments for infections and side effects.

Part C—Community Health Centers and Clinics

Over 247,000 persons living with HIV/AIDS receive medical care in Part C–funded community health centers and clinics each year. **\$211.9 million in 2011 and \$272.2 million in 2012** would allow Part C clinics to provide outpatient medical care to the 30,000+ people expected to enter care at those sites next year.

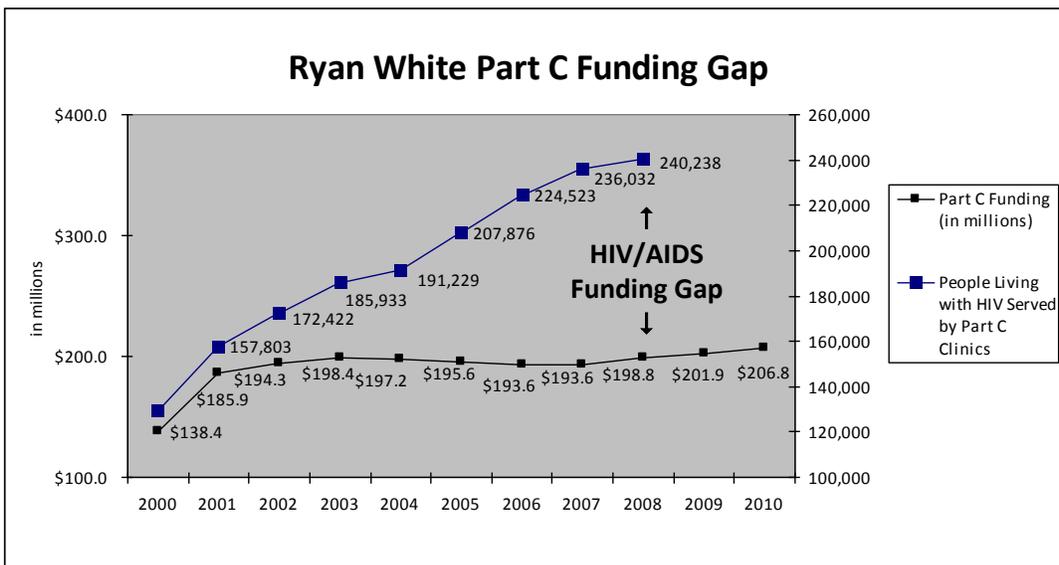
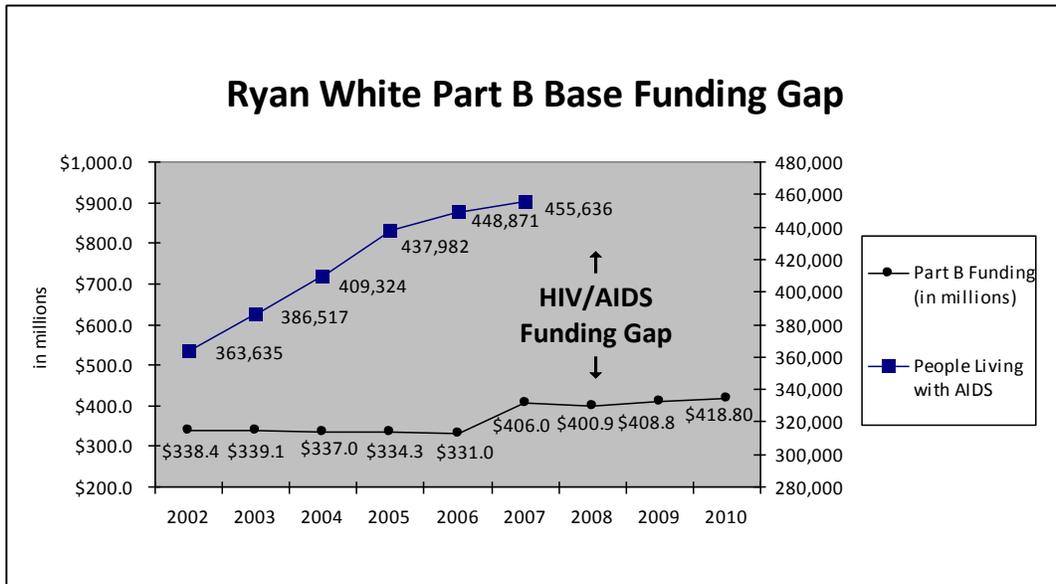
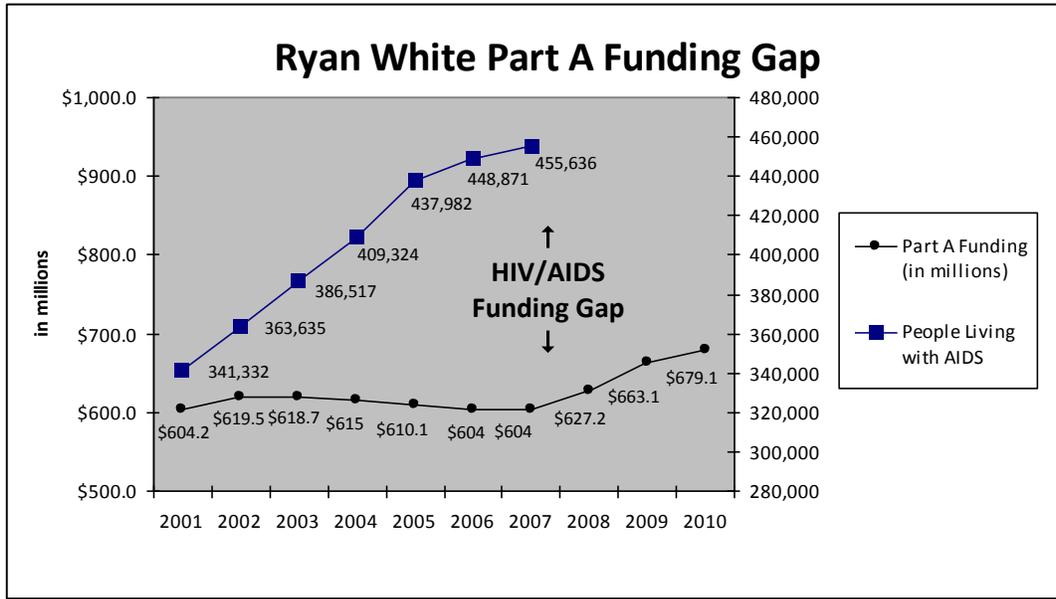
Part F—AIDS Education and Training Centers

\$37.4 million in 2011 and \$50 million in 2012 for AIDS Education and Training Centers would support the training of health care providers to care for growing patient caseloads and address the growing complexities of treating those with co-morbidities and drug side effects.

Funding Requests

We support the full community request for the entire Ryan White portfolio.

HIV/AIDS Funding Gaps: FY 2001–2010



OMB: The Ryan White HIV/AIDS Program Works

*The White House Office of Management and Budget’s assessment of the Ryan White Program found it to be in the **top 1% of all federal programs** in the area of “Program Results and Accountability.”*

In its 2007 Program Assessment Rating Tool (PART), OMB gave the Ryan White Program its highest possible rating of “effective”—a distinction shared by only 18% of all programs rated. According to OMB, effective programs “set ambitious goals, achieve results, are well-managed and improve efficiency.”

Ryan White Program PART Assessment Scores	
Purpose & Design	100%
Strategic Planning	86%
Program Management	91%
Program Results/Accountability	100%

Half of the OMB ranking is based on the category of “program results and accountability.” Out of the 1,016 federal programs rated—98 percent of all federal programs—the **Ryan White Program was one of seven** that received a score of 100% in “Program Results and Accountability.”

OMB’s Summary Assessment of the Ryan White Program

◆**The program has had a positive impact. It has contributed to the decline in the number of AIDS cases and deaths due to HIV/AIDS.** From 1999 to 2003 deaths due to HIV/AIDS went from 5.3 to 4.7 per 100,000. A cause of the decrease is increased use of antiretroviral medications. In 2000 the program's AIDS Drug Assistance Program (ADAP) served 128,078 clients. In 2005 ADAP served 143,339 clients.

◆**The program has exhibited strong and effective collaborations with similar programs.** The program collaborates with Federal, State and local partners, as well as with private and non-profit HIV/AIDS care, treatment and advocacy groups. By working with this wide range of partners, persons infected with and affected by HIV/AIDS receive coordinated comprehensive care and support services.

