# FY 2003 HHS PERFORMANCE REPORT SUMMARY TABLE OF CONTENTS

INTRODUCTION	1
DEPARTMENTAL MANAGEMENT	7
The President's Management Agenda	7
Strategic Management of Human Capital	
Competitive Sourcing	
Improving Financial Performance	
Expanding Electronic Government	
Budget and Performance Integration	
Other Management Issues	
BUDGET AND PERFORMANCE INTEGRATION AT HHS	1:
HHS Program Implementation	
Results-Oriented Budgeting and Planning Processes: Where We Are Now	
Integrating Budget and Performance: Lessons Learned from the OMB Pilots	
Integrating Budget and Performance: Next Steps	
Addressing Challenges to Budget and Performance Integration	
Addressing Chanenges to Budget and Ferrormance integration	17
PERFORMANCE REPORT SUMMARY	
Increase Access to Health Care	25
Decreasing the Number of Uninsured Children and Adults	25
Increasing Access to Quality Health Care for Underserved Populations	26
Expand Consumer Choices in Health Care and Human Services	20
Faith-based and Community Initiatives	
Emphasize Preventive Health Measures	20
Reducing Morbidity from Diabetes	
Promoting Healthy Behaviors	
Behavior Modification Research	
Benavior Modification Research	33
Respond to Bioterrorism and Other Public Health Emergencies	35
Building Public Health Infrastructure to Respond	
Building Laboratory Capacity to Respond	
Ensuring Food Safety	

Improve Health Outcomes	. 39
Reducing Deaths, Incidence, and Impact of Infectious Diseases	. 39
Improving Outcomes for Substance Abuse and Mental Health Services	. 42
Improve the Quality of Health Care	. 44
Improving Drug and Medical Device Safety	. 44
Improving the Quality of Care in Nursing Homes	
Increasing Easy Access to Health Information for Consumers	
Advance Science and Biomedical Research	. 48
Advancing Basic and Applied Biomedical research	. 48
Providing Faster Access to Drug Therapies	. 50
Improve the Well-being and Safety of Families and Individuals	. 52
Protecting Children and Youth	. 52
Enabling the Elderly to Live with Independence and Dignity	. 53
Strengthen American Families	
Increasing Economic Self-sufficiency of Low-income Families	. 54
Increasing Parental Responsibility and Income Support	. 55
Reduce Regulatory Burden on Providers, Patients, and Consumers	
Streamlining the Regulatory Development Process	. 57
Maximizing Collaboration with HHS Stakeholders	. 57
PERFORMANCE DATA COLLECTION	. 58
Measuring Program Performance	. 58
HHS National, Population-based Data Collection	. 59
Vital Statistics	. 62
Surveillance Systems	. 63
Non-HHS Data Collection	. 64
Program Evaluations	. 64
HHS Office of Inspector General Audits and Reports	. 65
Internal Management Information Systems	. 65
Administrative Systems	
Measuring Performance With States and Grantees	
Delivering Information to Users	. 67
Data Verification and Validation	
Status on Reporting on FY 1999 - 2001 Performance Goals	. 69

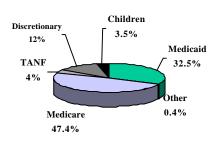
### INTRODUCTION

### WHO WE ARE AND WHAT WE DO

The Department of Health and Human Services is the United States government's principal agency for protecting the health of all Americans and providing essential human services, especially for those who are least able to help themselves. Whether it is through medical research, preventing the outbreak of infectious disease, assuring food and drug safety, administering the Medicare and Medicaid programs, providing financial assistance for low-income families, or a myriad of other important activities, the Department enhances the lives of all Americans.

The Department was once characterized by the General Accounting Office as presenting "...one of the more massive and complex management and program-related challenges in the federal government." HHS has over 63,000 employees and an FY 2003 budget of \$ 485 billion.

FY 2003 President's Budget

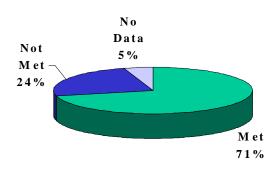


The Department works closely with officials from state, local and tribal governments. And most HHS-funded

services are provided at the local level by state, county or tribal agencies, or through private sector grantees. For FY 2001 HHS is reporting on over 300 program activities across the Department of Health and Human Services. In total, this translates to over 950 performance measures and targets. Each one of these measures and targets supports the Department's mission of protecting the health of all Americans and giving a special helping hand to those who need assistance.

HHS intends for the Annual Plan/Report process to be a full-fledged tool that managers at all levels can use to measure what their programs are achieving and determine how well those achievements are accomplishing the goals of the Department. A desired outcome of the Government Performance and Results Act (GPRA) is to develop linkages between performance and budget. To best link performance to budget, HHS has incorporated the performance goals into the budget submissions for the HHS agencies that administer the programs. In fact, HHS was among the first Federal

**HHS GPRA Results** 



departments to explicitly associate performance targets—or groups of targets—with a portion of the budget.

The graphic above reflects HHS-wide FY 2000 performance–goals met, goals not met, and instances where data is not yet available. As of January 2002, only 68 percent of data was available for the FY 2001 reporting year. To gain a more complete picture of overall results across the entire span of performance targets in HHS, results for FY 2000 were selected. Past performance is a reliable indicator of future results, and the reader can extrapolate from one year to the next with some confidence. As more data becomes available for FY 2001, this graphic will be updated.

### SUMMARY DOCUMENT AT-A-GLANCE

This Summary provides a snapshot of performance across the Department. These targets and measures were selected because they reflect the Secretary's priorities, or they continue the story of an enduring goal. Some of the most important results we're reporting this year include:

Combating Bioterrorism: Centers for Disease Control is protecting the Nation against bioterrorism by meeting its goal of assisting states in completing vulnerability assessments and drafting public health emergency response plans. By the end of 2002, at least 48 of the 55 states and territories will have completed their vulnerability assessment.

### Increasing Health Care Access:

Health Resources and Services Administration is increasing access to healthcare by meeting their target of serving 9.6 million low income, minority, and uninsured persons in FY 2000. It is estimated that 10.5 million were served in FY 2001. Welfare to Work: Administration for Children and Families is building upon the successes of welfare reform by assisting all states in meeting Congressionally established work participation rates of 40 percent in FY 2000.

For more detail on these and other programs, we encourage you to explore the individual agency Plans and Reports available on-line: www.hhs.gov/topics/planbudget.html.

This document includes:

Departmental Management: Early in his Administration, the President articulated a Management Agenda. This agenda includes: 1) Strategic Management of Human Capital; 2) Competitive Sourcing; 3) Improved Financial Performance; 4) Expanding Electronic Government; and 5) Budget and Performance Integration. The details of HHS efforts to meet these challenges is contained in the individual plans. This section contains a sample of these efforts.

Additionally, Departmental Management also summarizes other management issues that impact overall Department-wide performance. They derive from the work of the HHS Office of Inspector General, and the General Accounting Office.

**Budget and Performance Integration Project:** A key expectation of the GPRA is to gain a clearer understanding of what government is doing by linking what is being achieved to what is being spent.

The Administration seeks to move budget and performance integration from a general concept to a specific application, and indeed it is an element of the President's Management Agenda. This section highlights HHS'

Government should be results-orientedguided not by process but guided by performance. There comes a time when every program must be judged either a success or failure. Where we find success, we should repeat it, share it, and make it the standard. And where we find failure, we must call it by its name. Government action that fails in its purpose must be reformed or ended.

> -Governor George W. Bush

considerable successes, explains obstacles to be overcome, and points a direction for the future.

2001 Reports Summary: This most detailed section of the Departmental Summary captures a number of performance targets. As stated earlier, these targets and measures were selected because they reflect Secretary Thompson's priorities, or they continue the story of an enduring goal. The stories provide proof that HHS touches the life of virtually every American. The targets and measures are organized around the "One HHS Department-wide Outcome Goals." This construction was selected because it articulates the current priorities and vision of the HHS leadership team. A crosswalk between the Outcome Goals and the goals of the HHS Strategic Plan is included at the end of this section.

Performance Data Collection: HHS programs work closely with state, local, tribal, private, and business community partners to collect and analyze data for GPRA measurement. We make use of population-based data collection systems,

vital statistics, disease surveillance, administrative data, and other mechanisms. Each of these programs has strengths and weaknesses that this section details.

The complete HHS FY 2003
Performance Plan and Report is comprised of the Performance Plans and Reports prepared by the following agencies and staff components:

- Administration on Aging (AoA) serves as the primary federal focal point and advocacy agent for older Americans. Through a network of state and area agencies on aging, AoA funded programs deliver comprehensive in-home and community services; and make legal services, counseling, and ombudsmen programs available to elderly Americans.
- Administration for Children and Families (ACF) leads the nation in improving the economic and social well-being of families, children, and communities though federal grant programs like Head Start, Child Support Enforcement, Child Welfare Services, Child Care and Development, and Temporary Assistance to Needy Families (TANF).
- Agency for Healthcare Research and Quality (AHRQ) enhances the quality, appropriateness, and effectiveness of health services and access to such services, through the promotion of improvements in clinical and health system practices, including the prevention of diseases and other health conditions.
- Centers for Medicare & Medicaid

  Services (CMS) pays Medicare benefits;
  provides states with matching funds for

  Medicaid benefits; administers the State

  Children's Health Insurance Program

  (SCHIP); conducts research, demonstrations,
  and oversight to ensure the safety and quality
  of medical services and facilities

provided to Medicare beneficiaries; and establishes rules for eligibility and benefit payments.

- ► Centers for Disease Control and Prevention (CDC) monitors health; identifies and investigates public health problems; promotes healthy behaviors; and develops and advocates sound public health policies to prevent and control disease, injury, and disability.
- ► Food and Drug Administration (FDA) promotes improvement in the health of the American public by ensuring the effectiveness and/or safety of drugs, medical devices, biological products, food, and cosmetics; and by encouraging the active participation of business and the public in managing the health hazards associated with these products.
- ► Health Resources and Services Administration (HRSA) promotes equitable access to comprehensive, quality health care for all, with a particular focus on underserved and vulnerable populations.
- ► Indian Health Service (IHS) provides comprehensive health services for American Indian and Alaska Native (AI/AN) people, with opportunity for maximum tribal involvement in developing and managing programs to improve health status and overall quality of life.
- ► National Institutes of Health (NIH), through 25 institutes, centers, and divisions, NIH supports and conducts medical research, domestically and abroad, into the causes and prevention of diseases and promotes the acquisition and dissemination of medical knowledge to health professionals and the public.
- Office for Civil Rights (OCR) promotes and ensures that people have equal access to and opportunity to participate in and receive services in all HHS programs without facing unlawful discrimination. Through prevention

- and elimination of unlawful discrimination, the OCR helps HHS carry out its overall mission of improving the health and wellbeing of all people affected by its many programs.
- ► Office of Inspector General (OIG) improves HHS programs and operations and protects them against fraud, waste, and abuse. By conducting independent and objective audits, evaluations, and investigations OIG provides timely, useful, and reliable information and advice to Department officials, the Administration, the Congress, and the public.
- ► Program Support Center (PSC) provides a broad range of administrative services to HHS components and other Federal agencies on a competitive, fee-for-service basis. PSC services are provided in three business areas: human resources, financial management, and administrative operations.
- ► Substance Abuse and Mental Health Services Administration (SAMHSA), through its three centers, works to improve quality and availability of prevention, early intervention, treatment, and rehabilitation services for substance abuse and mental illness, including co-occurring disorders, in order to improve health and reduce illness, death, disability, and cost to society.
- Appeals Board (DAB) is an independent office established to provide conflict resolution services. These services are basically of two types: 1) adjudicatory hearings, appellate review of decisions of administrative law judges, and similarly structured formal and informal reviews of contested decisions; and 2) alternative dispute resolution (ADR), including mediation and other consensual processes and training related to ADR.

The Assistant Secretary for Administration and Management (ASAM) provides leadership for HHS departmental management, including human resource policy, grants management, acquisitions, and departmental operations. The ASAM also serves as the operating division head for the HHS Office of the Secretary.

Office of Assistant Secretary for Budget, Technology and Finance (ASBTF) advises the Secretary on all aspects of budget, information technology, and financial management, and provides general oversight and direction of the budgetary and financial organizations and activities of the Department.

Office of Assistant Secretary for Planning and Evaluation (ASPE) provides policy analysis and advice; guides the formulation of legislation; coordinates strategic and implementation planning; conducts regulatory analysis and reviews regulations; oversees the planning of evaluation, non-biomedical research, and major statistical activities; and administers evaluation, data collection, and research projects that provide information needed for HHS policy development.

Office of Public Health and Science (OPHS) provides senior professional leadership across HHS on population-based public health and clinical preventive services by providing scientifically sound advice on health and health policy to the Secretary, Departmental officials and other governmental entities and communicating on health issues directly to the American public; conducting essential public health activities through eleven program offices, and providing professional leadership on cross-cutting Departmental public health and science initiatives.

#### The HHS GPRA Format

Part I - Agency Context for Performance Measurement

- 1. Agency Mission and Long-Term Goals
- 2. Organization, Programs, Operations, Strategies, and Resources
- 3. Partnerships and Coordination
- 4. Summary FY 2001 Performance Report

Part II - Program Planning and Assessment

- 1. Program Description, Context, and Summary of Performance
- 2. Goal-by-Goal Presentation of Performance

Part III - Appendix to the Performance Plan

# NAVIGATING THE AGENCY PERFORMANCE PLANS AND REPORTS

HHS and its agencies developed a standardized format that was first introduced for the FY 2001 Performance Plans and FY 1999 Performance Reports. This format, shown in the figure, establishes a consistent order of presentation of information required by the law and Office of Management and Budget.