◆**The program has demonstrated improved management and oversight of the use of Federal funds.** The previous PART review and other assessments indicated deficiencies in the oversight of grantees' use of Ryan White funds. The program has taken corrective action by expanding grantee technical assistance and monitoring grantee financial accountability and performance.

Health Care Reform Implementation Priorities

Essential Health Benefits Package

Federal: advocate for a definition of the essential health benefits package in ways that provide the scope and level of services needed to meet the care and treatment needs of individuals living with HIV.

State and Local: urge state and local officials to weigh in with the Secretary, engage and train state Medicaid offices and key providers on new benefits, and engage state health officials to ensure that the Benchmark benefits package established for new Medicaid recipients includes the essential services needed for comprehensive HIV care.

State Option to Provide Health Homes for Medicaid Enrollees with Chronic Conditions

Federal: advocate for inclusion of HIV and AIDS in regulations defining what qualifies as a “chronic condition” in the Medicaid Health Home Program and ensure that states are provided with appropriate guidance as to how to set up these programs.

State and Local: encourage states to consider amending their state Medicaid plans to include this holistic coverage and thus become eligible for the 90% FMAP rates.

Increased Funding for Community Health Centers

Federal: push HRSA to encourage Community Health Centers applying for New Access Point grants to include comprehensive health and support services for people living with HIV and AIDS.

State and Local: encourage health centers to apply for grants to expand services for people living with HIV and AIDS. Clinics that are not in compliance with federal rules regarding qualified health centers should consider bringing themselves into compliance to be eligible for federal grants.

Funding for HIV/AIDS Prevention and Wellness Initiatives

Federal: advocate for HHS to target funds to support a broad range of HIV prevention and public health services needs, including grants for community-based organizations, funding for studies and initiatives addressing stigma, and funding to shore up state HIV/AIDS budgets.

State and Local: ensure that health centers and local and state health officials are aware of federal funding opportunities.

Primary Care Workforce Training and Expansion

Federal: push HHS to secure funding for training and retention of HIV/AIDS specialists as well as primary care physicians; work with HRSA to use the AIDS Education and Training Centers funded under Part F of Ryan White Programs as a model for broader health workforce training, especially around treatment for chronic conditions.

State and Local: work with states and localities to encourage health professional workforce development, such as by developing and collaborating with community health worker networks, and ensure that state and local health officials, health centers, and community-based organizations are aware of new federal funding opportunities.

Temporary High Risk Pools

Federal: push HRSA to explicitly allow Ryan White Program funds to be used to wrap-around risk pool coverage to address unmet care and service needs and to allow use of Ryan White funds to cover the premiums, copayments and deductibles of high risk pool insurance.

State and Local: push states that have opted to run their own plan to streamline the application process, such as by allowing HIV infection as an automatic eligibility criterion, and to use Ryan White funds for both wrap-around coverage and to meet beneficiary payment obligations.

Integration of Ryan White Programs into Health Care Reform Initiatives

Federal: work with HRSA and other federal agencies to advance the comprehensive and holistic models of care that have become the hallmark of Ryan White programs as health care reform is implemented, integrating Ryan White grantees and providers into both the Medicaid expansion and state exchanges; and develop recommendations for which care and service delivery systems funded by the Ryan White Program are replicable beyond HIV/AIDS services and should be used as a model for health care reform provisions (i.e., the “medical home” model).

State and Local: encourage Ryan White providers to integrate into Medicaid and state insurance exchange provider networks by developing the infrastructure necessary to contract with state Medicaid offices and state insurance exchanges. Educate and collaborate with Ryan White grantees to ensure seamless transition to insurance expansions going into effect over the next five years.

Section 1115 Medicaid Waivers

Federal: encourage CMS to work with states to successfully develop Section 1115 Waivers for people living with HIV specifically by asking that CMS create a new waiver initiative under Section 1115 to help states provide temporary Medicaid coverage through 2014 similar to the initiative that was created in response to Hurricane Katrina; expedite the application and review process; send a letter to state officials alerting states to the option of applying for a section 1115 waiver; promote the waiver option on its website; organize a conference call (or series of calls) that will include state Medicaid Directors and AIDS Directors to discuss the waiver option and address questions; appoint a designated CMS representative to provide technical assistance to states; and design a waiver template that includes what information states will need to provide to reach budget neutrality.

State and Local: encourage states to consider applying for a Section 1115 waiver.

Institute of Medicine: Determination of Essential Health Benefits

Activity Description

The Patient Protection and Affordable Care Act (PPACA), signed into law on March 23, 2010, will allow individuals and businesses to purchase health insurance directly through exchanges—competitive marketplaces where buyers can compare coverage. These exchanges will offer a choice of qualified health plans (QHPs) that vary in coverage levels but meet certain standards in categories of care and limits on patient cost sharing. The PPACA stipulates that these QHPs will cover the general categories of: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services including oral and vision care. Further details of an “essential health benefit” package are to be defined by the Secretary of Health and Human Services (HHS) based on the scope of benefits offered by a typical employer plan.

At the request of the Secretary of HHS, the IOM is undertaking a study that will make recommendations on the criteria and methods for determining and updating the essential health benefits package. The IOM will not define specific service elements of the benefit package. Instead, the IOM will review how insurers determine covered benefits and medical necessity and will provide guidance on the policy principles and criteria for the Secretary to take into account when examining QHPs for appropriate balance among categories of care; the health care needs of diverse segments of the population; and nondiscrimination based on age, disability, or expected length of life.

Additionally, the IOM will offer advice on criteria and a process for periodically reviewing and updating the benefits package.

The group has had two meetings in January and March (agendas follow) with a range of outside speakers, most from the federal government, the Hill, state health departments, insurance companies or policy experts. The January meeting also included testimony from a range of health provider associations (AMA, etc.) and four disease/condition-specific organizations:

- Autism Speaks
- National Coalition for Cancer Survivorship
- National Kidney Foundation
- Obesity Action Coalition

The group will have two additional meetings that are closed to the public (April and June) and expects to issue its report in September.

ADDITIONAL INFO, including audio files and all presentations:

<http://iom.edu/Activities/HealthServices/EssentialHealthBenefits.aspx>

Members

Dr. John R. Ball - (Chair)

John Ball is recently retired, previously serving as Executive Vice President of the American Society for Clinical Pathology from 2002-2010.

Dr. Elizabeth A. McGlynn

The RAND Corporation

Mr. Michael S. Abroe

Milliman, Inc.

Dr. Michael E. Chernew

Harvard Medical School

Dr. Paul Fronstin

Employee Benefits Research Institute

Dr. Robert S. Galvin

Equity Healthcare Blackstone Group

Ms. Marjorie Ginsburg

Center for Healthcare Decisions, Inc.

Dr. David S. Guzick

University of Florida

Dr. Sam Ho

UnitedHealth Group

Mr. Christopher F. Koller

State of Rhode Island

Ms. Amy B. Monahan

University of Minnesota, Minneapolis

Dr. Alan R. Nelson

Dr. Linda A. Randolph

Developing Families Center, Inc.