### IMPROVING THE PLANS AND REPORTS

While the development of plans and reports is a decentralized process, HHS has made several improvements:

All agencies have aligned their plans with the goals of the Administration, and emphasized or added measures that reflect the Secretary's priorities.

Plans and reports reflect our continuing leading-edge linkage of performance and budget.

# CROSS-WALK TO THE HHS STRATEGIC PLAN

Generally, agencies are likely to have more output goals than outcome goals, which reflect broad standards, benefits to a wide community, or incidences on a national level. There has been increased emphasis throughout the government and in the performance measurement community on outcome goals. As a result, the examples of performance in this Department Summary are organized around a set of HHS priority areas called the "One HHS" Departmentwide Outcome Goals. These flow smoothly from the HHS Strategic Plan. The following table is a cross-walk of these priority areas and the current HHS Strategic Plan. The HHS Strategic Plan submitted to Congress in September 2000 is being revised to reflect new health and human services priorities.

### Cross-walk of Department-wide Outcome Goals and Strategic Plan Goals

Current Strategic Plan Goals	One HHS Outcome Goals			
Reduce the Major Threats to	Improve Health Outcomes			
Health and Productivity of All Americans	Emphasize Preventive Health Measures			
Improve Access to Health Services and Ensure the Integrity of the Nations	Increase Access to Health Care			
Health Entitlement and Safety Net Programs	Expand Consumer Choices in Health Care and Human Services			
Improve the Quality of Health Care and Human Services	Improve the Quality of Health Care			
Improve the Economic and Social Well-Being of Individuals, Families and Communities in the United States	Improve the Well-Being and Safety of Families and Individuals, especially Vulnerable Populations Strengthen American			
	Families			
Improve the Nation's Public Health Systems	Prepare for and Effectively Respond to Bioterrorism and other Public health Emergencies			
Strengthen the Nation's Health Sciences Research Enterprise and Enhance Its Productivity	Advance Science and Medical Research			
	Reduce Regulatory Burden on Providers, Patients, and Consumers of HHS Services			

Note: OMB Circular A-11 requires Federal agencies to summarize the findings and recommendations of agency program evaluations in the GPRA performance report. The most recent document that includes HHS evaluations is the Departmental report to Congress, *Performance Improvement 2001: Evaluation Activities of the U.S. Department of Health and Human Services*. It can be found at <a href="http://aspe.hhs.gov">http://aspe.hhs.gov</a>.

### DEPARTMENTAL MANAGEMENT

This section addresses the President's Management Agenda and other management issues that impact overall Department-wide performance.

### THE PRESIDENT'S MANAGEMENT AGENDA

President Bush envisions a government that has a citizen-based focus, is results-oriented, and where practicable, market-driven. To improve the functioning of government and achieve efficiencies in its operations, the President highlighted a series of government-wide management reforms for the federal government in the President's Management Agenda. During the period leading up to the FY 2003 GPRA submission, the Department continued to place special emphasis on these reforms. They include:

- Strategic Management of Human Capital
- Competitive Sourcing
- Improved Financial Performance
- Expanding Electronic Government
- Budget and Performance Integration

Work continues to progress in these five areas throughout the Department, and in some cases there are already impressive results. Because some of these are areas of new or expanded emphasis, new goals and measures have been developed to capture on-going activity. Even these new goals and measures are expected to show positive results.

# STRATEGIC MANAGEMENT OF HUMAN CAPITAL

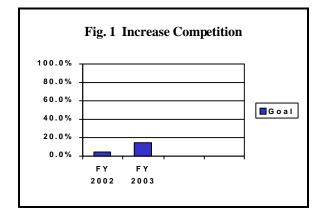
The first priority of the President's Management Agenda is to make government citizen-centered. HHS has established a vision of a unified HHS-"One Department"-that will be free of unnecessary layers and be collectively strong to serve the American people. To achieve this, HHS plans to reduce duplication of effort by consolidating administrative management layers, reduce the number of personnel offices, and consolidate the public affairs and legislative affairs functions. HHS will continue to reshape its organization to meet the standard of excellence in attaining outcomes important to the nation. HHS will make better use of the civil service flexibilities currently in place to acquire and develop talent and leadership. Some specific initiatives that live up to the challenge include:

SAMHSA is completing two major initiatives that will provide the foundation for setting performance goals for de-layering management levels and streamlining the organization. First, a Workforce Analysis for Planning and Restructuring is nearing completion that will: examine the demographics of the permanent workforce; provide information on SAMHSA's seasonal, temporary, and intermittent workforce; evaluate the skills of the workforce, and baseline the supervisor-tostaff ratio. These analyses will be used to develop a Strategic Workforce Plan that will facilitate development of appropriate performance measures.

- ► FDA is making significant efforts to further de-layer the agency and allow for a more effective and streamlined organization. Specifically, FDA is already committed to increasing the supervisory span of control and consolidating administrative functions in the agency.
- ► CDC has developed a Restructuring and De-layering Plan that contains 14 specific goals. These goals include: improving supervisory ratios; increasing the span of control; reducing the number of organizational units; increasing delegations of authority; and eliminating duplicative administrative functions.
- ► AoA conducted an extensive review of workforce and structural conditions and found that improvements are necessary in organizational layers, grade structure, and skill mix. AoA has included performance measures in its GPRA plan to increase employee to supervisor ratio; achieve a measurable reduction in the average grade of employees; and hire new employees in conformance with skills required in the agency's workforce plan.

#### **COMPETITIVE SOURCING**

Many tasks Federal employees perform—like data collection, administrative support, and payroll services—can be



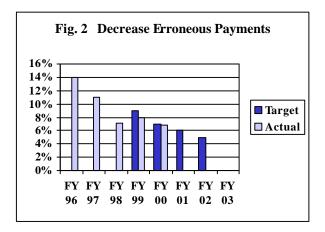
accomplished in the commercial marketplace. When potentially commercial tasks are considered for competition, quality service and reasonable costs are often the result. In accordance with the Federal Activities Inventory Reform (FAIR) Act, HHS is assessing a variety of activities in terms of their potential for competition.

In the last year the Department submitted its third annual Commercial Activities
Inventory under the FAIR Act. The Office of the Secretary worked with the agencies to improve the accuracy and consistency of the inventory. Building on that success and accepting the new challenge, HHS agencies have committed to the goal of competing or directly outsourcing 5 percent of their inventory in FY 2002 (see Figure 1). The goal for FY 2003 will be an additional 10 percent.

### IMPROVING FINANCIAL PERFORMANCE

The Secretary has made the establishment of a Unified Financial Management System a Department-wide management priority, consistent with his "One HHS" approach. The FY 2003 Departmental Management performance plan includes a performance measure to assess progress toward the achievement of this goal (See FY 2003 General Departmental Management budget submission, Finance Goal 4). Specifically, the UFMS will be implemented to replace five legacy accounting systems currently used across the agencies and staff componants. The UFMS will integrate the Department's financial management structure and provide HHS leaders with a more timely and coordinated view of critical financial management information, including more accurate assessments of the cost of HHS programs. It will also promote the consolidation of accounting operations and thereby reduce substantially the cost of providing accounting services throughout HHS. Similarly, UFMS, by generating timely, reliable and consistent financial information, will enable Agency Heads and program administrators to make more timely and informed decisions regarding their operations.

Medicare accounts for nearly half of the HHS Budget. Therefore, CMS' positive results in reducing improper payments are especially noteworthy. CMS has virtually cut the Medicare fee- for-service error rate in half over the past few years.



The complexity of Medicare payment systems and policies, and the numbers of contractors, providers, and insurers involved in the Medicare fee-for-service program create vulnerabilities. However, CMS has kept the error rate under 8 percent for the past two years, and exceeded its GPRA targets for FY 1999 and FY 2000 (see Figure 2). The most recent data for FY 2000 shows an error rate of 6.8 percent, exceeding the target of 7.0 percent. The substantial reduction in the error rate over the past years demonstrates that the Medicare contractor claims processing system has improved. CMS is committed to further reducing the error rate by focusing on potential areas of vulnerability like those

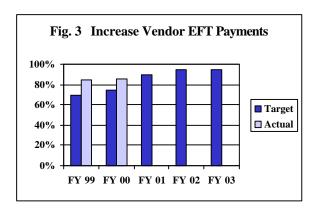
identified by the Office of Inspector General. They believe that by aggressively addressing specific high risk areas they can meet the goal of reducing the error rate to 5 percent by FY 2002.

### EXPANDING ELECTRONIC GOVERNMENT

The HHS Electronic Government Vision is to use information technology in concert with the Department's program and management priorities to create "One HHS." Aggregation and consolidation of HHS information technology initiatives will result in a more cost-effective information infrastructure and a more unified, responsive access for the public. HHS is at the forefront of streamlining the government grants process using information technology, as well as providing skills training and support to HHS employees electronically.

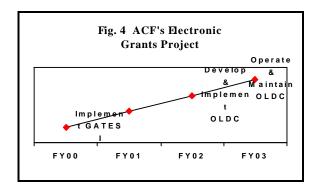
Department of Treasury guidelines established targets for converting to Electronic Funds Transfer (EFT) for all federal agencies (69 percent for FY 1999 and 75 percent for FY 2000). Each HHS agency has an automated process for tabulating the number and types of payments made. This information is used to compile quarterly EFT Reports.

HHS established goals for grant payments, salary payments, vendor payments, and travel payments based on the Treasury guidelines. HHS met or exceeded our goals in every area except salary payments, where HHS achieved a 99 percent payment rate against a 100 percent goal. In the challenging area of vendor payments-where the target has risen every year-HHS



can point to impressive results. In the most recent year (see Figure 3) HHS exceeded its target and increased the percentage of vendor payments to 86 percent.

ACF continues to show exceptional results developing and implementing the Grants Administration, Tracking and Evaluation System (GATES). GATES was designed to support decision-making and



accountability in a decentralized environment. GATES will replace more than 30 incompatible, outmoded legacy systems operating on a variety of platforms to support grants administration. Having completed the conversion and replacement efforts (see Figure 4), all ACF grants are now awarded through GATES. In FY 2002-2003, ACF will implement a next generation of electronic grant-making using an "On-line Data Collection (OLDC) Initiative" to enable grantees and potential grantees to submit the required information over the Internet.

In addition, by expanding electronic government through technology-based systems, organizational productivity is increased. CDC provides two examples of this work in its description of IT capabilities and in its use of technology-based learning and data mining techniques. And to help efforts to measure the productivity of electronic government initiatives, NIH highlights performance measures for IT systems on its website.

# BUDGET AND PERFORMANCE INTEGRATION

HHS' entire Government Performance and Results Act effort is aimed at more closely integrating performance and budget. Unlike many other federal agencies, HHS has already organized performance measures around budget elements. In most cases, agency performance reports include summary tables that associate performance goals with total funding for that activity. The Department participated in detailed discussion with OMB on performancebudget linkage at SAMHSA and HRSA throughout the summer of 2001, identifying the several challenges to this activity and exploring solutions. A detailed discussion of the future direction of this initiative was provided in Section 3, Performance-Budget Integration Project. In the coming year HHS will explore, with OMB, the feasibility and potential benefits that may be accrued from integrating program performance and funding for federal public health grants to states.

### OTHER MANAGEMENT ISSUES

Finally, the HHS GPRA Plans and Reports address a number of important management issues that can affect overall performance, or are linked to fraud, waste and abuse. Some of the most important challenges are identified in the OIG's list of Top Management Challenges. The table below identifies the issue, summarizes progress, and points to the appropriate Plan/Report where more information is available. For more information on OIG activities and reports, visit <a href="http://oig.hhs.gov">http://oig.hhs.gov</a>.

In addition, another perspective of overall Department management issues is detailed in GAO-01-748, *Health and Human Services - Status of Achieving Key Outcomes and Addressing Major Management Challenges.* In most instances our performance, summarized directly from the GAO report and reflected in the next table, improved since the GAO's last report.

Timely implementation of recommendations and correction of management deficiencies are essential to improving the efficiency and effectiveness of the Department's programs and operations. HHS is committed to following up these recommendations. In fact, in response to the recommendations in the 2001 report, the Department developed new goals for strategic human capital management, and information security.

### **Management Issues Identified** by the HHS Inspector General

Management Issue	Program Progress	GPRA Performance Measure(s)
Bioterrorism	Several activities underway	CDC
Medicare Contractors	Unqualified opinion of CMS' financial statement; significant improvements	CMS
Protection of Critical Infrastructure	Several coordinated information technology actions in progress	DM
Pricing Prescription Drugs	Further analysis required	
Nursing Facilities	Meaningful progress	CMS
Medicare Payment Error Rate	Significant progress	CMS
Medicare Managed Care	Some progress	CMS
Child Support Enforcement	Some progress	ACF
Oversight of PPS Implementation	Monitoring and analysis on-going	CMS
Abuses in Medicaid Payment Systems	New regulations phasing in	CMS
Medicare Payments for Mental Health Services	Some progress	CMS

# Management Issues Identified by the General Accounting Office

Management Issue	Program Progress	GPRA Performance Measure(s)
Less fraud, waste, and error in Medicare and Medicaid	Some progress	CMS
Beneficiaries receive high- quality nursing home services	Progress	CMS
Poor and disadvantaged families and individuals become self- sufficient	Mixed progress; limited data	ACF
Improved prevention of infectious diseases	Mixed progress	CDC, CMS, HRSA, IHS, NIH
Reduced use of illegal drugs	Some progress	SAMHSA
Public has prompt access to safe and effective medical drugs and devices	Significant progress	FDA
Strategic human capital management	Mixed approach	HHS-wide
Information security	Mixed approach <sup>1</sup>	HHS-wide

<sup>&</sup>lt;sup>1</sup> The Departmental Management GPRA Plan for FY 2003 reflects a new, more unified approach to these challenges and discusses performance measures to address them.