Dr. James E. Sabin

Harvard Medical School

Dr. John Santa

Consumers Union **Mr. Leonard D. Schaeffer**

University of Southern California

Dr. Joe V. Selby

Kaiser Permanente Medical Care Program

Dr. Sandeep Wadhwa

3M Health Information Systems

ASPE Remarks to the IOM Meeting on Essential Health Benefits

- Good morning. I'm Sherry Glied, the Assistant Secretary for Planning and Evaluation. The ASPE is the principal advisor to the Secretary of the U.S. Department of Health and Human Services on policy development and policy coordination.
- It is exciting to be here as you begin this study that will provide assistance to the Department in our work and will ultimately result in insurance coverage of essential health benefits for millions of Americans. Our tasks are difficult and complicated, and we value the assistance we will receive from this endeavor.
- I'd like to start by thanking Dr. Ball for his introduction and for chairing this Committee.
- I'd also like to extend my thanks to Roger Herdman and Cheryl Ulmer for their work assembling a panel with the broad expertise vital to conducting a thoughtful examination of the issues that must be considered as we go forward.
- The Administration is proud of the work we've done thus far in implementing the Affordable Care Act, and we are continuing to move ahead with full implementation of its provisions. You will hear more shortly about legislative intent, but I'll highlight the main requirements of the law as they relate to essential health benefits.
- To expand health insurance coverage to millions of Americans, the Affordable Care Act identified at least ten "essential" categories of items and services that must be included in a package of benefits:
 - Ambulatory patient services;
 - Emergency services;
 - Hospitalization;
 - Maternity and newborn care;

- Mental health and substance use disorder services, including behavioral health treatment;
 - Prescription drugs;
 - Rehabilitative and habilitative services and devices;
 - Laboratory services;
 - Preventive and wellness services and chronic disease management; and
 - Pediatric services, including oral and vision care.
- The Affordable Care Act delegated authority to define essential health benefits (EHBs) to the Secretary of Health and Human Services.
- Congress specified that the scope of EHBs should be equal to the scope of benefits provided under a typical employer plan. Work by the Department of Labor, of which you will hear more shortly, will help inform that determination.
- Additionally the Secretary, in defining and updating essential health benefits, must:
 - Ensure that such essential health benefits reflect an appropriate balance among the specified categories of care so that benefits are not unduly weighted toward any category;
 - Not make coverage decisions, determine reimbursement rates, establish incentive programs, or design benefits in ways that discriminate against individuals because of their age, disability, or expected length of life;
 - Take into account the health care needs of diverse segments of the population, including women, children, persons with disabilities, and other groups; and
 - Ensure that health benefits established as essential not be subject to denial to individuals against their wishes on the basis of the individuals' age or expected length of life or of the individuals' present or predicted disability, degree of medical dependency, or quality of life.

- Further, the Affordable Care Act allows use of those utilization management practices in common use by group health plans and health insurance issuers at the time of enactment and bars the issuance of regulations that would prohibit their use.
- EHBs are required to be offered by qualified health plans participating in Exchanges beginning in 2014, issuers in the individual and small group markets, Medicaid benchmark and benchmark-equivalent plans, and State basic health programs for low-income individuals not eligible for Medicaid. Federal regulations on lifetime and annual limits also apply in the context of EHBs.
- As the Department works to define EHBs, there are many factors we are keeping in mind. We realize that our decisions will lead to a set of coverage standards for significant segments of both private and public insurance markets across the country.
- We recognize the need to provide clear direction to the States and insurance industry. We understand that, under the Act, States are obligated to pay for benefits they mandate above and beyond those required by the Secretary. We also acknowledge the Nation's diversity and the need for flexibility across the States in addressing their varying circumstances and priorities.
- We recognize the need to provide meaningful coverage while ensuring an affordable premium. Above all, we strive to remember the interests of consumers and patients.
- We have sought your help because of the IOM's expertise in establishing processes, long history of successfully convening diverse groups of stakeholders, and your reputation for objectivity and even-handedness.

- This Committee’s report will be an important component of our approach to defining EHBs. ASPE will work closely with the Center for Consumer Information and Insurance Oversight and other HHS agencies in taking next steps as soon as possible after receiving the Committee’s recommendations.
- It is against this backdrop that your work begins. What we are looking for from you are your thoughts and advice on a process and considerations the Department needs to take into account in its initial establishment of EHBs and in updating them over time.
- You know, and it is worth emphasizing for those in the audience who may not, that we do not expect this Committee to identify the individual elements or the detailed provisions of a package of essential health benefits. Instead, we are looking for a framework for considering EHBs that will be logically cohesive, address statutory requirements, and serve us now and in the future. We seek your guidance on questions such as these:
 - At what level of specificity should essential health benefits be framed? How are issues of time, duration, frequency, scope and specific services best addressed?
 - What defines and distinguishes a medical service from a non-medical service? How should this distinction be considered and applied in the context of defining EHBs?
 - How can a federal standard for benefits coverage best reconcile state and regional variations in practices and benefits coverage patterns, including variations in state-mandated benefits? How much flexibility should be given to States or to Exchanges?
 - What can be learned from the practices of employers who offer multiple plans about plan design, consistency and fairness?
 - Considering the varying health needs of diverse populations, what policy principles and criteria should be taken into

account to prevent discrimination? How can these considerations best be balanced against the content of a “typical employer plan” and the cost of insurance coverage?

- Assuming that insurers continue to have a role in deciding exactly which services to pay for, what information is needed to monitor the decisions that are made, how should that information be collected, and how should that information be used, if at all, in updating the definition of EHBs? What are the roles of Exchanges, States and the Federal Government in this task?
 - What criteria should be used to adjust EHBs over time and what should the process be for their modification? How can we ensure that over time modifications to EHBs are consistent with initial benefit design but reflect evolving science?
-
- To accomplish its work, it is critical that the Committee obtain public input—through forums such as this workshop—from a wide variety of stakeholders. That work is well underway. In addition to the views we will hear today and tomorrow, the IOM has received over 300 responses to a set of questions posted on its website that are being reviewed both at the IOM and within the Department. Also, numerous organizations have contacted us at HHS and shared their views. We value their insights and engagement in this process.
 - I’d like to close by thanking you for having accepted this difficult task. Your guidance is critical to us and will help ensure that millions of Americans receive coverage for the essential benefits they need to live healthier, more productive lives.

Committee on Determination of Essential Health Benefits

Statement

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Introduction

Good afternoon. Let me begin by thanking the Committee for this opportunity to appear before you today.

This Committee's work concerns one of the foundational aspects of the Affordable Care Act. My remarks focus on the legislative framework of the essential health benefits statute, because of the extent to which this framework must guide the Committee's deliberations. This Statement reflects my research into the legislative, administrative, and judicial aspects of the regulation of the content of health insurance in both the public and private markets.

The essential health benefits statute is unique. Because its legislative history is quite limited, the text itself takes on particular importance. The provisions of the statute differ significantly from the highly detailed coverage terms of Medicare Parts A and B. Similarly, its provisions differ from the coverage provisions of the Employee Retirement Income Security Act, which governs virtually all private employer-sponsored health benefit plans and which (with the important exception of the insured small group market)² remains unaffected by the essential health benefits provision. In referencing broad benefit categories, the essential health benefits statute bears some resemblance to the structure of the Medicaid benchmark coverage statute³ and the Children's Health Insurance Program (CHIP).⁴ At the same time, however, the statute is substantially more robust and in certain respects carries echoes of Medicaid's heretofore unique non-discrimination rule.

I begin with an overview of the legal structure of health insurance coverage and then turn to the provisions of the statute, concluding with recommendations for the Committee's deliberations.

¹ Support for this statement comes from the Commonwealth Fund, and the analysis presented here is based in part on a forthcoming policy brief prepared for the Fund.

² PHSA §2707, added by PPACA §1201

³ 42 USC §1396u-7

⁴ 42 U.S.C. §1397cc(a)

The Legal Structure of Health Insurance Coverage

Health insurance coverage entails legal and financial risk. For this reason the health benefit services companies that sell licensed insurance and third party administered products logically seek to structure their products to provide as much risk exposure protection against the covered population. These risk avoidance techniques go well beyond simply strategies for assuring that insurance pays only for medically necessary care and allow insurers to exclude and deny health care and treatment that are justified by the clinical and scientific evidence but considered to fall outside the scope of coverage.⁵

A review of the extensive case law generated by health benefit and coverage disputes over the decades -- and that through the discovery process offers incomparable insight into the coverage practices of both public and private insurers -- underscores the various structural and drafting strategies used by insurers to limit coverage risk:

Definitions and terms related to specific benefit categories or specific treatment items and services within categories: By defining a coverage term narrowly, an insurer or plan administrator can shield itself from risk. For example, defining speech therapy as therapy needed to restore previous speech function, an insurer can prevent its exposure to the costs associated with developmentally disabled children who demonstrate a clinical need for speech therapy to attain speech. An insurer also can eliminate its exposure to an individual with muscular dystrophy who needs therapy from a clinical perspective to maintain a level of speaking function or avert the loss of speech.

Definitions of “medical necessity” and “experimental.” In defining broad terms such as medical necessity, insurers and plan administrators similarly can place limits on coverage. Perhaps the two most important definitions in this regard are “medical necessity” and “experimental,” both of which can be used to narrow the scope of otherwise available coverage. A medical necessity definition that ties coverage to restoration or recovery would have such a limiting impact on coverage, because its impact would be to place certain types of treatments (i.e., treatments to aid in development or avert loss of function or maintain function) beyond the scope of coverage, regardless of the facts of the case. Similarly, a definition of experimental that excludes any treatment not proven effective through scientifically structured clinical trials would in turn result in the exclusion of most accepted forms of medical treatment from the terms of the plan.

Coverage exclusions. Plan documents may contain coverage exclusions whose impact is to place otherwise covered benefits outside the scope of a plan, even when the documented clinical and scientific evidence for coverage may be evident. These exclusions can be based on the patient’s condition or characteristics or linked to the treatment setting (e.g., otherwise-covered speech therapy when furnished in a school

⁵ One of the clearest examples of such an exclusion is the “intoxication” exclusion, by which on “moral” grounds, insurers and health plans routinely exclude coverage for the type of clinically effective treatments identified by Elizabeth McGlynn and colleagues in “The Quality of Health Care Delivered to Adults in the United States,” *New Eng. Jour. Medicine* 348:2635-2645 (June 26, 2003) Table 5.

setting). For example, clinically appropriate physical therapy for a child with developmental disabilities might be excluded on the basis that it is “behavioral” or “educational,” either because one purpose of the intervention is to aid in proper development or because the need for therapy is identified in an individualized educational plan. (Not surprisingly, perhaps, many coverage denial cases involve children with physical, mental, behavioral, and developmental disabilities).

Embedding treatment guidelines into plan documents. Treatment guidelines can be used as informal aids that guide coverage determinations. Insurers and plan administrators also can embed treatment guidelines into plan documents, in which case the limits operate as fixed coverage limits that automatically narrow the scope of coverage to whatever might be contained in the guideline, regardless of whether a patient’s particular condition or clinical and other evidence might suggest a different or more intensive approach.⁶

Numerical limits on certain treatments. A plan can contain fixed limits on services such as 10 outpatient therapy sessions or 30 days of hospitalization per spell of illness or exclusion of certain types of treatments such as complications in connection with an underlying condition whose treatment is excluded.⁷ Such limitations on coverage would, in the absence of other language, apply across the board regardless of patient condition.

Reserving discretion to interpret and apply plan terms and limiting the opportunity to challenge denials resulting from individual utilization review. In the absence of federal or state law to the contrary, a plan administrator or insurer can reserve to itself the discretion to define the terms of its plan.⁸ This reservation in turn creates a deferential standard in the courts (unless a conflict of interest is found to exist).⁹ (The Affordable Care Act establishes independent external review as a right of all ERISA health plan participants and beneficiaries,¹⁰ although how this right ultimately affects the ERISA deference standard is yet to be decided by the courts.)

The Provisions of the Affordable Care Act and the Essential Health Benefits Statute

Elsewhere, the Affordable Care Act addresses issues of transparency and access to independent reviews. These provisions ultimately have the potential to temper the level

⁶ See, e.g., *Jones v The Kodak Medical Assistance Plan*, 169 F.3d 1287 (10th Cir. 1999); *Mondry v American Family Mutual Insurance Co.* 557 F. 3d 781 (7th Cir., 2009).

⁷ See, e.g., *Kenseth v Dean Health Plan*, 610 F. 3d 452 (7th Cir., 2010)

⁸ The authority to reserve discretion to interpret plan documents in the case of ERISA-governed plans was set forth by the United States Supreme Court in *Firestone Tire and Rubber v Bruch*, 489 U.S. 101 (1989). In the context of insured health plans, several states have enacted laws barring the use of discretionary clauses, which have been upheld under ERISA as “saved” on the ground that they are laws that regulate insurance. *Standard Ins. Co. v Morrison*, 584 F. 3d 837 (9th Cir., 2009), *cert. den. sub nom, Standard Ins. Co. v Lindeen*, 130 S. Ct. 3275 (2010)

⁹ *Metropolitan Life Insurance Company v Glenn*, 554 U.S. 105 (2008)

¹⁰ PHSA §2719, added by PPACA §1001 and applied to ERISA through PPACA §1563

of deference accorded insurers and plan administrators in cases in which plan documents related to coverage must be interpreted and applied.

The essential health benefits statute itself principally focuses on the actual content of coverage. Under the terms of the Act, the provisions apply to the individual and small group markets both inside and outside state health insurance Exchanges.¹¹ As a result, the statute has the potential to transform coverage in these markets on a national scale. Furthermore, because a relatively handful of companies are so influential in the design of insurance and health plan products, coverage changes flowing from the essential benefit statute eventually may reverberate through the larger group markets as well, whether insured or self-insured.

The following provisions of the statute set forth the core parameters of the Secretary's decision-making powers where essential health benefits are concerned:

First, the statute sets forth the HHS Secretary's definitional duties. Specifically the statute directs the Secretary to "define the essential health benefits *except that such benefits shall include at least the following general categories and the items and services covered within the categories*: A. ambulatory patient services; B. emergency services; C. hospitalization; D. maternity and newborn care; E. mental health and substance use disorder services, including behavioral health treatment; F. prescription drugs; G. rehabilitative and habilitative services and devices; H. laboratory services; I. preventive and wellness services and chronic disease management; and J. pediatric services, including oral and vision care [italics added].¹² The statute thus not only enumerates 10 general categories of covered services and benefits but also specifies that the categories include the items and services covered within the categories.

Second, the statute imposes certain requirements related to the Secretary's interpretation of coverage. Specifically, the statute provides that the "Secretary shall ensure that the *scope of the essential health benefits . . . is equal to the scope of benefits provided under a typical employer plan, as determined by the Secretary*" [italics added].¹³ The concept of benefit scope would commonly be understood as relating to the items and services falling within each general category. Under the statute, the question of scope is an empirical one that is to be informed by an employer plan survey to be conducted by the Department of Labor. The question of scope, furthermore, is not merely legal but under the terms of the statute is also actuarial, since equality in coverage must be actuarially certified.¹⁴

Complicating the question of equal scope is the fact that common exclusions used by insurers and plan administrators mean certain general categories of services (e.g., behavioral services, habilitative services) are seldom found in an employer plan; if

¹¹ PHSA §2707, added by PPACA §1201. A small group that self insures would not be subject to the essential health benefit requirements, since self insured plans are not governed on matters of benefit content by laws that regulate insurance.

¹² PPACA §1302(a) and (b)

¹³ PPACA §1302(b)(2)(A)

¹⁴ PPAA §1302(b)(2)(B)

present at all, they may contain limits far below the standard of treatment. Indeed, were the scope of behavioral or habilitation services to be equal to that found in the typical employer plan, the essential health benefit package conceivably might contain zero coverage for certain general benefit categories.

Third, the statute sets forth certain “required elements for consideration.” The core elements are as follows: In “defining” essential health benefits, the Secretary “shall” (A) “ensure” that the essential health benefits “reflect an *appropriate balance among the categories*. . . so that benefits are not *unduly weighted* toward any category;” (B) not make “coverage decisions, determine reimbursement rates, establish incentive programs, or design benefits in ways that *discriminate* against individuals *because of their age, disability, or expected length of life*;” (C) “*take into account* the health care needs of diverse segments of the populations, including women, children, persons with disabilities, and other groups;” and (D) “ensure that health benefits established as essential not be subject to denial to individuals against their wishes *on the basis of* the individuals’ age or expected length of life or of the individuals’ present or predicted disability, degree of medical dependency, or quality of life”.¹⁵ [italics added]

Key Considerations That Can Guide the Committee’s Deliberations

1. Who decides the scope of coverage?

Under the terms of the statute, it is the HHS Secretary who, aided by a survey conducted by the Department of Labor, decides the scope of coverage including the coverage categories, the items and services that fall within coverage categories, and therefore, the definitional terms that apply to categories, items, and services. These decisions are expressly left to the discretion of the Secretary, not insurers or plan administrators, although the Secretary conceivably could instruct insurers and plan administrators to utilize the terms and definitions in their most popular group health products as long as such terms and definitions are not discriminatory within the meaning of the statute.

2. How to define coverage categories, as well as items and services within coverage categories, that are not contained in plan documents?