## **BUDGET AND PERFORMANCE INTEGRATION AT HHS**

### MEASURING PROGRAM PERFORMANCE

The Department of Health and Human Services (HHS) has always recognized the potential of the Government Performance and Results Act (GPRA) in helping us obtain better performance data to manage our programs and inform our budget decisions. In fact, many of our early GPRA implementation decisions were driven by the desire to integrate performance data into our budget decision-making processes.

In the Fall of 2001, HHS embarked on a project with a dual goal of substantially improving the link between budget and performance in our FY 2004 budgets and performance plans and supporting the President's Management Agenda. HHS is committed to working with budget analysts and decision makers in HHS, OMB, and Congress to ensure that they have meaningful performance data to inform budget decisions.

HHS GPRA, budget, and finance staff met to discuss ways HHS currently links budget and performance, identify new approaches, and describe and address critical challenges. Prior to the meetings, we provided attendees with a set of background materials on linking budget and performance. We then shared the results of our internal assessment with OMB and GAO and incorporated their input. We also incorporated lessons learned from OMB's performance budgeting pilot in 2000 and our experiences in working with OMB this year to better link budget and performance for several HHS programs.

Additionally, we are providing comments to the General Accounting Office (GAO) on its Request for Views on *Results-Oriented* 

Agency Budget Practices, which describes a "framework for agency budget practices that can help guide an agency toward incorporating performance information into the budget process." This report was very useful in framing our work.

### **HHS PROGRAM IMPLEMENTATION**

HHS accomplishes its mission to enhance the health and well-being of all Americans through the collaborative efforts of the over 300 programs that are administered by our agencies and staff components. HHS administers these programs in collaboration with partners – state, local, and tribal governments, grantees, and contractors – who implement these programs in the states and local communities. In fact, most of the \$488.8 billion of HHS program funding for FY 2003 will be spent by these program partners.

Therefore, the performance goals and results in the HHS performance plans and reports reflect the combined commitment, effort, and resources of HHS programs and their state, local, tribal, and non-governmental partners. This method of implementing programs directly impacts program accountability, goal development, and performance budgeting for HHS programs.

# RESULTS-ORIENTED BUDGETING AND PLANNING PROCESSES: WHERE WE ARE NOW

The desire to use performance data to better inform budget decisions for HHS programs was a key factor in decisions about the fundamental organizational structure of our performance plans and reports. In order to facilitate the use of performance information in our budget decision-making processes, we combined our performance plans and reports with our budget submission. Therefore, the HHS budget submission consists of the budget justifications, performance plans, and performance reports developed by each HHS agency and staff component, which include individual budget justifications, plans, and reports for the program activities that comprise their budget.

We also integrated our performance reports into the performance plans to provide budget analysts and decision makers with a multi-year picture of planning, reporting, analysis, and reassessment of strategies and goals. For each program activity (in some instances we aggregated program activities as provided for under GPRA), we linked a set of performance goals to the program's budget request. To facilitate an assessment of trends, we provided a table that presents multi-year budget dollars, goals, targets, and performance. Performance data and targets are updated along with the budget dollars at each step in the budget process.

This concept of integration of our budgets, plans, and reports is an integral component of the HHS budget submission and supports the inclusion of performance information into the HHS budget process. Our early integration of these documents also fostered planning and budgeting practices that have been effective in integrating the use of performance information in our budget decisions. Agency-level practices that we identified during our internal discussions include:

 Establishing formal and informal coordination processes with budget, GPRA, and finance staff

- Conducting joint budget and planning activities with budget, planning, and finance staff
- Involving program managers to utilize their knowledge of program strategies, performance, costs, service recipients' needs, etc.
- Issuing joint budget and GPRA guidance
- Holding joint planning meetings early and throughout the budget cycle
- Developing budget requests, outputs, and performance goals and targets simultaneously
- Sharing drafts of budgeting and planning documents
- Integrating performance information into presentations at the Secretary's Budget Council and Congressional Appropriations Committee hearings.

Department-level practices that have fostered the use of performance information in budget decisions include:

- Integrating the GPRA performance planning, reporting, and budget functions at the department level
- Issuing joint budget and GPRA guidance
- Involving OMB in early GPRA planning sessions, including the development of the common format developed for HHS plans and reports
- Providing technical assistance to agencies and programs on performance measurement and budget linkage
- Requiring concurrent submission and review of drafts of the agency budgets and performance plans
- Including performance information in briefing materials for the Secretary's Budget

Council meetings and Secretarial decision meetings.

# INTEGRATING BUDGET AND PERFORMANCE: LESSONS LEARNED FROM THE OMB PILOTS

OMB's report on the government-wide performance budgeting pilot conducted in FY 2000, which included FDA, identified the following challenges to linking budget and performance:

- "Budgeting is often based on the structure of funding requests to the appropriations committees, and the structure does not always correspond to performance goals."
- "In many instances, measuring the effects of marginal, annual budget changes on performance is not precise or meaningful."
- "As a general matter, we are working to move from our almost total reliance on output measures to outcomes. However, it is much more difficult to associate specific resource levels with outcomes, particularly over short periods of time."
- "The ability to establish clear linkages between program outcomes and funding levels varies depending on the nature of the program and the number of relevant external factors."
- "Delays in collecting data on programs, sometimes because of necessary reliance on program partners for data collection, presents a challenge to synchronization of budget and performance data" (OMB 2001).

During the FY 2002 budget process, OMB worked with HHS and the Health Centers Program to better integrate budget and performance. This community-based network delivers preventive and primary care services to the underserved and uninsured populations in approximately 4,000 communities across the country.

HHS and OMB staff met with program managers to discuss the implications of a proposed multi-year budget increase with the goal of increasing the number of people served in the Health Centers. The discussions involved exploring how various implementation strategies would affect achievement of the goal. For example, expanding existing sites would result in an increase in the number of people served in the near term, whereas developing new sites would result in increases in services and the number of people served in later years. HHS also considered how the rapid expansion of services would affect the program's ability to maintain its current high performance on its quality-of-care performance goals. Based on these discussions, HRSA added a new goal to expand the infrastructure of the Health Center Program to support an increase in services, with specific targets for new sites, new satellite sites, and expanded sites.

# INTEGRATING BUDGET AND PERFORMANCE: NEXT STEPS

The overarching theme of internal discussions on how HHS could better link budget and performance was the need to establish a continuous dialogue between program managers, budget analysts, and decision makers in our agencies, the Department, OMB, and Congress. We need to develop a shared understanding of the logic behind our choice of performance goals, the significance of our performance data, and its implications for budget decisions.

Fundamental to linking budget and performance is understanding the

relationships between program investments, inputs, outputs, and outcomes. While the relationship between investments, inputs, and outputs is fairly straightforward, the relationship between investments and outcomes is more complex. Good communication will ensure better understanding of these relationships and the strength of the connections. In addition, improved communication and a shared understanding of these relationships can greatly mitigate the challenges to integration, such as third-party program implementation, that will be discussed later in this paper.

In the months ahead, we plan to engage program managers, budget analysts, and decision makers in answering the questions: who needs what information, when, and in what format, which was another key theme of our discussions. This will enable us to provide the information our budget analysts and decision makers need to consider program performance in budget decisions. Specific questions we need to answer are:

- Do our current budgets/plans/reports contain the performance information you need to make budget decisions?
- What performance information do you need that we have not provided?
- How can we better articulate the relationships between dollars, inputs, outputs, and outcomes?
- Have we presented data in the most useful way? At the most appropriate time?
- How can we better present performance information for high level decision makers (Secretary and agency heads)?
- Have you identified examples of agency/program plans that have effectively linked budget and performance?

We believe that the performance information desired by various decision makers is likely to be different and include both performance data and contextual information. At some decision points, detailed information will be needed. At other decision points, a summary presentation will be desired. Also, our budgets, plans, and reports may not be the only vehicles needed to communicate performance information effectively. We may need to develop additional formats for presenting performance information in various situations.

Based on feedback from the users of our performance information, we will assess the effectiveness of our current mix of performance goals and the formats we use to present this information to decision makers. We will consider whether we should pursue more complete integration of our performance plans and reports with our budget submissions, a key question raised in our internal discussions. We will work to better integrate program evaluation findings, human capital needs, and information technology issues in our budgets, plans, and reports. We will also work with the HHS leadership and programs to assure that our plans address the management challenges identified in the President's Management Agenda and HHS Inspector General and GAO management reports.

Additionally, we will work with budget analysts and decision makers in our agencies, the Department, and OMB to identify additional results-oriented budgeting and planning practices and will pursue the practices identified by GAO. We will continue our research into work published by others such as the Organization for Economic Co-operation and Development (OECD), publisher of *Integrating Financial Management and Performance Management*, which provided valuable perspective for our internal discussions.

# ADDRESSING CHALLENGES TO BUDGET AND PERFORMANCE INTEGRATION

The challenges to linking budget and performance information that were identified in the OMB pilot, the GAO Framework, and in the literature on this subject all apply to some extent to HHS programs. In this section, we focus on a few overarching challenges that significantly affect our ability to link budget and performance information. This section describes these challenges, how we have addressed them to date, and how we plan to continue to address them.

In the coming months, we will engage decision makers in identifying new approaches to address these challenges. Many of these challenges are the result of the way we implement federal programs or fundamental issues in program assessment. Good communication between the program managers, budget analysts, and decision makers is critical addressing these challenges and maximizing our ability to link budget and performance.

### Third-Party Program Implementation:

Third-party program implementation, often referred to as third-party government, presents significant challenges for accountability and linking budget and performance. Most HHS programs are implemented through third-party administrative and financing arrangements: grants, cooperative agreements, and contracts with state, local, and tribal governments and non-profit and for-profit organizations.

This program implementation structure affects our ability to predict the total dollars that will be spent on a program in future years, set national performance targets with precision, and articulate the link between human resources and results. It also demands that we involve program partners in

the development of national performance goals, complicates data collection, and contributes to data reporting lags.

Key attributes of the funding mechanisms that affect our ability to link budget and performance are: whether the grant operates as a program or a funding stream, the amount of flexibility provided to the grantee to determine program attributes, and the variety of activities that can be funded.

- When the grant operates as a funding stream, federal funds are merged with state and local funds, other federal grant funds, and Medicare and Medicaid funds, to support state or local activities allowed under the grant. For many of these programs, the federal contribution is only a small part of the total dollars that produce program results. However, the outputs and outcomes reported by grantees and included in the HHS budgets and performance plans represent the combined investments and efforts of the multiple funders. Linking the federal dollars to these outputs and outcomes presents an incomplete picture of the investment required to achieve these results. For example, federal program dollars provide only 27 percent of the funds that support the Health Center program. Other contributors include: Medicaid/ SCHIP, 34 percent; state/local/other federal, 18 percent; third-party payers, 8 percent; Medicare, 7 percent; and self pay, 6 percent.
- ► State, local, and tribal governments are frequently given significant flexibility to determine eligibility requirements and type and level of services provided in order to respond to local needs and preferences. Also, many grants allow states to fund a wide range of activities with grant funds. For example, in the Social Services Block

Grant, states can invest the grant funds in any combination of over 40 service categories depending on state needs. This flexibility to address local issues makes it difficult to project the total dollars that will be spent on a program and develop national performance targets with precision.

- ► Third-party program implementation also affects our ability to set national targets for program increases because HHS programs have difficulty projecting the total dollars that will be spent by all funders in a future year. For example, states can use the increase in federal funds to supplant the state contribution if the grant does not include a matching funding requirement. Also, an increase in federal funds may not result in an increase in state and local support for the program.
- Third-party program implementation affects HHS' ability to link its human capital needs to program output and outcome goals. A wide variety of governmental, non-profit, and private entities in communities across the country perform the day-to-day activities that lead to outcomes for HHS programs, rather than federal employees. For example, SAMHSA's grantees provide substance abuse and mental health services to the American public, not SAMHSA's federal employees. The federal human capital skills needed in when programs are implemented by third parties are not the same as for direct service provision. HHS needs employees with grants management, technical assistance, contracting, and contract management skills.

HHS and its components have developed human capital plans with long-term objectives and quantitative performance targets for assuring that we have the skills needed to manage our programs. We can integrate the results of this planning process into our plans to better articulate the contribution of the federal employees to our

programs, however, relating the federal human capital needs to program goals does not provide a complete picture of the resources needed to achieve those goals. For many programs, the information we have on the human capital needs of our program implementers is not detailed enough to link to the achievement of program goals and targets. Requiring other governmental entities and grantees to provide the amount of data that would be needed to create this linkage is not feasible for practical and political reasons.

Accountability for program results is also complicated by third-party program implementation. The federal funds are frequently used to influence what are essentially state and local programs. The priorities of states, tribes, local communities, and the federal government are not always the same, and the flexibility provided by these funding mechanisms enables our partners to make choices that may not support the achievement of national performance targets.

Given the significant role our partners play in program design and implementation, HHS programs have engaged their partners in developing national performance goals to report on program objectives under GPRA.

David Frederickson examines GPRA implementation in a diverse set of third-party program implementation situations at CMS, FDA, HRSA, IHS, and NIH in *The Potential of the Government Performance and Results Act as a Tool to Manage Third-Party Government.* Frederickson notes, "While this diversity provides flexibility to HHS' efforts to improve America's health, it also adds extraordinary complexity to the implementation of a uniform goal-setting and performance-measurement system, such as GPRA."

Finally, third-party program implementation is a major contributor to data lags for HHS programs because performance data rolls up from the local and state levels. This presents a challenge to synchronization of budget and performance data, which is discussed further in this document in the section, "Performance Data Lags".