As noted, through total exclusion or the use of exclusionary definitional terms, plan documents may exclude entire classes of coverage categories or items and services within coverage categories. In such circumstances the duty clearly lies with the Secretary to develop the definitions that convey scope, since to limit her interpretation only to items and services found in plan documents risks reading entire coverage categories out of the statute. Terms such as “behavioral” services and “habilitative” services therefore may necessitate a review of the literature as well as consultation with experts in the field in order to ensure that effective treatments are properly brought within the terms of coverage.

3. What is an “appropriate balance” among coverage categories?

¹⁵ PPACA §1302(b)(4)(A)-(D)

In the context of the statute, the concept of “appropriate balance” appears to relate to the actuarial value of the benefit categories in relation to the total premium so that to at least some degree, all items and services are represented. Furthermore, this determination is to be made by the Secretary in consultation with the CMS chief actuary and does not appear to signal an actuarial equivalency test that can be independently applied by insurers and plan administrators. Indeed, in cases in which Congress has permitted an actuarial equivalency test, it has been explicit in permitting such an approach.¹⁶

4. *What does it mean to not discriminate against individuals because of their age, disability, or expected length of life and how far does the non-discrimination prohibition extend?*

With the exception of discrimination based on sex, civil rights laws addressing discrimination against individuals based on status (being an individual with a disability, on the basis of race or national origin, or on the basis of age) have not been understood as reaching the content of health insurance.¹⁷ The clearest precedent for the prohibition found in the essential benefit statute can be found in the Medicaid statute, whose “reasonableness” provision¹⁸ has, since the law’s original enactment,¹⁹ been understood by both the agency²⁰ and the courts²¹ as barring arbitrary limits in required services based solely an individual’s condition, diagnosis, or type of illness. Furthermore, at least two recent court decisions suggest that at least some courts also will reject coverage denials under Medicare where the basis of the denial is the arbitrary exclusion of otherwise covered services based on absence of “recovery” potential.²²

Of particular importance to the Committee would be the following considerations:

- *The circumstances in which age reasonably can be a coverage factor that rests on clinical and scientific evidence.* The statute bars discrimination, not the use of patient characteristics when such characteristics rest on a reasonable clinical and scientific evidentiary base. A decision cannot be made “on the basis of age,” but a decision based on clinical factors of which age is a recognized factor (such as

¹⁶ See, e.g., Children’s Health Insurance Program and the Medicaid benchmark coverage statute, *supra*.

¹⁷ See, e.g., *See Doe v. Mutual of Omaha Insurance Co.*, 179 F.3d 557 (7th Cir. 1999), cert. denied, 528 U.S. 1106 (2000) (The public accommodations provisions of the ADA do not reach the content of private health insurance); *Alexander v. Choate*, 469 U.S. 287 (1985) (Section 504 of the Rehabilitation Act does not reach the content of public health insurance); see also Sara Rosenbaum, *Insurance Discrimination Based on Health Status* (Georgetown University, O’Neill Institute) <http://www.law.georgetown.edu/oneillinstitute/national-health-law/legal-solutions-in-health-reform/Discrimination.html> (Accessed January 5, 2011); Mary Crossley, “Discrimination Against the Unhealthy in Health Insurance,” *Kansas Law Review*, 54 (2005): 73-153, at 85-87.

¹⁸ 42 U.S.C. §1396a(a)(17)

¹⁹ The precursor to the federal non-discrimination rule can be found in the *Handbook of Public Administration, Supplement D*, issued in 1966 by HEW.

²⁰ 42 C.F.R. §440.230(c0)

²¹ See, e.g., *Pinnecke v Preiser* 623 F. 2d 546 (8th Cir. 1980)

²² See, e.g., *Papciak v Sibelius* ___ F. Supp. 2d ___, 2010 WL 3885605 (W.D.Pa.); *Anderson v Sibelius*, ___ F. Supp. 2d ___, 2010 WL 4273238 (D.Vt.) ;

when best to immunize a child against certain diseases), would not be a decision whose basis is age.

- *The types of situations in which coverage decisions would impermissibly discriminate on the basis of disability.* Presumably the Committee will be guided by the Americans with Disabilities Act in defining the concept of disability, since the ADA addresses the issue of employee health benefits and individual insurance coverage outside of the content of coverage context.²³ As noted, a common discrimination scenario that arises under private health insurance is one in which a “restore” or “recover” test is part of the item specific or broad terms of coverage or practice guidelines embedded into plan documents that define the scope of coverage and what is excluded from coverage. Tests that require recovery or restoration inherently discriminate against individuals for whom the appropriate clinical basis of an intervention is its impact on the attainment or maintenance of function or the aversion of functional loss. When these conditions are present, the fact that a covered treatment also may be reflected in an employment plan, an individualized education plan, or some other document addressing the work-related, social, developmental, or educational needs of a patient should not be a permissible basis of exclusion.
- *The circumstances under which an individual’s expected length of life is appropriate.* In the case of hospice treatment, for example, length of life would appear to be a proper consideration. On the other hand, the statute withdraws expected length of life as a criterion where reasonable clinical and other relevant evidence shows an individual’s ability to benefit from a treatment, with the concept of “to benefit” defined to encompass attainment and maintenance of health as well as avoidance of deterioration).

In sum, what the statute bars is discrimination in coverage design and plan administration. Limits are not prohibited; what are prohibited are limits that discriminate. Thus, hospitalization of 30 days per spell of illness or 60 physical therapy treatments may limit medically necessary care, but they do so without regard to the underlying condition. To be sure, such limits fall with particular severity on the sickest members of the coverage groups and are undesirable for many reasons (the most desirable result is of course to have enough scientific and clinical evidence to be able to make coverage design and administration decisions solely on the basis of the evidence). But courts have ruled that across-the-board limits on scope are not discriminatory against persons with disabilities under federal civil rights laws, nor, presumably, would across-the-board limits “discriminate” against individuals because of age or expected length of life. What makes the conduct of insurers “discriminatory” is the use of coverage terms, limits and exclusions that fall solely on protected groups that cannot meet the qualification standards for whatever coverage is available.

It is also important to note that the scope of the statute’s non-discrimination provision sweeps broadly, reaching questions of both coverage design and plan administration

²³ ADA Titles I and III and §505 (related to the insurance “safe harbor”)

activities related to the implementation of coverage, including “coverage decisions,” “reimbursement rates” and “incentive programs.” In this context there thus are two types of coverage decisions: decisions related to plan design (what benefits, items and services will be covered for any member) and the application of plan design to individual patients (that is, whether a particular covered item or service be allowed for a particular patient given her clinical condition and other relevant and reliable evidence). Coverage decisions related to plan design, as well as permissible approaches to reimbursement rates and incentive programs, plainly are within the province of the Secretary under the law. Individual coverage decisions would most likely be made by a plan administrator during the course of utilization review and claims appeal provisions of the Affordable Care Act.

In the context of the non-discrimination provision, an important precedent to consider is regulations implementing the 2008 mental health parity amendments. These amendments have been interpreted by the Departments of Health and Human Services, Labor, and Treasury as addressing issues of both coverage design and plan administration as well as discrimination in both quantitative (i.e., day limits, treatment frequency limits) and non-quantitative matters (discriminatory terms and definitions, discriminatory medical necessity standards, discriminatory use of embedded treatment guidelines).²⁴

5. How might the health needs of diverse population segments be taken into account?

The question of coverage that takes the needs of diverse populations into account is one that appears to address the decision-making process rather than a particular result. Thus, through the rulemaking process, including requests for information and comments, as well as by referencing evidence-based treatment guidelines where available (such as guidelines for the treatment of conditions affecting women, children, persons with disabilities, and other groups), the Secretary would appear to fulfill the requirements of the statute.

6. How might the Committee approach the bar against coverage denials against an individual's wishes on the basis of age, expected length of life, or present or predicted disability, degree of medical dependency, or quality of life?

As with the question of discrimination, the bar against denials on the basis of age, expected length of life, or present or predicted disability, degree of medical dependency, or quality of life can be read as barring the use of any of the prohibited factors as the sole basis for denial, or the use of coverage terms that exclude otherwise covered treatments *a priori* on prohibited grounds. Thus, coverage terms that exclude treatments because they are not restorative would constitute a denial based on present or predicted disability, medical dependency or quality of life. By contrast, however, unwise in relation to access to necessary medical care, an across-the-board limit on treatment for all persons, while disproportionately affecting persons with serious illnesses, medical dependency, or disability, would not be a limitation that turns on a prohibited factor. Similarly, an individual coverage decision that denies an otherwise medically necessary and

²⁴ See 75 Fed. Reg. 5410-5451 (Feb. 2, 2010). See 45 C.F.R. §146.136(a) defining the scope of parity in relation to both qualitative and quantitative treatment limits.

appropriate treatment on the basis of the individual's status as a person with a disability or medical dependency, obviously would be prohibited.

In sum, the key concept that runs throughout the statute is "on the basis of." In health insurance, questions of coverage, whether arising as part of a plan design that applies to all members, or as a result of the application of design to a particular case, would optimally always be grounded in clinical and scientific evidence regarding appropriateness of treatment. The use of arbitrary limits unrelated to the need for care is always unwise because of the impact of such limits on persons who need care. At the same time, certain arbitrary limits are inherently discriminatory because they fall exclusively on persons with disabilities or serious illness, the prime example being the use of a recovery test. Viewed in this light, the Committee might consider a recommendation that permissible coverage limitations and exclusions be restricted to those that apply across the board rather than falling exclusively on sub-populations with health conditions that either prohibit "recovery" or that, because they are present at birth, make recovery irrelevant.

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Office of Media Affairs

MEDICARE FACT SHEET

FOR IMMEDIATE RELEASE
Mar. 31, 2011

Contact: CMS Office of Media Affairs
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What Providers Need to Know:

Accountable Care Organizations

On March 31, 2011, the Centers for Medicare & Medicaid Services (CMS), an agency within the Department of Health and Human Services (HHS), proposed new rules under the Affordable Care Act to help doctors, hospitals, and other health care providers better coordinate care for Medicare patients through Accountable Care Organizations (ACOs). ACOs create incentives for health care providers to work together to treat an individual patient across care settings – including doctor’s offices, hospitals, and long-term care facilities. The Medicare Shared Savings Program will reward ACOs that lower growth in health care costs while meeting performance standards on quality of care and putting patients first. Patient and provider participation in an ACO is purely voluntary.

Under the proposal, ACOs – teams of doctors, hospitals and other health care providers working together – would coordinate and improve care for patients with Original Medicare – Medicare Parts A and B. ACOs would have to meet high quality standards to ensure patients are happy with the care they receive and have better health outcomes. And if ACOs can help save money by getting patients the right care at the right time, they can share in those savings with Medicare. As proposed, ACOs could also have to pay back Medicare for failing to provide efficient, cost-effective care. The new program would begin on January 1, 2012.

This fact sheet describes the proposals to ensure that ACOs provide high-quality care, including proposed quality measures, and a proposed method for scoring the performance of the ACO for purposes of the Medicare Shared Savings Program. There will be a 60 day public comment period on this proposed rule. CMS encourages all interested members of the public, including providers, suppliers, and Medicare beneficiaries to submit comments so that CMS can consider them as it develops final regulations on the program.

-More-

What is an ACO?

Under the proposed rule, an ACO refers to a group of providers and suppliers of services (e.g., hospitals, physicians, and others involved in patient care) that will work together to coordinate care for the patients they serve in Original Medicare. The goal of an ACO is to deliver seamless, high-quality care for Medicare beneficiaries, instead of the fragmented care that often results from different providers receiving different, disconnected payments. The ACO would be a patient-centered organization where the patient and providers are partners in care decisions.

The Affordable Care Act specifies that an ACO may include the following types of groups of providers and suppliers of Medicare-covered services:

- ACO professionals (i.e., physicians and hospitals meeting the statutory definition) in group practice arrangements,
- Networks of individual practices of ACO professionals,
- Partnerships or joint ventures arrangements between hospitals and ACO professionals, or
- Hospitals employing ACO professionals.
- Other Medicare providers and suppliers as determined by the Secretary

In the proposed rule, the Secretary has made clear that certain critical access hospitals are eligible to participate in the Shared Savings Program.

How Could Providers Participate?

To participate in the Shared Savings Program, providers must form or join an Accountable Care Organization (ACO) and apply to CMS. An existing ACO will *not* be automatically accepted into the Shared Savings Program. If accepted, they would serve at least 5,000 Medicare patients and agree to participate in the program for three years. Medicare providers who join an ACO that participates in the Program would continue to receive payment under Original Medicare fee-for-service (FFS) rules.

The statute also requires each ACO to establish a governing body representing ACO providers of services, suppliers, and Medicare beneficiaries. The ACO would be responsible for monitoring

and reporting of the care it delivers. The proposed rule outlines a monitoring and reporting plan that includes analyzing claims and specific financial and quality data, producing quarterly and annual aggregated reports, performing site visits, and conducting beneficiary surveys.

How Would Shared Savings Work?

Under the proposed rule, Medicare would continue to pay individual providers and suppliers for specific items and services as it currently does under the Original Medicare payment systems. CMS would also develop a benchmark for each ACO against which ACO performance is measured to assess whether it qualifies to receive shared savings, or be held accountable for losses. The benchmark is an estimate of what the total Medicare fee-for-service Parts A and B expenditures for ACO beneficiaries would otherwise have been in the absence of the ACO, even if all of those services would not have been provided by providers in the ACO. The benchmark would take into account beneficiary characteristics and other factors that may affect the need for health care services. This benchmark would be updated for each performance year within the three-year performance period.

CMS is proposing to implement both a one-sided risk model (sharing of savings only for the first two years and sharing of savings and losses in the third year) and a two-sided risk model (sharing of savings and losses for all three years), allowing the ACO to opt for one or the other models. CMS believes this approach would have the advantage of providing an entry point for organizations with less experience with risk models, such as some physician-driven organizations or smaller ACOs, to gain experience with population management before transitioning to a risk-based model, while also providing an opportunity for more experienced ACOs that are ready to share in losses to enter a sharing arrangement that provides a greater share of savings, but at the risk of repaying Medicare a portion of any losses.

CMS is also proposing to establish a minimum sharing rate that would account for normal variations in health care spending. The minimum savings rate is a percentage of the benchmark that ACO expenditure savings must exceed in order for an ACO to qualify for shared savings in any given year. Under the proposed rule, ACOs in the one-sided risk program that have smaller populations (and having more variation in expenditures) would have a larger MSR and ACOs with larger populations (and having less variation in expenditures) have a smaller MSR. Under the two-sided approach, CMS is proposed a flat 2 percent minimum sharing rate.

If an ACO meets quality standards and achieves savings exceeding the minimum saving rate, the ACO would share in savings, based on the quality score of the ACO. The proposed rule would

provide for additional shared savings for ACOs that include beneficiaries who receive services from a Federally Qualified Health Center or Rural Health Clinic during the performance year.

ACOs that Participate in the Two-Sided Risk Model Can Obtain Greater Shared Savings

To qualify for shared savings, ACOs must meet certain quality and performance standards and have total per capita costs for assigned beneficiaries in the performance year to be both below the estimated updated benchmark and above the minimum savings rate. Once the ACO surpasses the minimum savings rate, it may share in savings if it is eligible to receive shared savings based on its quality performance score. To provide a greater incentive for ACOs to adopt the two-sided risk approach, the maximum sharing percentage is 60 percent for ACOs in the two-sided model compared to 50 percent in the one-sided model. In addition, under the two-sided model, ACOs would receive shared savings for the first dollar after the minimum savings rate is achieved. In contrast, under the one-sided model, ACOs would share on savings after a 2 percent threshold is met, with an exemption for small ACOs in rural or underserved communities. Under both models, an ACO would be eligible for a greater portion of shared savings the higher its quality and performance score.

The proposed rule also provides a methodology for determining shared losses for ACOs in the two-sided model (or year three of the one-sided model) if the per capita cost per beneficiary were more than 2 percent higher than the benchmark. As with shared savings, the amount of shared losses would be based in part on the ACO's quality performance score. Additionally, CMS is also proposing a shared loss cap of 5 percent of the benchmark in the first year of the Shared Savings Program, 7.5 percent in the second year, and 10 percent in the third year.

Participation in the First Program Year Allows for ACOs to Obtain the Maximum Sharing Rate if they Successfully Report Quality Measures

CMS is encouraging providers to participate in the Shared Savings Program in 2012 by setting the quality performance standard to reporting only. ACOs would be eligible for the maximum sharing rate (60 percent for the two-sided model and 50 percent for the one-sided model) if the ACO generates sufficient savings and successfully reports the required quality measures. This flexibility would allow newly formed ACOs a grace period as they start up their operations and learn to work together to better coordinate patient care.