### How HHS has addressed this issue:

For many HHS programs, grantees are required to report information on resources received from other sources to ensure state matching requirements or maintenance of effort. HHS programs use this historical data on the contributions of the various partners to project total funding and set national performance targets. They also include a discussion of the financial contributions of various funding partners in their performance plans. However, we need to better articulate to budget analysts and decision makers the degree of precision with which program managers are able to set national performance targets in this program implementation environment.

With regard to accountability, HHS has had significant success in working with its program partners to develop and report on national performance goals, which has improved program management and accountability. For example, the Indian Health Service (IHS) resolved a complex coordination issue concerning tribes' discretion in providing IHS-funded medical services under the Indian Self-Determination Act. While IHS can not mandate that the tribes submit performance data, it has created a bottom-up approach to budget formulation and performance measurement with full participation by tribal leaders. This has led to a shared understanding of GPRA and the importance of reporting on performance data in the IHS budget. As a result, the tribes have been voluntarily submitting performance data. ACF has had

similar success in establishing performance measures in programs dependent upon voluntary submission of performance data, i.e. the Temporary Assistance for Needy Families (TANF), Child Care, and the Community Services Block Grant (CSBG) programs.

HHS has also been successful in working with its program partners to develop national performance goals for programs that have significant flexibility to determine eligibility requirements or how funds are spent. CSBG is an example of a program given significant flexibility in how funds are spent, and ACF was able to work with the states to develop a core set of national performance goals. CMS and the states have developed a national performance goal for childhood immunizations; however, because of the flexibility afforded the states in designing their Medicaid programs, each state sets its own annual target. Because this is the only national health care quality goal that has been developed for Medicaid, CMS has a set a FY 2003 goal to establish a CMS/state partnership to improve health care quality for Medicaid and SCHIP populations using performance goals.

Many of the challenges listed here are inherent in third-party implementation of federal programs. However, some can be impacted by policy decisions, such as the inclusion of a matching funding requirement in the grant. Our ability to address these issues depends on the shared understanding by program managers and decision makers about how third party government impacts efforts to link budget and performance.

Attribution of Program Activities and Outputs to Outcomes: Improved health and social outcomes for the American people are influenced by the combined effects of multiple HHS programs, other federal, state, and local government programs, non-

governmental programs, and other mitigating factors (i.e. state of the economy). Attributing a change in the outcome to the funding or strategies of any of these individual programs – whether it's a federal, state, or a United Way program – requires a sophisticated level of analysis and evaluation.

In order to link budget decisions to program outcomes, we need to know what evidence is available on the connection between the federal program dollars, outputs, and outcomes and the strength of the evidence. Data on performance goals can identify positive or negative trends. However, we need to conduct program evaluations to determine which particular program strategy or funder is responsible for a change in the outcome, evaluate the relative contributions of multiple programs and funders, and assess the impact of other mitigating factors on the outcome.

Programs whose outcomes include improved safety for the public provide an illustration of the challenges in linking federal budget dollars to program outcomes. How does one measure what would have happened in absence of the intervention? How does one correlate a budget increase that funds 100 more food inspections and a reduced incidence of foodborne illness when there are so many intervening factors? How does one assess the true cost of these prevention efforts when the federal dollars are used to influence the broader safety efforts of an industry? As OMB found in the 2001 performance budgeting pilot:

"FDA has a strategic goal of preventing unnecessary injury and deaths caused by adverse drug reactions, injuries, medication errors, and product problems. It is difficult to tie this goal to budget decision making. The FDA, through its pre-market review process and post-market surveillance and compliance monitoring efforts, can reduce the probability that adverse events will occur. However.

some rare adverse drug effects can not be detected until a drug becomes widely used by the general population. Furthermore, FDA can influence, but not control, some factors that affect health outcomes, such as prescribing behavior of health care providers or consumer behavior. For these reasons, FDA can not guarantee that a new drug will not cause adverse events, no matter how thorough its pre-market review process is." (OMB 2001)

How HHS has addressed this issue:

HHS programs use logic models, supported by evidence-based strategies, and program evaluations to establish the link between program funds and outputs to outcomes. However, we acknowledged in our recent discussions that we could use these more effectively in the performance plans to explain the strategic logic behind our performance goals.

A clear logic model provides a credible link between program inputs, outputs, intermediate outcomes, and outcomes. The strength of any program logic model lies in the scientific evidence that supports the associations. Two tools that HHS programs have used to strengthen this link are evidence-based strategies and program evaluations.

Medical research has demonstrated the connection between many medical interventions and reduced morbidity and mortality, for example, between immunizations and reduction in infectious diseases and aspirin therapy and a reduction in the risk of a heart attack for those who have already had one. Such interventions become standards of care and are referred to as evidence-based practices. Therefore, a program can measure the percent of a population immunized or the percent of patients with coronary disease prescribed daily aspirin therapy and use the research as evidence of the causal link between these

outputs and improved health outcomes. This is a very cost-effective way to measure the impact of a program because these types of output activities are easier, cheaper, and faster to measure than outcomes. This is an area where our investment in NIH research has made significant contributions to program effectiveness and performance measurement.

For unproven and/or multifaceted interventions, program evaluations can determine the extent to which a specific program, rather than other programs or mitigating factors, is responsible for the outcome, and provide evidence of the link between outputs, intermediate outcomes, and outcomes. Program evaluations help us understand the reasons for the performance trend, identify how we can address problems and replicate successes, and attribute the outcome to our activities.

Head Start is conducting a program evaluation to establish evidence of a causal link between outputs and outcomes for this human services program, as medical research has done for health programs. For example, to determine whether Head Start is meeting its outcome goal to increase children's school readiness, HHS is undertaking a sixyear study that examines improved quality of service comparing outcomes for Head Start children to non-Head Start children and takes into account variable conditions such as parenting practices, demographics, and socioeconomic situation. The study will then determine the conditions that positively or negatively impact the outcome.

While studies like these require a significant investment of funds and time, they enable programs to focus their efforts on proven strategies and outputs with established contributions to long-term outcome goals. Also, by establishing the causal links between outputs and outcomes, they enable a more cost-effective approach

for measuring program impact on an annual basis.

Given the importance of program evaluations in assessing program performance, we need to ensure the relevancy, quality, and timely distribution of our evaluations. We also need to ensure that HHS has the analytical capability to provide budget analysts and decision makers with evidence-based information concerning the relationship between our strategies, outputs, and the desired outcomes.

In order to improve the quality of program evaluations in HHS, we conduct an annual peer review process, in which outside experts review nominated HHS evaluations for excellence in several methodological categories. The reviewers provide extensive feedback on the quality of the evaluations to agency evaluation officers and project officers, both in writing and through an HHS-wide open feedback session.

In addition, HHS has undertaken a planning assessment pilot designed to more closely link planning and evaluation activities. The initiative will focus on HHS' Strategic Objectives 1.2, reduce the incidence and impact of injuries and violence in American society, and 1.3, improve the diet and level of physical activity of Americans. We are developing logic models and conducting literature searches in order to develop a synthesis of the relative effectiveness of the strategies currently in use. When completed, the project will provide us with a better understanding of how planning, budgeting, performance measurement, and evaluation can be used to effectively document how multiple programs contribute to crosscutting outcomes.

Long-Term Nature of Investments in Outcomes: Many HHS programs address significant health and social problems that require the long-term investments and efforts

of a multitude of partners in order to improve outcomes, for example, obesity, diabetes, and economic self-sufficiency. Measuring the effects of marginal, annual federal budget changes on outcomes that may take decades to achieve is not precise or meaningful. However, improved outcomes for these programs are critical to the health and welfare of the American people, and there is a concern that a focus on annual budget and performance linkage will foster a bias for funding programs that can show more immediate results.

For example, an increase in access to cancer screening could lead to measurable reductions in morbidity and mortality in a population within several years. However, to effectively address the prevention of obesity, diabetes, or cardiovascular disease in a population could require a decade or more. A major determinant of these conditions was the lifestyle of population (e.g., diet and exercise patterns) the previous ten years before the planned intervention. When the role of the family is factored into the influence on preventive behavior for these conditions, the time frame for seeing measurable benefits of lifestyle related interventions can be an entire generation.

The nation's investment in medical research has a long history of successes. However, research is another area where linking annual investments to outcomes is difficult. Scientific research is best viewed as an enterprise for the long run – to account for the intrinsic difficulties and uncertainties of probing the unknown. Typically, the incremental advances as well as the medical breakthroughs are the result of multiple years' investments. Discoveries and significant advances typically emerge in an uneven way over time and can be difficult to predict in advance.

How HHS will address this issue:

HHS program managers need to work with budget analysts and decision makers to identify ways to better articulate the link between long-term budgetary investments and improved outcomes for these programs in our plans. More use of logic models supported by evidence-based strategies can help. Further investment in program evaluation can also help by providing evidence of the causal link between interventions (outputs and intermediate outcomes) and their impact on long-range outcomes. We also need to better articulate the role of the various contributors and intervening factors that influence outcomes for these programs.

An idea proposed in our discussions is that a possible approach to addressing this issue is to proceed on two parallel tracks: a long-term track that describes the strategic plan for an initiative, the outcome goal, who would be helped, etc., and a shorter-term track in which we would present and report on the incremental steps that are needed to achieve the outcome.

Performance Data Lags: The length of time needed to collect and report data for our performance goals presents a challenge to synchronization of budget and performance data. For many HHS goals, the lag between the end of the fiscal year and reporting of data can be nine months to two years. Compounding this, the budget development cycle begins about eighteen months before the beginning of the fiscal year. Therefore, the most recent financial and performance data available to the program to inform target setting can be several years old.

Delays in reporting on goals occur for many reasons. For example:

► States and grantees need time to collect, verify, evaluate, and report data to HHS following the end of the reporting year, and

then HHS programs must verify, aggregate, and evaluate the data before reporting the results in the performance plans.

- ▶ The time needed to measure a change from point A to point B. For example, data to report on CDC's goal on the percent of tuberculosis patients reported in 2002 who complete a course of treatment within 12 months of initiation of treatment will be available in June 2004. The last cases reported in 2002 (on December 31) will complete their 12 months treatment period on December 31, 2003. Then CDC needs six to nine months to tabulate, verify, and report the data.
- ► In addition, some HHS performance goals are not reported on annually because the data collections used to report on the goals are not conducted annually. For example, the Youth Risk Behavior Surveillance System, which is used to report on many HHS goals, is conducted every other year.

### How HHS has addressed this issue:

Where available, HHS programs provide earlier trend data for performance goals and other related data to facilitate assessment of program results. Also, see *Data to Measure Program Performance* in this Summary for a discussion of the data systems that support program planning and performance measurement at HHS and efforts underway to enhance the timeliness, accuracy, and completeness of our performance data.

Calculating the Full Cost of Programs and Activities: For most HHS programs, the federal investment is only a part of the total dollars that are invested to produce the outputs and outcomes. For these programs, linking the full cost of the federal investment in the program to the outputs and outcomes produced will not present a complete picture of program cost. Requiring states and grantees to provide the amount of data

needed to complete the picture of total costs is not feasible for practical and political reasons. For those instances in which HHS funds the full cost of program outputs, however, full cost information can be useful for budget decision-making.

### How HHS will address this issue:

HHS is implementing a Unified Financial Management System (UFMS) to replace five legacy systems. UFMS will be comprised of two primary sub-components, one for CMS and another for NIH and the remaining agencies. We are currently determining the management cost accounting requirements for the UFMS that will support decision making and accountability with the capability of linking HHS financial costs with program performance and budget information. The goal of UFMS is to provide the full HHS portion of costs for services and products that influence program outcomes, and be a standard, efficient system that can accrue costs spent throughout HHS on Departmental programs or initiatives. The system will provide HHS managers with timely and relevant HHS cost information to help monitor and improve their program results.

# Incorporating the FY 2002 Performance Report and Accountability Report: The Reports Consolidation Act of 2000 and OMB's current guidance on performance reports in A-11, Part II, provides for three performance reporting options, including the option exercised by HHS to integrate its performance plans and

HHS to integrate its performance plans and reports. However, the current OMB guidance on the form and content of agency financial statements requires that federal agencies incorporate their FY 2002 performance reports with their FY 2002 accountability reports.

We believe the current integration of our budgets, plans, and reports supports the use

of performance information in our budget decisions, and we are considering further integration to make the data more accessible and useful to our decision makers. In addition, the accelerated schedule for producing the accountability report will increase our difficulties with timely reporting of data. In order to meet the time line for producing the FY 2001 accountability report, we had to set a cutoff date for including new data that was earlier than that for the performance reports.

### How HHS will address this issue:

If required to incorporate the performance report into the accountability report, HHS may continue to report on performance in its budgets and performance plans to facilitate the use of performance information in budget decision making. However, the differing schedules for these documents will mean that the GPRA data reported in the budget and performance plans will be more current than that in the accountability report for many goals. To meet this challenge and the intent of accounting requirements, GPRA data reported in the accountability report will have to be supplemented with performance information from other sources.

### **CONCLUSION**

HHS is committed to working with budget analysts and decision makers in HHS and OMB to ensure meaningful performance data to inform budget decisions. The desire for better performance data to manage programs and inform budget decisions has been a key factor in the implementation of GPRA in the Department. In discussions last Fall, HHS components generally agreed that the implementation of GPRA, particularly work with program partners to develop national goals and reporting systems, has provided HHS program managers with better

data to manage HHS programs. HHS has also identified many practices that have helped us use this information to inform our budget decisions. As we develop our FY 2004 budgets and performance plans, we intend to greatly expand our use of this information in budget decisions.

### **INCREASE ACCESS TO HEALTH CARE**

# DECREASING THE NUMBER OF UNINSURED CHILDREN AND ADULTS

State Children's Health Insurance Program (SCHIP): The implementation of SCHIP has driven enormous change in the availability of health care coverage for children and in the way governmentsponsored health care is delivered.

The investment by states and territories, communities, and the federal government has resulted in significant expansions in coverage, as well as new systems for enrolling children. Mail-in applications for children are now used in SCHIP-funded child health programs and in Medicaid in most states, and paperwork requirements imposed on families applying for coverage have been reduced significantly in many states.

CMS and the states exceeded the FY 2001 goal to enroll an additional 1,000,000 children in SCHIP or Medicaid over the FY 2000 level. In fact, due to the overwhelming success of the program, the states enrolled 3,441,000 children over the FY 2000 level.

Over four million children participated in SCHIP-funded coverage (either a separate child health program or a Medicaid expansion) in FY 2001, and many more were enrolled in "regular" Title XIX Medicaid through increased outreach efforts and application simplification strategies undertaken as a result of SCHIP.

Elderly and Disabled: One of our most vulnerable populations is our elderly and disabled Medicare beneficiaries who do not have public or private supplemental insurance. Although Medicare provides beneficiaries with a basic set of health benefits, the beneficiaries still are required to

pay a significant amount out-of-pocket for premiums, deductibles, and co-insurance. This cost can be prohibitive for many beneficiaries, particularly for the approximately 12 percent who do not have private or public supplemental insurance.

Several programs were enacted to help low-income Medicare beneficiaries with their Medicare cost-sharing expenses. However, a substantial proportion of individuals eligible for these programs are not enrolled. CMS, in partnership with other federal agencies, states, providers, and community organizations, conducts outreach and enrollment activities to increase enrollment.

CMS met its FY 2001 goal to exceed the national enrollment rate in states receiving a federal grant, but did not meet its goal to increase enrollment by four percentage points in those states where the FY 2000 target was not achieved. This may be because as FY 2001 unfolded, CMS chose to focus on a national technical assistance and tool development strategy rather than focus limited resources on just three states. In FY 2002, CMS will refocus this goal on increasing beneficiaries' awareness of their eligibility for these programs. CMS is working with states, the advocacy community, and other interested parties to develop a comprehensive strategy to increase awareness of eligibility for Medicare Savings programs.

# INCREASING ACCESS TO QUALITY HEALTH CARE FOR UNDERSERVED POPULATIONS

Community Health Centers: The Health Centers form a cost-effective, integrated safety net for underserved and uninsured children, adults, migrant workers, homeless individuals, public housing and U.S./Mexico border residents in approximately 4,000 communities across the country. The Health Centers met their target to serve 9.6 million low income (87 percent), minority (65 percent), and uninsured persons (43 percent) in FY 2000 and estimate serving 10.5 million in FY 2001. These 10.5 million persons represent about 10 percent of the nation's uninsured, 10 percent of its 33 million Medicaid recipients, and 20 percent of the 43 million underserved people.

There is mounting evidence that access to a usual and regular source of care can reduce and even eliminate health status disparities among subsets of the population, and Health Center patients are far more likely to have a usual and regular source of care than poor people of color in the Nation. The high quality primary health care received in the Health Centers has been shown to reduce hospitalizations and emergency room use, reduce annual Medicaid costs, and helps prevent more expensive chronic disease and disability for these populations. The most recent data indicates:

- Reductions in Medicaid costs for a comparable group seeking health care elsewhere range from 30 to 34 percent, according to a Health Center Medicaid Beneficiary Effectiveness study.
- Health Center Medicaid patients are 22 percent less likely to be inappropriately hospitalized than Medicaid beneficiaries who obtain care elsewhere.

Cancer Screening for Women: CDC's National Breast and Cervical Cancer Early Detection Program (NBCCEDP) is a cross departmental program with the National Cancer Institute, Indian Health Service, and Food and Drug Administration that provides cancer screening for underserved women, particularly low-income, older and racial/ethnic minority women. Through March 2001, the program has provided more than three million screening tests to over 1.3 million women, diagnosed 10,649 breast cancers, 45,154 precancerous cervical lesions, and over 700 cases of invasive cervical cancer.

CDC's performance goals relate to identifying breast and cervical cancer at the early, localized stage because early detection significantly increases the survival rate. In addition, treatment costs for breast cancer diagnosed at the localized versus advanced stage may be as much as 31 percent lower. In 2000, excluding breast cancers diagnosed on an initial screen in the NBCCEDP. 66 percent of women aged 40 and older were diagnosed at the localized stage. The age adjusted rate of invasive cervical cancer in women aged 20 and older was 16 per 100,000 Pap tests provided, excluding invasive cervical cancers diagnosed on an initial screen.

Female patients at HRSA's Health Centers received age-appropriate breast and cervical cancer screening at rates that exceed Healthy People 2010 goals: 88.5 percent of users received up-to-date Pap tests, 62.5 percent received up-to-date mammograms, and 80.5 percent received up-to-date clinical breast exams in FY 1995. Data on FY 1999 targets will be available in September 2002.

The Title X Family Planning Program provides a broad range of preventive reproductive health services to a population that is predominately low-income and who have less access to health screening and preventive services. In 2000, Title X clinics provided 2.9 million Pap tests and 2.8 million breast examinations. In FY 2002, the Program set targets to provide 3.0 million Pap tests and 2.8 million breast exams, or between six and seven Pap smears and breast exams for every 10 female clients. The program is working to develop measures that also monitor the number of abnormal tests and appropriate referrals for follow-up.

A Healthy Start for Children - Prenatal Care: HRSA and OPHS are strongly committed to achieving the Healthy People 2010 goal of getting 90 percent of all pregnant women into prenatal care in the first trimester. Early identification of maternal disease and risks for complications are critical to providing a healthy start for children. The proportion of pregnant women entering prenatal care in the first trimester has increased steadily for all population groups over the last decade from 75.8 percent in 1990 to 83.2 percent in FY 1999. Progress has slowed in recent years suggesting that the easiest improvements already have been made, and that further gains are likely to be slow. Additional research is needed to identify new strategies for getting pregnant women to begin prenatal care in the first trimester of pregnancy. Accordingly, HRSA and OPHS have set FY 2002 and FY 2003 targets at 84 percent.

IHS Well Baby Care: Well child visits improve post-neonatal mortality and are a recognized national standard of care. They also provide an opportunity for educational interventions with parents concerning diet and nutrition, injury prevention, and prevention of family violence. As part of

larger efforts to improve child and family health, IHS set a goal to increase the proportion of American Indian/Alaskan Native (AI/AN) children receiving a minimum of four well child visits by 27 months of age. In FY 1999, 38.5 percent of AI/AN children received a minimum of four well child visits. Data to report on the FY 2000 target of a three percent increase will be available in April 2002.

Health Care Access for Head Start Children: Because healthy children are better able to learn, Head Start works to ensure every child is in a comprehensive health program that includes immunizations, medical, dental, mental health, and nutritional services. In FY 2001, the percent of children in Head Start who receive needed medical, dental, and mental health services are again below Head Start's aggressive target levels.

In FY 2001, 88 percent (178,840) of children received necessary medical treatment after being identified as needing medical treatment, less than the 92 percent target. Since Head Start children rely primarily on Medicaid services, Head Start suspects that levels of reimbursements to providers, particularly dental health providers, discourages the provision of services to Medicaid recipients. As a result, Head Start children experience delays in receiving such services. In FY 2001, 77 percent of children received dental services, below the 90 percent target. Dental treatment targets may be difficult to reach in the future as dental providers accepting Medicaid are scarce in some communities. This may also be a factor in mental health treatment for young children. In FY 2001, 77 percent of children received care for emotional or behavioral problems, less than

the 83 percent target. In spite of these obstacles, Head Start has set higher performance targets for FY 2001 through FY 2003.

# EXPAND CONSUMER CHOICES IN HEALTH CARE AND HUMAN SERVICES

# FAITH-BASED AND COMMUNITY INITIATIVES

HHS is the principal agency for protecting the health of all Americans and providing essential human services, especially for those who are least able to help themselves. While the Department can point to many successes that improve the lives of Americans, there are still those who fall prey to drugs or alcohol; are awaiting adoption; are dependent on temporary assistance to needy families; or otherwise disadvantaged.

The President established Centers for Faith-based and Community Initiatives in five major cabinet departments, including HHS. The mission of each center is to evaluate policies, funding programs, and agency communications and technical assistance strategies to ensure that they emphasize effectiveness and hospitality to faith- and community-based organizations. HHS is committed to partnering with faith-based and community caregivers who are close to the hardships of people and trusted by those who in need. The goal is to provide a level playing field for those groups that have traditionally been distant from government.

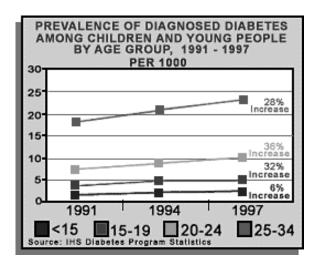
To meet the challenge and ensure that our goals are enduring, ACF, HRSA, and SAMHSA are including specific performance measures in their GPRA plans to track the participation of faith- and community-based organizations. For FY 2002, these agencies will establish baseline numbers of applications in selected direct grant programs. This will require putting in place a coordinated outreach effort, technical assistance, and mechanisms to assess the

number and quality of faith- and community-based applications. For FY 2003, the agencies are dedicated to increasing the number of applications for these grants by as much as 10 percent. In this way, HHS will become more hospitable to grassroots and small-scale programs, and leverage from their unique strengths to make a real difference in the lives of disadvantaged Americans.

## EMPHASIZE PREVENTIVE HEALTH MEASURES

### REDUCING MORBIDITY FROM DIABETES

*Diabetes:* Nearly 16 million Americans suffer from diabetes, and the number of new cases is increasing by approximately 800,000 per year. Diabetes is the seventh leading cause of death in the United States and American Indian and Alaskan Native (AI/AN) adults are almost three times more likely to have diabetes than the general population. A recent alarming trend is the increase in prevalence of type 2 diabetes in



children and adolescents, which has risen from 28 to 36 percent from 1991 to 1997.

Diabetes is the primary cause of new cases of blindness, non-traumatic amputations, and kidney failure in adults. Many of these complications can be prevented or delayed with appropriate monitoring and treatment.

State Diabetes Control Programs

(*DCPs*): CDC supports DCPs to educate health professionals and persons with diabetes about the disease and its complications. The programs also identify high-risk populations, improve the quality of

diabetes care, involve communities in controlling diabetes, and increase access to care – with measurable success. For example, over a two-year period, the New York DCP, which collaborates with 14 regional community coalitions and three diabetes centers of excellence, reduced hospitalization rates by 35 percent and decreased lower-extremity amputation rates by 39 percent.

In FY 2001, CDC met its goal to have 100 percent of DCPs adopt and implement guidelines for improving the quality of care for persons with diabetes. Influencing positive change in the preventive care practices undertaken in health systems is essential to the task of reducing complications of diabetes.

Results for CDC's goal to increase annual eye and foot exams for diabetics show progress as well as the challenge of collecting national diabetes data. Data from the FY 2001 Behavioral Risk Factor Surveillance System (BRFSS) from 12 of 16 DCPs funded to conduct comprehensive statewide efforts showed that they had achieved CDC's target for increasing the percentage of diabetics who receive annual foot exams. Although the data showed an increase in eye exams, the target was not met.

States conduct the BRFSS survey annually, however not all states include the questions on diabetes care each year. CDC usually has BRFSS data for 10-12 of the 16 states each year. It is possible that with all 16 states reporting, the target for eye exams would be achieved. CDC encourages all states to include the diabetes questions

regularly, and will continue to work with the DCPs to influence the preventive care practices of health systems and to inform providers and persons with diabetes about the importance of annual eye and foot exams.

Diabetes Care for American Indians and Alaskan Natives: CDC collaborates with IHS to support the National Diabetes Prevention Center, which was established to address the serious diabetes epidemic in American Indians and Alaskan Natives (AI/AN).

Recent research conducted by NIH has provided important new tools that IHS and the tribes can use to slow the rise of new cases of type 2 diabetes. Four American Indian Centers participated in the recent NIH clinical trial that compared diet and exercise treatment to treatment with Metformin in adults with impaired glucose tolerance and found that even modest lifestyle changes cut the incidence of diabetes by more than half among those most at risk.

IHS has been cited as a model of community involvement and program effectiveness for the use of the IHS *Diabetes Care and Outcome Audit* to measure diabetes care in AI/AN communities. The Diabetes Care Audit assesses a range of diabetes care and education for approximately 80,000 IHS diabetes patients. These measures have been incorporated into the National Council on Quality Assurance/American Diabetes Association proposal for national performance benchmarks for diabetes care.

IHS chose four of the Diabetes Audit measures as GPRA goals because of their proven benefits in reducing morbidity and mortality from diabetes: increasing the percent of persons diagnosed with diabetes with improved control of blood sugar, blood pressure, and cholesterol and the percent

assessed for kidney health. Of particular importance in terms of long-term improvements in diabetic morbidity, trends from 1994-2000 audit data indicate a continued improvement in blood sugar and cholesterol levels and assessments of kidney health. Blood pressure control has been relatively unchanged.

The improvement in control of LDL cholesterol is likely due to several factors: a better awareness in both providers and patients through the National Cholesterol Education Program efforts; increased provider awareness of the growing problem of cardiovascular disease (CVD) in AI/AN through efforts to publicize results of the Strong Heart Study, which shows the rate of CVD in AI/AN is increasing while it is decreasing in the general population; and better availability of statin drugs in pharmacies which are very effective in treating dyslipidemias.

Annual changes in blood pressure control have not been statistically significant and can be attributed to the sample population changing each year. Furthermore, the alarming increase in overweight and obese youth and adults and the rising incidence of cardiovascular disease among patients with diabetes may have a significant impact on the outcomes of this measure. The IHS National Diabetes Program is encouraging programs to use the new diabetes funding to enhance their clinical care programs, including better blood pressure screening and more aggressive treatment, assessment of cardiovascular risk, as well as increased funds to the pharmacy budget to purchase newer, more effective anti-hypertensive agents.