The Proposed Quality Measurement is Aligned with Other CMS Quality Initiatives

CMS has proposed to measure quality of care using nationally recognized measures in five key domains: patient experience, care coordination, patient safety, preventive health, and at-risk population/frail elderly health. These measures are aligned with the measures in other CMS programs such as the Electronic Health Records (EHR) and Physician Quality Reporting System (PQRS). An ACO that successfully reports the quality measures required under the Shared Savings Program would be deemed eligible for the PQRS bonus.

ACOs may not participate, however, in any other shared savings program or demonstration under the Center for Medicare and Medicaid Innovation or Independence At Home Medical Practice pilot program to ensure that savings are not counted twice.

Existing Clinically Integrated Entities Need Not Form New Entities to Participate in the Shared Savings Program

If an ACO is already comprised of a self-contained financially and clinically integrated entity that has a pre-existing board of directors or other governing body, the ACO need not form a separate governing body or create a new legal entity. The existing entity, however, must be recognized under applicable State law, be capable of receiving and distributing shared savings and repaying shared losses, and meet the other ACO functions identified in the statute.

How ACOs Help Doctors Coordinate Care

Health care providers have reported that an important barrier to improving care coordination is lack of information. While they may know about the services they provide to the beneficiary, they don't know about other services provided to the beneficiary. To better treat patients and to coordinate their care, ACOs would be able to request claims information about their patient from CMS. Before doing so, ACOs must notify a beneficiary in writing that it would request the beneficiary's claims information from CMS. ACOs must allow beneficiaries to opt-out of having their claims information shared with the physician and the ACO. This opting out of having claims information shared, however, does not affect the patient's participation in the ACO or CMS's use of the patient's data for purposing of assessing quality or cost measures. This notification must happen the first time the ACO cares for the beneficiary.

Alignment of CMS Requirements and Other Federal Laws

CMS has worked closely with agencies across the Federal government to facilitate participation in the Shared Savings Program by coordinating federal fraud and abuse requirements, tax guidance, and antitrust considerations. In particular, the Federal Trade Commission and the Antitrust Division of the Department of Justice have proposed an antitrust policy statement that clarifies application of the antitrust laws to Medicare Shared Savings Program -approved ACOs that negotiate and contract with commercial payers. *See: Medicare Fact Sheet: Federal agencies address legal issues regarding Accountable Care Organizations*

The Shared Savings Program NPRM will appear in the April 7, 2011 issue of the *Federal Register*. CMS will accept comments on the proposed rule until June 6, 2011, and will respond to them in a final rule to be issued later this year. The Shared Savings Program will begin operating on January 1, 2012.

For more information, please see:

www.ofr.gov/inspection.aspx?AspxAutoDetectCookieSupport=1

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Perspective

Launching Accountable Care Organizations — The Proposed Rule for the Medicare Shared Savings Program

Donald M. Berwick, M.D., M.P.P.

A common criticism of U.S. health care is the fragmented nature of its payment and delivery systems. Because in many settings no single group of participants — physicians, hospitals, public or

private payers, or employers — takes full responsibility for guiding the health of a patient or community, care is distributed across many sites, and integration among them may be deficient. Fragmentation leads to waste and duplication — and unnecessarily high costs.

Section 3022 of the Affordable Care Act (ACA) establishes the Medicare Shared Savings Program for accountable care organizations (ACOs) as a potential solution.¹ The creation of ACOs is one of the first delivery-reform initiatives that will be implemented under the ACA. Its purpose is to foster change in patient care

so as to accelerate progress toward a three-part aim: better care for individuals, better health for populations, and slower growth in costs through improvements in care. Under the law, an ACO will assume responsibility for the care of a clearly defined population of Medicare beneficiaries attributed to it on the basis of their patterns of use of primary care. If an ACO succeeds in both delivering high-quality care and reducing the cost of that care to a level below what would otherwise have been expected, it will share in the Medicare savings it achieves.

On March 31, 2011, the De-

partment of Health and Human Services took a major step toward establishing ACOs by issuing a notice of proposed rule-making that will define how physicians, hospitals, and other key constituents can adopt this new organizational form. The issuing of the proposed rule follows months of obtaining informal and formal input from throughout the health care delivery system, but at this point the rule is only a proposal. The Centers for Medicare and Medicaid Services (CMS) will carefully review the comments we receive in response to the proposed rule before issuing a final rule later this year.

A critical foundation of the proposed rule is its unwavering focus on patients. We envision that successful ACOs will honor individual preferences and will

engage patients in shared decision making about diagnostic and therapeutic options. Information management — making sure patients and all health care providers have the right information at the point of care — will be a core competency of ACOs. Held to rigorous quality standards (see table), ACOs will be expected to be proactive in their orientation and to regularly reach out to patients to help them meet their needs for preventive and chronic health care. Patients who seek care at their ACO will know that their physicians are part of that ACO, but as beneficiaries of fee-for-service Medicare, they will continue to be free to seek care from any Medicare provider they wish. They will not be locked into seeing only particular health care providers.

U.S. health care is diverse in its leadership, organization, and structure; we expect that ACOs will be similarly diverse. Under the proposed rule, institutions and health care providers interested in forming an ACO will have considerable flexibility in the structure they assume. ACOs may be led by physicians in group practices, networks of individual practices, hospitals employing physicians, or partnerships among these entities and other health care providers. Whatever the leadership of an ACO, physicians and Medicare beneficiaries will have important seats at the table. The proposed rule stipulates that an ACO will be governed by a body that primarily comprises the health care providers in that ACO but also incorporates the voices of the community and the Medicare patients it serves. We expect that the transition to ACOs will unlock many opportunities and challenges; broad represen-

tation in ACO governance will ensure that these opportunities and challenges are met by an engaged set of critical stakeholders.

The financial opportunity for an ACO to achieve shared savings will vary according to its initial tolerance for risk. Two different models are proposed. In the first model, ACOs earlier in their evolution can elect to assume a smaller share of upside gains but no risk of loss for 2 years and then transition in year 3 to accepting risk. In the second model, organizations that are willing to take on both upside gains and downside risk can qualify for a higher proportion of shared savings from the start. The newly chartered Center for Medicare and Medicaid Innovation will concurrently launch aggressive testing of innovative models for a nationwide technical support platform for ACOs, to complement the numerous ongoing efforts in which the private sector is already engaged. The Center for Medicare and Medicaid Innovation is also now exploring ways to test alternative models of ACOs that differ from the models specified in the proposed rule.²

What can we reasonably expect of the coming wave of ACOs? We know that not all previous efforts at developing a model of shared savings have met expectations.³ But many, like the Medicare Physician Group Practice (PGP) Demonstration, have offered important lessons on the best ways to achieve both quality improvement and cost savings.⁴ Through their quality-improvement efforts, all 10 participants in the PGP demonstration met at least 29 of the 32 quality goals, most of which were process measures related to coronary artery

disease, diabetes, heart failure, hypertension, and preventive care.⁵ And 6 of the 10 demonstration sites produced savings — \$78 million in total. Although this amount represents only a small fraction of total Medicare expenditures, it also represents a step in the right direction.

The proposed rule for ACOs draws on these lessons in an effort to develop a more robust model for shared savings. Although the savings achieved in the PGP experience were only modest, the demonstration helped to identify several factors that are critical to improving quality and increasing the opportunities for shared savings: an integrated organization that supports expending resources on programs to improve quality and reduce the provision of unnecessary services; dedicated physician leadership with a proven ability to motivate the implementation of quality-improvement programs; and a central role for health information technology in enabling the organization to manage population health and receive feedback at the point of care. The opportunities to refine new ACO models will be many; these lessons from the PGP demonstration and elsewhere will be important launching points for the transition to fully accountable care.