Diabetes Care in Community Health Centers: CDC's state-based diabetes

control programs partner with HRSA's Health Centers to improve the health status of persons with diabetes who receive care at these sites. Patients at the Health Centers have rates of diabetes that far exceed national rates for comparable racial/ethnic and socioeconomic groups. Yet, Health Center patients with diabetes are twice as likely to have their glycohemoglobin tests performed at regular intervals than the national norm. The Health Centers met their FY 1999 goal of 60 percent, up from the baseline of 43 percent in FY 1998. In FY 2002, the Health Centers will report on their FY 1999 goal to increase the proportion of diabetics who have an annual dilated eye exam to 90 percent from 57 percent in FY 1994.

Diabetes Care for Medicare Beneficiaries: CMS has worked with CDC, the American Diabetes Association, the National Committee for Quality Assurance, and others to develop a goal to increase biennial eye exams for Medicare beneficiaries diagnosed with diabetes in order to prevent blindness associated with this disease. CMS contracts with the Peer Review Organizations (independent physician organizations in the states) to improve the rate of eye exams among diabetic beneficiaries. CMS set an FY 2001 target of 68.3 percent and reported a rate of 68.1 percent for the period ending in FY 2000, up slightly from the 67.8 percent baseline for the period ending in FY 1999. CMS will report FY 2001 data in Spring of 2002.

*Diabetes Research:* The NIH Research Assessment Working Group, the independent panel of experts that assessed NIH's performance on its research goals in FY 2001, cited a study that they felt epitomized preventive research in its use of long-term, population-based data.

The 20-year study using a cohort of 121,000 female nurses convincingly showed an increased risk of heart disease in persons with diabetes, thus calling attention to a need to develop appropriate prevention and therapeutic strategies. In addition, the study demonstrated that this risk could be markedly reduced with exercise.

On the basis of this and other reports, national diabetes associations now recommend aggressive management of diabetic patients to reduce cholesterol, high blood pressure, smoking, and obesity. Exercise and diet play important roles in diabetes management and cardiovascular disease prevention.

### PROMOTING HEALTHY BEHAVIORS

Teen Smoking: Multiple agencies in the Department work together to prevent and reduce smoking among youth. CDC conducts surveillance activities and works with community-based programs, health communication campaigns, and schools, NIH funds research, and SAMHSA conducts tobacco use surveillance and implements regulations on minors' access to tobacco. Other federal departments, state and local governments, non-governmental organizations (e.g., American Cancer Society, Robert Wood Johnson Foundation), and healthcare providers also play a significant role in reducing teen smoking.

Between 1991 and 1997, cigarette use among youth (grades 9-12) increased from 27.5 percent to 36.4 percent, although the rate of increase slowed from 1995 to 1997. Data released from CDC's Youth Risk Behavior Survey in June 2000 indicate that the percentage of youth who smoke dropped slightly to 34.8 percent in 1999, meeting CDC's and OPHS' joint goal to reduce teen smoking to 34.6 percent in FY 1999.

Success in reducing the youth smoking rate is attributed to restrictions on the tobacco industry, increased state funding for tobacco control programs, technical assistance from the federal government to determine effective tobacco-control strategies, and coordination of tobacco-control efforts among public agencies and non-governmental organizations.

Tobacco Sales to Minors: SAMHSA supports the states in reducing retail sales of tobacco to youth by providing guidance on state-level policy making, assisting states in identifying retailers, and developing retail outlet lists. In addition, SAMHSA provides guidance on improving collaboration between state and local authorities responsible for complying with the requirements of the Synar Amendment.

More states are curtailing tobacco sales to minors. In FY 1997, only four states had tobacco retail sales violations at or below 20 percent. By FY 2001, the number dramatically increased to 30 states, exceeding SAMHSA's target of 26.

HIV Prevention in Youth: HIV prevention education programs in schools have been demonstrated to reduce risk behaviors in youth, including behaviors that affect their risk of becoming infected with HIV.

CDC funds state and local education agencies and national, non-governmental organizations to implement HIV prevention education programs in schools. The percent of high school students that have been taught HIV prevention in school has increased from 83 percent in FY 1991 to 91 percent in FY 1999, meeting CDC's goal to maintain the percentage at 90 or greater.

In its FY 2001 plan, CDC added the leading health indicator on responsible sexual behavior from Healthy People 2010: increase

the proportion of adolescents (grades 9-12) who abstain from sexual intercourse or use condoms if sexually active.

FY 1999 data indicate that the proportion of all adolescents who abstained or used condoms was 85 percent, moving towards CDC's FY 2001 target of 89 percent. The FY 1999 rate for black/African American adolescents was 83 percent and the rate for Hispanic/Latino adolescents was 84 percent. CDC set FY 2001 targets for these groups at 87 and 88 percent, respectively.

### BEHAVIOR MODIFICATION RESEARCH

The NIH Research Assessment Working Group, the independent panel of experts that assessed NIH's performance on its research goals in FY 2001 noted significant research results that focus on behavior as a way to prevent disease and disability.

Exercise: Several studies demonstrated that exercise improves physical fitness, whether in women seeking to reduce coronary heart disease, older people with osteoporosis, female caregivers experiencing stress-induced high blood pressure and disrupted sleep, or children participating in a skeletal strengthening program of jumping.

Examination of exercise-induced health benefits, however, brings two issues to attention: 1) physical exercise alone may not provide all the benefits associated with an exercise routine, and 2) exercise requires behavioral modification.

Two studies delineated an important role of exercise by demonstrating how social engagement can provide health benefits that cannot be achieved by exercise alone. In one study, assisted walking for patients with Alzheimer's disease provided a chance for social interaction, and it was the 30 minutes of conversation three times a week that reduced the patients' physical decline. Likewise, a study of older people exercising in different environments led to the conclusion that a social setting improves the participant's psychological measures. The health benefits of exercise derive partially, if not fully, from addressing social needs for these two groups of people.

Two other studies bring to the forefront the necessity of modifying behavior in the interest of good health. One study showed that intensive lifestyle intervention was most effective in achieving exercise and weight control goals in overweight individuals at risk for type 2 diabetes. Medication alone had limited success and only in particular patient populations. This study indicated that behavior modification could be an effective means of lowering risk of disease. Unfortunately, differential responses to behavior modification may limit such successes: although both men and women in one study received physical activity counseling, only women derived any long term benefits. The Working Group noted that an understanding of what motivates people will greatly aid preventive research.

Modifying Dangerous Behaviors in Young People: Several studies assessed the effectiveness of intervention programs, focusing on decreasing such disparate occurrences as sexual activity, crime, high school drop out rates, or alcohol abuse. Each study revealed important factors that can positively influence behavior. A common theme in these studies was the importance of community—either as an arena for performing service-oriented activities or as a force for controlling behavior within the group.

Other studies highlighted by the Working Group identified outside influences or personality variables that affect dangerous behaviors. Promotions by cigarette companies exemplify an outside influence that increased smoking in adolescents. Rebelliousness and risk taking behaviors in fifth graders predicted cigarette smoking by 12th grade. And early onset drinkers took more risks, which identified this group as likely to sustain more injuries. Only one study noted a positive correlation between a predictive element and prevention of dangerous activities: that of virginity pledges by some adolescents. The Working Group applauded these research outcomes because each identified behavior or outside influence could potentially be manipulated to decrease disease and/or disability.

# RESPOND TO BIOTERRORISM AND OTHER PUBLIC HEALTH EMERGENCIES

### BUILDING PUBLIC HEALTH INFRASTRUCTURE TO RESPOND

### State and Local Preparedness:

Traditionally, the responsibilities of the state health departments have been disease surveillance and management, however, health departments are now redefining their roles to respond effectively to an intentional release of biological organisms or hazardous chemicals into an unsuspecting population.

CDC is assisting state and local health departments complete comprehensive assessments of their capacity for bioterrorism preparedness and response. Analysis of these assessments will allow grantees to prioritize their resources and efforts. By the end of FY 2002, at least 48 of the 55 states and territories will have completed their vulnerability assessments and 42 will have completed their draft public health emergency response plans.

In addition, state, territorial, and local health departments have begun to build critical communication links with other assets in the health-care and emergency response community (e.g., hospitals, emergency departments, acute-care centers, police, fire, EMS, local emergency management agencies) and other first response organizations to assess local capacities and coordinate responses.

Metropolitan Medical Response

System: OPHS' Office of Emergency Preparedness (OEP) is responsible for the coordination and management of federal health, medical, and health related social services response and recovery to major

emergencies, federally declared disasters, and terrorist acts. As such, OPHS directs MMRS development program, which provides a mechanism to forge a local integrated response which links multiple local, state and federal agencies as well as private health care institutions that will serve as the initial responders to any weapon of mass destruction (WMD) event. In FY 2000, OEP awarded 25 new MMRS contracts for systems development, and modified 25 contracts awarded during FY 1999 to include funding for capabilities to respond to bioterrorism. In FY 2001, OEP awarded 25 more contracts with metropolitan areas for continued development of MMRS and amended contracts awarded in FY 2000 to provide funds for a biological terrorism response component.

### Surveillance and Epidemiology

Capacity: Because a covert biological or chemical attack will most likely be detected locally, disease tracking systems at state and local health agencies must be ready to detect unusual patterns of disease and injury, and epidemiologists at these agencies must have expertise and resources for responding to reports of rare, unusual, or unexplained illnesses. CDC is working to integrate surveillance for illnesses resulting from biological and chemical terrorism into the U.S. disease surveillance systems. CDC is also developing new methods for rapidly detecting, evaluating, and reporting suspicious health events that might indicate covert terrorist acts.

In FY 2001, CDC provided funding for bioterrorism surveillance and epidemiology coordination to all state health departments and selected major metropolitan cities and territories to enhance their capacity to detect, investigate and mitigate health threats posed by bioterrorism agents.

(NPS): The NPS was deployed for the first time in response to the September 11th terrorist attacks. CDC mobilized a NPS "push package" to New York City within seven hours as well as a push package to Washington, DC, following the attack on the Pentagon. In response to the anthrax attack,

National Pharmaceutical Stockpile

Washington, DC, following the attack on the Pentagon. In response to the anthrax attack, NPS delivered almost 3.75 million tablets of three different antibiotics for post-exposure prophylaxis of employees in affected buildings, postal workers, mail handlers, and postal patrons.

Communication Systems: Within four hours of the attack on the World Trade Center, the Health Alert Network (HAN) began transmitting emergency messages to the top 250 public health officials in 50 states, seven large cities and Guam. In the months that followed, over 67 health alerts, advisories and updates were transmitted reaching an estimated 1 million frontline public and private physicians, nurses, lab clinicians, and state and local health officers. Using in-state systems built with CDC funds, states were able to augment and tailor the HAN alerts to their unique situations. CDC and its HAN grantees also established and maintained Internet websites to provide information to the public. Since September 11, there have been 73 million hits, five million visits, and 12 million requests for information on the CDC bioterrorism website.

The Epidemic Information Exchange (Epi-X), an Internet-based, secure communication system promotes easier,

more accurate, and real-time reporting of suspect outbreaks or other emerging health threats, including those related to bioterrorism. At the end of FY 2001, 650 public health officials, including all state epidemiologists, local health officials, and members of the military, participated on Epi-X. Epi-X, which has medical editorial staff available 24 hours/day, seven days/week, is moderated for quality by CDC staff.

Responding to ideas from public health officials, Epi-X plans to provide secure communications for multi-state outbreak response teams, and plans to develop links between disease surveillance programs and local health alert systems and improve software to automate the recognition of similar disease outbreaks across jurisdictions.

Hospital Preparedness: As part of the President's Homeland Security initiative, HRSA's Hospital Preparedness Program will improve the capacity of the Nation's hospitals and emergency departments to respond to biological, chemical and radiological terrorist attacks as well as to situations involving large scale or mass casualties.

### BUILDING LABORATORY CAPACITY TO RESPOND

Biological Agents: Because most bioterrorist agents receive little public health attention on a day-to-day basis, the nation's ability to rapidly diagnose these infections is limited, both at the national level and in state and local public health laboratories. CDC ensures that frontline state and large city public health laboratories are prepared to rapidly and accurately diagnose agents

causing public health problems through the Laboratory Response Network. This multilevel network of public health laboratories provides essential diagnostic capabilities in state and large metropolitan areas and centralized, state-of-the-art national reference capacity at CDC.

Lab clinicians from all 50 states have been trained in the handling and testing of critical biologic agents, and many public health laboratories across the country have been renovated and upgraded to allow adequate safety for improved diagnosis of potential bioterrorism agents. In addition, seven new rapid assays were developed in FY 2001 for real-time PCR and antigen detection for potential bioterrorism agents.

CDC's Rapid Response and Advanced Technology Laboratory (RRAT) can provide rapid identification of biological agents that are rarely seen in the United States. Other disease specific laboratories at CDC provide additional research and surge capacity for diagnostic testing. CDC and partners have identified the biological agents most likely to be involved in a terrorist attack and are developing rapid assays to assist in detecting these agents at the state and local levels. From September 11 through October 4, 2001, an estimated 7,500 laboratory samples were processed at CDC's RRAT and specialty laboratories.

Chemical Agents: In the event of a chemical terrorist incident, not only would there be a need to analyze samples from persons who were actually exposed to an agent, but there also could be extensive demand for services for persons who think they were exposed. To address this need, CDC has developed a rapid toxic screen that can identify up to 150 different agents in a blood sample. CDC has also funded five laboratories to install new state-of-the-art laboratory equipment to measure nerve

agents in human samples, and grantees have successfully completed a round of proficiency testing to demonstrate their understanding of the method. In addition, CDC has developed testing methods for nerve agents, nitrogen mustards, sulfur mustards, lewisite, hydrogen cyanide, cyanogen chloride, BX, tricothecene mycotoxins, ricin, heavy metals, selected toxic industrial chemicals, and incapacitating agents.

Laboratories and Decontamination
Infrastructure: HRSA's Hospital
Infrastructure (Laboratories and
Decontamination) Program will fund
expenses for necessary infrastructure
improvements and expansions for hospital
laboratory capacity, the purchase of personal
protective equipment, decontamination
facilities and other equipment for
decontamination of biological and chemical
agents so that hospitals will be prepared to
respond to bioterrorism acts.

#### **ENSURING FOOD SAFETY**

FDA aims to decrease the threat of contamination in the food supply. They minimize this threat by paying close attention to imported products at the country of origin before products are exported and at the border as well as inspecting high-risk food establishments annually.

Food Import Inspections: Imported foods now constitute more than 10 percent of the U.S. food supply, and for some commodities, such as many fresh fruits and vegetables, 40 percent or more are imported. FDA data show that the number of imported food entries has doubled over the past seven years and that imports are expected to increase by an additional 30 percent by FY

2002. Part of their strategy to ensure the safety of imported goods is to increase the number of physical examinations of imported foods, targeting violative products at the border and preventing their entry. FDA conducted 12,169 physical exams in FY 2001. Since September 11<sup>th</sup>, FDA has altered this goal to double import inspection levels in FY 2002 to 24,000 and again in FY 2003 to 48,000, focusing on high-risk ports and devoting more resources and manpower to achieving these targets.

Inspection of High-risk Food Establishments: FDA, in conjunction with the states, inspects food establishments that produce foods with the greatest risk for microbial contamination and those foods requiring specific components for a safe and nutritious product. Foods following under this definition include infant formula, medical foods, scrombotoxic seafood, molluscan shellfish, low acid canned and acidified foods, ready to eat foods such as processed fresh fruits and vegetables, bakery goods (with filling), soft and soft ripened cheeses, cooked pasta dishes, prepared salads, and heat and serve products. FDA estimates that there are approximately 7,000 such establishments in its establishment inventory. In FY 2000, FDA and states inspected 5,700 high-risk food establishments or 91 percent (target 90-100 percent). In FY 2001, the field inspected 74 percent of the identified possible inventory of high-risk product/process domestic firms (target 90-100 percent). This decrease is due to FDA redirecting resources to critical BSE related efforts.

*DNA Sequence of E. Coli:* Recently, NIH investigators mapped the DNA sequence of the food-borne pathogen E. coli O157:H7 and compared it to the benign form of E. coli that was sequenced in 1996. Some

important and surprising differences were noted between the two strains.

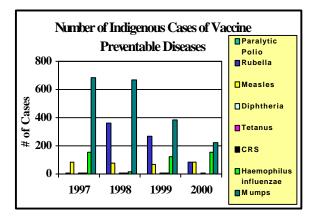
E. coli O157:H7 has a much larger genome and contains approximately 1,300 genes not found in the harmless strain, including some genes that are very similar to those of the bacterium Salmonella and the plague-causing organism Yersinia. E. coli O157:H7 also has a gene that encodes the extremely potent Shiga toxin, originally found in the dysentery-causing microorganism Shigella.

Since infection with Shigella is managed differently than infection with E. coli O157:H7, it is important to be able to differentiate between the two organisms. The development of a test to differentiate between the two organisms may stem in part from the DNA sequence. In addition, the DNA sequence is a preliminary step toward developing an effective vaccine against or treatment for the infection.

### **IMPROVE HEALTH OUTCOMES**

### REDUCING DEATHS, INCIDENCE, AND IMPACT OF INFECTIOUS DISEASES

Vaccine Preventable Diseases: By all counts, efforts by the CDC and its partners to protect children in the U.S. from vaccine-preventable disease have been a success. Cases of most vaccine-preventable diseases of childhood are down more than 97 percent from peak levels before vaccines were available, moving toward the Health People



2010 target of zero cases. Vaccine coverage levels for preschool children are at an all-time high for all racial and ethnic groups.

No cases of paralytic polio due to indigenous transmission of wild polio virus have been reported in the U.S. since 1979 and only 63 reported cases of measles occurred in 2000.

Only 387 cases of mumps were reported in FY 1999; in FY 2000, the incidence was further reduced to 323 cases, well under CDC's goal of 500 cases. This reduction is linked to the effectiveness of the Measles-Mumps-Rubella vaccine and its coverage rate.

Conjugate vaccines for the prevention of *Haemophilus influenzae* type b (Hib) are highly effective and have led to near

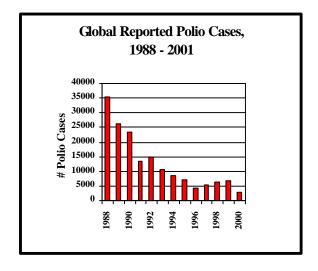
elimination of invasive Hib disease, the main cause of bacterial meningitis. The development of the Hib vaccine was realized through decades of work by NIH government scientists, along with colleagues in hospitals and universities and vaccine developers in the pharmaceutical industry. *Haemophilus influenzae* type b (Hib) invasive disease has declined by more than 99 percent in children under five since the introduction of the vaccine.

However, in 2000, the number of possible cases reported did increase from 122 cases in 1999 to 167 cases. Therefore, it is possible that, although the total number of cases increased in 2000, the number of type b cases (both serotyped and not) - for which the vaccine is effective - may have remained the same or decreased. Beginning with the 2000 data, CDC will be reporting both the number of serotype b + unknown serotype cases as well as the number of serotype b cases only to alleviate some of this ambiguity.

#### Global Polio and Measles Elimination:

CDC and its domestic and international partners have committed to achieving the World Health Organization's (WHO) goal of global elimination of poliomyelitis by 2005. Global polio incidence has declined by more than 99 percent from about 350,000 cases in 1988 to 2,867 cases in 2000, about 250,0000 lives have been saved and 4 million cases of childhood paralysis have been avoided.

Globally, measles caused an estimated 880,000 deaths in 1999 and was the leading cause of death among children under five years of age from a vaccine-preventable disease. Based on surveillance data for



2001, 45 of 47 countries and territories appear to have interrupted measles transmission. CDC and its global partners have set a goal to reduce the cumulative global measles-related mortality rate by 50 percent by FY 2005.

#### Sexually Transmitted Diseases:

Working with other countries, USAID, and international and U.S. government agencies, CDC has set a goal to reduce the number of new HIV infections among 15-to-24-year-olds in sub-Saharan Africa from an estimated 2 million by 2005. In FY 2001, CDC strengthened voluntary counseling and testing (VCT) programs in 18 countries (target 19) and expanded technical assistance and support to improve national surveillance programs for HIV, STDs and TB to 18 countries (target 15).

CDC is also enhancing support for programs that provide interventions to prevent perinatal transmission of HIV in 13 countries (target 10) in FY 2001. CDC will continue to identify barriers to these services and evaluate the outcomes of interventions

on both infants and mothers and to assess ways to expand prevention to infants' fathers as well.

U.S. rates of primary and secondary (P&S) syphilis declined by 88 percent from 1990 to 1999, and preliminary data from 2000 indicate a continuation of this trend. Although the 5.4 percent decline in the number of P&S syphilis cases reported in 1999 is less than the decline of approximately 20 percent per year since the last major syphilis epidemic in 1990, it is possible that this smaller decline at least partially reflects improved case findings and reporting resulting from the national syphilis elimination effort. Syphillis is extremely concentrated geographically. Approximately 80 percent of U.S. counties have eliminated syphilis, and 93 percent have a syphilis rate of < four per100,000 in FY 2000 (target >90 percent). Of the counties that have not eliminated syphilis, the largest numbers of cases of (P&S) syphilis were reported from 22.

### Prevention of STD-Related Infertility:

More than 50 percent of all preventable infertility among women is a result of sexually transmitted diseases (STD), primarily chlamydia and gonorrhea. CDC and OPHS support surveillance, screening, treatment services in publicly funded family planning and STD clinics because they represent settings with the highest prevalence rates for these diseases.

Overall, there was a small decline in chlamydia prevalence in FY 2000 (5.2 percent) among women under age 25 attending family planning clinics. Prevalence decreased in four of ten DHHS regions from 1999 to 2000 most likely due to the effectiveness of screening and treatment, while expansion of screening to populations with higher prevalence may have contributed to increases in six other regions.

Based on the recent performance measures, CDC lowered the target to < five percent beginning in FY 2002. Of concern, however, is the continued rise in chlamydia in high-risk women under age 25 who are Job Corps participants. The FY 2000 rate continues at greater than 11 percent, significantly above CDC's target of eight percent. Since there has been little or no change in chlamydia prevalence among Job Corps participants and CDC does not have targeted prevention activities for Job Corps, it is recommended that the target for FY 2002 be adjusted to 10 percent and to nine percent for FY 2003

CDC did not meet its goal to decrease gonorrhea to less than 250 per 100,000 for women aged 15-44 attending family planning clinics; the FY 2000 rate was 284 per 100,000. Between 1999 and 2000, gonorrhea rates increased in all regions of the country except for the South which experienced a slight decline. Expanded screening, more sensitive diagnostic tests, and improved reporting may account for a portion of the increase. However, rates may have increased in some populations and geographic areas. The southern states continue to have the highest rates of any region. Reasons may include poverty levels and access to quality healthcare and preventive services.

Effective interventions for these diseases have been demonstrated, but are not reaching all those in need. Future declines in prevalence will require efforts to increase public and provider awareness of the problem, an increase in screening and treatment in high-risk populations, and expansion in prevention messages.

Vaccine Research: The NIH Research Assessment Working Group, the independent panel of experts that assessed NIH's performance on its research goals in FY 2001, noted significant progress in

vaccine development. Vaccines are being produced for otitis media (ear infection), Ebola, dengue virus, AIDS, and Leishmania (parasite). A more effective tuberculosis vaccine is also under development.

The vaccine study evoking the most attention by the Working Group not only prevented memory impairment, but also resulted in better learning and memory performances by transgenic mice modeling Alzheimer's disease. The results of this and other studies will propel further vaccine research.

### Utilization of Prevention Guidelines:

Examples of how prevention guidelines can improve patient outcomes include prenatal Group B streptococcal disease and central line-associated bloodstream infections.

CDC has made substantial progress in reducing prenatal Group B streptococcal disease the most common cause of severe infections in newborns. Providers and obstetric departments have quickly adopted recommended prevention strategies, resulting in a decline in disease that is more rapid than expected. Neonatal group B streptococcal infections have declined 70 percent since 1995, from 1.3 per 1,000 in 1995 to 0.4 per 1,000 in FY 1999, exceeding the target of 0.9 per 1,000, however, preliminary data for FY 2000 show a rise in disease incidence (0.6 per 1,000 births up from 0.4).

Through the implementation of health communication campaigns and other active prevention efforts, CDC has exceeded their target of reducing central line-associated bloodstream infections of 4.4 infections to 3.9 infections in FY 2000. Further progress is anticipated based on additional plans for educational and behavioral interventions.

### IMPROVING OUTCOMES FOR SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES

#### Substance Abuse Treatment:

Research has consistently shown that drug abuse treatment can be effective in reducing drug use and the consequences of addiction. SAMHSA increases access to treatment services through the Substance Abuse Prevention and Treatment (SAPT) Block Grant and three Targeted Capacity Expansion grant programs.

The SAPT block grant provides funding to the States for treatment and prevention services for persons at risk of abusing alcohol and other drugs. Estimates from the Treatment Episode Data Set (TEDS) indicate that 1,587,510 persons have been served through the SAPT block grant in FY 1999. SAMHSA projects serving 1,525,688 persons in FY 2000, with increases in future fiscal years to reflect funding increases designed to reduce the treatment gap. TEDS data represents admissions to treatment, not unique persons served during the year. However, TEDS is used to track access to services because of limitations in the data reporting capacity of the states.

The Targeted Capacity Expansion (TCE) Grant Program addresses gaps in treatment capacity by supporting rapid and strategic responses to area-specific demand for substance abuse treatment services. In FY 2001, 20,507 clients were served, an increase from 7,304 served in FY 2000.

In addition, the TCE HIV Grant
Program, which addresses critical gaps in
substance abuse treatment and HIV/AIDS
services served 9,024 clients in FY 2001
(preliminary data). The TCE Community
Substance Abuse and HIV/AIDS Outreach
Program, which works to reduce the
transmission of HIV by assisting out-oftreatment intravenous drug users in adopting

risk reduction and safe-sex practices, and by providing access to substance abuse treatment and health education, served 193,279 clients in FY 2001.

In the TCE Program, the performance targets for client outcomes were reached for goals to increase the percent of adults receiving services who had a permanent place to live in the community and had reduced criminal justice involvement. However the goals for employment, reduced illegal drug related health, behavior, social consequences, and past month substance use were not reached.

The targets for these indicators have been lowered for future years reflecting the difficulty in treating individuals with a chronic relapsing disorder, particularly during difficult economic times when hiring recovering individuals is not a top priority.

#### Substance Abuse Prevention:

Substance abuse prevention programs are critical to reducing the nation's treatment gap. SAMHSA assists states and communities to increase the availability and quality of substance abuse prevention services by strengthening state capacities to assess their needs according to identified risk and protective factors, gather data on the effectiveness of their programs, and invest in science-based prevention strategies.

Based on prevention research, SAMHSA and the states designed a conceptual framework for prevention programs that includes six strategies: information dissemination, education, alternative activities, problem identification and referral, community mobilization, and environmental activities. SAMHSA set a goal to increase the number of states using funds in each of

the six areas as an indicator of the progress by the States in developing a comprehensive prevention system.