Accountable care is not a panacea but rather one of a number of complementary initiatives chartered by the ACA to help achieve the three-part goal of lower costs, improved care, and better health. Other delivery-reform efforts such as expanded use of medical homes, bundled payments, value-based purchasing, adoption of information technology, and payment reforms are under way or under consideration. A critical

Proposed Measures for ACO Quality-Performance Standards.*

Aim: improved care

Patient and caregiver experience	<ul style="list-style-type: none"> • Getting timely care, appointments, and information • How well your doctors communicate • Helpful, courteous, respectful office staff • Patients' ratings of doctor • Health promotion and education • Shared decision making • Health status or functional status
Care coordination — transitions	<ul style="list-style-type: none"> • Risk-standardized, all-condition readmission • 30-Day post-discharge physician visit • Medication reconciliation • Care transitions measure • Management of ambulatory-sensitive conditions: diabetes; chronic obstructive pulmonary disease (COPD); congestive heart failure (CHF); dehydration; bacterial pneumonia; urinary tract infections (UTIs) • % of all physicians meeting HITECH meaningful use requirements
Care coordination — information systems	<ul style="list-style-type: none"> • % of PCPs meeting HITECH meaningful use requirements • % of PCPs using clinical decision support • % of PCPs meeting eRx incentive program requirements • Patient registry use
Patient safety	<ul style="list-style-type: none"> • Health care–acquired conditions composite (includes foreign object retained after surgery, central-line–associated bloodstream infections [CLABSI], falls and trauma, catheter associated UTI, and others) • CLABSI bundle use

Aim: improved health

Preventive health	<ul style="list-style-type: none"> • Influenza immunization • Pneumococcal vaccination • Mammography screening • Colorectal cancer screening • Cholesterol management for patients with cardiovascular conditions • Adult weight screening and follow-up • Blood-pressure measurement • Tobacco-use assessment and intervention • Depression screening
At-risk population — diabetes	<ul style="list-style-type: none"> • Composite and individual measures (glycated hemoglobin, LDL cholesterol <100 mg/dl, blood pressure <140/90 mm Hg, tobacco nonuse, aspirin use) • Poor glycemic control (glycated hemoglobin >9%) • Blood pressure control in diabetes • Screening rates for microalbuminuria • Dilated eye exam; foot exam
At-risk population — heart failure	<ul style="list-style-type: none"> • Left ventricular function assessment • Left ventricular function testing • Weight measurement • Patient education • Heart failure prescription rates for left ventricular systolic dysfunction (LVSD) • Angiotensin-converting-enzyme inhibitor or angiotensin-receptor blocker (ACE/ARB) rates for LVSD • Warfarin therapy for patients with atrial fibrillation
At-risk population — coronary artery disease	<ul style="list-style-type: none"> • Coronary artery disease (CAD) composite and individual measures (oral antiplatelet therapy for patients with CAD; drug therapy for lowering LDL cholesterol; beta-blocker for patients with CAD with prior myocardial infarction; LDL cholesterol <100 mg/dl; ACE/ARB therapy for patients with CAD and diabetes, LVSD, or all of the above)
At-risk population — hypertension	<ul style="list-style-type: none"> • Blood-pressure control rates (<140/90 mm Hg) • Hypertension plan of care
At-risk population — COPD	<ul style="list-style-type: none"> • Spirometry evaluation • Smoking-cessation counseling • Bronchodilator therapy based on FEV₁
At-risk population — frail elderly	<ul style="list-style-type: none"> • Screening for fall risk • Osteoporosis management in women who had a prior fracture • Monthly INR for beneficiaries on warfarin

* Most measures and standards would be based on rates within the total eligible population. HITECH denotes the Health Information Technology for Economic and Clinical Health Act, LDL low-density lipoprotein, FEV₁ forced expiratory volume in 1 second, INR international normalized ratio, and PCPs primary care physicians.

success factor for ACOs will be their effective integration with these other efforts.

Whatever form ACOs eventually take, one thing is certain: the era of fragmented care delivery should draw to a close. Too many Medicare beneficiaries — like many other patients — have suffered at the hands of wasteful, ineffective, and poorly coordinated systems of care, with consequent costs that are proving unsustainable. CMS believes that with enhanced cooperation

among beneficiaries, hospitals, physicians, and other health care providers, ACOs will be an important new tool for giving Medicare beneficiaries the affordable, high-quality care they want, need, and deserve.

Disclosure forms provided by the author are available with the full text of this article at NEJM.org.

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Changing the Game

What Health Care Reform Means for Gay, Lesbian, Bisexual,
and Transgender Americans

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March 2011

Introduction and summary

President Barack Obama moved forcefully to tackle injustice and discrimination against lesbian, gay, bisexual, and transgender Americans by signing into law two bills long championed by LGBT and human rights organizations.* First is the Matthew Shepard and James Byrd, Jr. Hate Crimes Prevention Act, which expanded the 1969 federal hate crimes law to include crimes motivated by bias against someone’s real or perceived sexual orientation or gender identity. Second is the repeal of “Don’t Ask, Don’t Tell,” the military’s ban on service by openly gay, lesbian, or bisexual individuals.

But as Dr. Martin Luther King, Jr. reminded us almost fifty years ago, “Of all the forms of inequality, injustice in health care is the most shocking and inhumane.” The Affordable Care Act, the health care reform law passed in March 2010, seeks to remedy this injustice by transforming the U.S. health system. The law expands access to health and affordable health care for millions of people in America, including gay and transgender Americans and others who are among our society’s most vulnerable.

Thanks to the Affordable Care Act, many gay and transgender Americans who were never able to afford health insurance or health care soon will be able to apply for Medicaid or affordable private coverage in every state. They will not be subject to denials of insurance coverage on the basis of pre-existing conditions or to arbitrary rescission of vital coverage when they become ill. The Affordable Care Act is also key to efforts such as expanding cultural competency in the health care workforce to include LGBT issues, making preventive care available to everyone who needs it, improving data collection to better identify and address health disparities, and recognizing the increasing diversity of America’s families.

* This paper uses “LGBT” and “gay and transgender” interchangeably. Both terms refer to the full range of people who identify as gay, lesbian, bisexual, and/or transgender.

Despite these and other benefits for the LGBT community, the impact of the Affordable Care Act on gay and transgender people and their families remains largely unexplored. This report explains how the new health law already affects this community, and how they and their allies can continue to advocate for broad inclusion as the law is fully implemented between now and 2014.

In the pages that follow, we first provide an overview of the need for health care reform, including the health disparities experienced by gay and transgender Americans that the law must address. This is followed by a brief discussion of several provisions of the Affordable Care Act that hold particular promise for improving the health and well-being of the LGBT community. Next, we investigate four major areas where efforts by LGBT advocates and their allies in each state will be key to ensuring that the new health law delivers the largest possible positive results for the LGBT community when the law is fully implemented by 2014. Specifically, these areas are:

- Achieving comprehensive nondiscrimination protections in health insurance exchanges
- Establishing LGBT-inclusive data collection policies
- Recognizing and including LGBT families in all health reform activities
- Supporting community-based health interventions that are LGBT-inclusive

In each of these four areas we include recommendations for federal officials and state governments. Briefly, those recommendations include:

- Establish comprehensive and LGBT-inclusive nondiscrimination policies and practices in health insurance exchanges
- Improve our knowledge base on LGBT health disparities, by including sexual orientation and gender identity demographic questions in federal health surveys
- Recognize and include gay and transgender families in the new health law, by making sure that definitions of family are not solely based upon marriage and adoption laws that automatically exclude LGBT families
- Create community-based healthcare interventions that are responsive to the needs of gay and transgender people

We will examine these recommendations in more detail at the end of the paper. But first we discuss why our nation's healthcare system has been badly in need of reform, and the barriers to good, affordable care that LGBT people currently face.

About the Center for American Progress

The Center for American Progress is a nonpartisan research and educational institute dedicated to promoting a strong, just and free America that ensures opportunity for all. We believe that Americans are bound together by a common commitment to these values and we aspire to ensure that our national policies reflect these values. We work to find progressive and pragmatic solutions to significant domestic and international problems and develop policy proposals that foster a government that is “of the people, by the people, and for the people.”

About the National Coalition for LGBT Health

The Coalition is committed to improving the health and well-being of lesbian, gay, bisexual, and transgender individuals through federal advocacy that is focused on research, policy, education, and training.

The LGBT community includes individuals of every sexual orientation, gender, gender identity, race, ethnicity, and age; regardless of disability, income, education, and geography. Our members are dedicated to effecting change by uniting this rich diversity at the national level.

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