Eighty-eight percent of the states and jurisdictions (53 of 60) reported using funds in all of the six prevention strategies in FY 2001, up substantially from 56 percent in FY 1996, but below the 100 percent target. All states and jurisdictions use funds in at least some of the six strategies. SAMHSA believes that increased technical assistance will enable all states and jurisdictions to meet this target.

Community Mental Health Services for Children: SAMHSA's Comprehensive Community Mental Health Services for Children and Their Families Program funds states to develop comprehensive, community-based systems of care for children and adolescents with serious emotional disturbances. The program increases access to quality mental health services for children and families in their local communities by promoting system change.

The program has been successful in encouraging collaborative arrangements across child-serving sectors, such as education, juvenile justice, child welfare, and mental health. Cross-agency treatment planning has increased from 40 percent in FY 1997, to 62.3 percent in FY 2001. This is a 56 percent increase over the baseline, and exceeds the FY 2001 target of 50 percent.

Results for children in services for at least twelve months show significant improvements benefitting their lifelong development and quality of life:

► The number of treatment days for children in restrictive inpatient institutional care has decreased by 43 percent from the baseline in 1998; this decrease has been maintained over time.

- ► The baseline for regular school attendance was 70 percent in FY 1997; in FY 2001 this had increased to 80 percent.
- ► The baseline for children having more than one living arrangement after six months of service was 76 percent in FY 1997. Data from FY 1998 through 2001 range from 24 to 27 percent, demonstrating that the program has achieved greater beneficial levels of stability for children in their living environments.

In addition, positive clinical outcomes are higher toward the latter years of the grant program as demonstrated in the chart (Figure 1), suggesting increased effectiveness of systems of care as they develop over the five-year period.

50%
45%
40%
35%
30%
25%
26.8%
30%
29.8%
31.5%
First (N=157)
Second (N=1245)
Fourth (N=1159)
Fourth (N=1159)

Figure 1. Six-month Improvement <sup>1</sup> in Behaviors and Emotions <sup>2</sup> by Grant Year Cohort <sup>3</sup>

1 Improvement was calculated using the Reliable Change Index (RCI)
2 Behaviors and emotions were measured using the Child Behavior Checklist (CBCL)
3 Grant Year Cohort - Group of children who entered the system of care during a given funding yea
Total N=4420

### IMPROVE THE QUALITY OF HEALTH CARE

### IMPROVING DRUG AND MEDICAL DEVICE SAFETY

FDA's adverse event reporting strategies are part of an HHS wide effort to promote patient safety and prevent medical errors. Its key objectives are to: develop a comprehensive adverse event reporting capability; analyze problems surfaced by these reports so that appropriate interventions can be designed; and educate both health professionals and patients about problems and solutions associated with appropriate product use. FDA investigates safety reports to identify serious, rare, or unexpected adverse events, distributes dear colleagues letters, or even takes regulatory action on certain drugs or medical devices.

Drug letv: I

Safety: Drug event reporting system enables FDA to provide faster access to drugs while maintaining a watchful eye once released on the market. The system has been operational for nearly five years and contains nearly two million individual safety reports (ISR). In CY

Adverse Event Reporting at Work: Reuters reported in January 2002, that FDA's adverse event reporting system supported early confirmation of a complication associated with etanercept, a drug taken by 77,152 Rheumatoid Arthritis patients. After a patient suffered MS-like symptoms, doctors searched the database and discovered 19 other patients who experienced similar problems. Doctors were advised to monitor patients for these symptoms and avoid prescribing the drug to those with MS or a family history of MS.

2000, over 270,000 ISRs were received and after investigation, 30 percent represented

serious events or unexpected events. It is estimated that 280,000 ISRs were received in CY 2001. FDA has continuously made technology improvements to the system, conducting a pilot program in FY 1999 for electronic submission of ISRs, involving manufacturers with approved products. FDA also developed and piloted data retrieval system to provide reviewers with quick access to adverse event reporting systems data and reduce reviewers' reliance on hard copy reports. In FY 2000 and FY 2001, FDA continued their efforts to increase participation in electronic submission of ISRs.

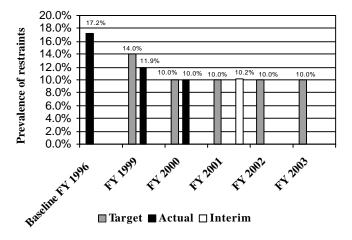
Medical Device Safety: FDA's

comprehensive program to regulate medical devices not only provides pre-market review but has in place the Medical Device Surveillance Network System (MeDSuN), a post-market reporting system where medical professionals can report any serious adverse events. The MeDSuN System is a pilot program that educates and encourages hospital personnel to accurately identify and report injuries and deaths associated with medical products. FDA can then provide warnings to users or even recall those products. MeDSuN becomes even more important as FDA decreases their involvement in reviewing lower risk medical devices. FDA aims to expand implementation of MeDSuN to 180 systems by FY 2003. In FY 2001, FDA recruited 25 hospitals into the reporting network, falling short of their target of 75 hospitals. This is most likely due to extended software development, unanticipated program changes, and increased information technology security requirements.

### IMPROVING THE QUALITY OF CARE IN NURSING HOMES

The State Survey and Certification program ensures that Medicare and Medicaid beneficiaries in nursing homes receive quality care in a safe environment. Nursing home patients are a vulnerable population group, susceptible to complications and morbidities resulting from physical restraints and pressure ulcers. As part of CMS's state certification effort, surveyors have been

#### **Prevalence of Physical Restraints**



instructed to pay particular attention to decreasing nursing homes' use of physical restraints and to their ability to prevent and treat pressure ulcers as key quality of life measures.

Physical restraints refer to any manual method, mechanical device, material, or equipment attached or adjacent to the patient that the individual cannot remove easily and that restricts freedom of movement or normal access to one's body. Restraints should be used only when required to treat medical symptoms and should never be used

as a substitute for adequate patient supervision. The use of physical restraints can cause incontinence, pressure sores, loss of mobility, and other morbidities. Many providers and consumers still mistakenly hold, however, that restraints are necessary to prevent residents from injuring themselves.

In order to promote reduced use of physical restraints, state and CMS surveyors who conduct annual inspections of nursing homes pay close attention to nursing homes' use of restraints and cite any improper use. CMS will also be conducting a training program which will be broadcast by satellite and carried live over the Internet for state surveyors in the near future. States and CMS have been successful in reducing the use of restraints from 17.2 percent in 1996 to 10.0 percent in FY 2000, meeting their target. Interim FY 2001 data indicate use of physical restraints is just above the 10.0 percent target.

▶ Pressure ulcers refer to any lesion caused by pressure resulting in damage of underlying tissues, often referred to as bedsores. Pressure ulcers are an undesirable outcome that can be prevented in most residents except those at very high risk.

CMS sponsors a variety of activities to decrease the prevalence of pressure ulcers through an education program; enhancing methods of surveyor detection of pressure ulcers using quality indicator reports; more detailed, uniform guidance to surveyors to consistently detect pressure ulcers and treatment deficiencies; more effective enforcement procedures to sustain compliance with Federal requirements; and campaigns to raise national awareness of this significant health care problem. Interim FY 2001 data indicate the prevalence of pressure

ulcers is 10.7 percent (target 9.6 percent). The increase in prevalence is most likely due to better detection efforts.

# INCREASING EASY ACCESS TO HEALTH INFORMATION FOR CONSUMERS

### Dissemination of Research Findings:

The NIH Research Assessment Working Group, the independent panel of experts that assessed NIH's performance on its research goals in FY 2001, cited several groundbreaking developments for sharing and disseminating information:

- ► GenBank, the NIH human genome public information resource, for accelerating gene disease discovery.
- ► MEDLINE and MEDLINEplus, for providing the public with access to published research findings on any biomedical subject. Approximately 30 percent of the 400 million annual searches are conducted by consumers. One reviewer noted that improvements to these databases have "exploded the potential for sharing information worldwide".
- National Heart, Lung, and Blood Institute (NHLBI) website, for the overwhelming positive response of the disparate groups related to heart, lung, and blood diseases when it premiered.

Medicare and You: In order to help Medicare beneficiaries make more informed health care decisions, CMS initiated the National Medicare & You Education Program (NMEP) called Medicare & You. Through a toll free number, website, and handbook, NMEP aims to increase access to health care information and provide information on the various health care options available to Medicare beneficiaries. In Fall 2000, CMS kicked off a national media campaign and implemented a number of new and expanded services to make it

easier for Medicare beneficiaries to learn about their choices, which included expanding phone service availability at 1-800-MEDICARE to 24 hours a day, seven days a week; introducing a web-based Medicare Personal Plan Finder on <a href="https://www.medicare.gov">www.medicare.gov</a> to help consumers compare their health plan choices; enabling customer service representatives at 1-800-MEDICARE to provide more in-depth help to callers on finding the health plan choice that is best for them; and conducting a publicity campaign.

These strategies will support several performance goals, including goals to improve beneficiary understanding of basic features of the Medicare program and to increase adult immunization and mammography rates. With such strategies in place, CMS is on target to increase the percentage of beneficiaries who seek information from Medicare and report that information received answered their questions to 77 percent by FY 2004 from 67 percent in FY 1999. They are also on track to increase awareness among beneficiaries on the different health plan options available to them within Medicare to 57 percent by FY 2004 from 47 percent in FY 1999. CMS has also increased the number of callers and website visitors, nearly 18.5 million in CY 2001 and increased user satisfaction across the board.

CDC Website, Toll-free Number: CDC disseminates timely, credible health information to help consumers, providers, policy makers, and researchers make informed decisions about personal and public health. CDC's toll-free number provides callers with immediate access to automated prerecorded voice multi-lingual information on public health topics or automated faxed

information, data, and graphics to any fax machine upon request. The toll-free number ensures access to the hearing impaired and by persons without Internet access. CDC's website continues to be one of the most popular government websites and is especially important in providing trusted health information to consumers and health professionals. In FY 2001, 3.6 million visited the CDC website or called the toll-free number, which was a combined increase of 29 percent over FY 2000 levels.

Information on Mental Health Treatment and Services: SAMHSA's Knowledge Exchange Network (KEN) provides information about mental health treatment services to consumers, their families, policy makers, providers and researchers. Requests for materials and publications and Internet access have significantly increased since 1996.

In FY 2001, 855,113 publications were distributed. This is a 55 percent increase over FY 2000, exceeding the targeted 50 percent increase. While the number of individual publication requests has decreased, bulk orders are on the rise. Grantees and organizations are requesting larger quantities of documents.

In FY 2001, there were 1,179,718 web site contacts, a 67 percent increase over FY 2000. Since the September 11th attacks, user activity to the KEN homepage increased from 96,507 in August to 126,617 in September and 146,346 in October.

User activity on KEN's Disaster Mental Health Services link has also dramatically increased: August, 724; September, 13,531; October, 7,808; November, 7,429; December, 4,675. This link provides information on preparedness and mental health needs that develop in the aftermath of disasters. It also includes a feature to assist

individuals in locating mental health services near their locality.

Substance Abuse Prevention and Treatment Information: SAMHSA's National Clearinghouse for Alcohol and Drug Information (NCADI) provides comprehensive, customer-friendly information about substance abuse prevention, intervention, and treatment.

SAMHSA met its FY 2001 target for a 260 percent increase in information requests. Calls to the Treatment Helpline, which operates 24 hours, seven days a week, rose to 199,155. Treatment calls tend to be longer, yet the average on-hold time across both prevention and treatment calls is 11 seconds, which compares well to industry standards.

In FY 2001, overall customer satisfaction was 97.5 percent, exceeding the 85 percent target. The target for FY 2002 has been raised based on these results.

Detailed results from the FY 2001 customer satisfaction survey include: 95.5 percent of customers requesting materials for work were very satisfied, 99 percent of customers requesting materials for personal use were very satisfied, 90.5 percent of customers rated the value of the service they received as excellent, 95.5 percent received their materials within two weeks, and 85 percent of customers received everything from their order.

### ADVANCE SCIENCE AND BIOMEDICAL RESEARCH

### ADVANCING BASIC AND APPLIED BIOMEDICAL RESEARCH

National Institutes of Health Research Program: Each year, the NIH Research Assessment Working Group, an independent panel of experts, convenes to assess information on NIH's recent research achievements and the extent to which NIH research has yielded important discoveries, knowledge, and technologies that can be applied to the development of new or improved diagnostics, treatments, and prevention strategies measures.

In FY 2001, the Working Group concluded that NIH had substantially exceeded its five qualitative research goals. Significant advancements noted in the Assessment Working Group's report include:

- Human Genome: NIH continues to produce important developments in genetics and genomics-fueled by tools that come out of the human genome project. Substantial advances were made in understanding the biology of diseases that affect nearly every organ system, including heart disease, cholesterol absorption in the intestine. autism, Parkinson's disease, Fanconi anemia (the hematological system), and interstitial lung disease. Progress was made toward increasing the understanding of some rare diseases and also in the understanding of complex conditions where a variety of genes contribute to disease. Examples of complex diseases where advances occurred are Crohn's disease and type 2 diabetes.
- Adult Stem Cells: Among the many areas where NIH-supported research exceeded its goals, research into adult stem cells is one of the most exciting.

  Investigators are learning that stem cells

derived from adult tissues have far greater ability to assume specialized function than was previously known. Stem cell researchers appear to be at the threshold of an entirely new field that carries vast therapeutic potential.

Decline in Disability in Older Americans: The 1999 National Long Term Care Survey indicates that the rate of disability among older Americans has declined over the past two decades. There were 7 million chronically disabled Americans in 1999, which is 2.3 million fewer that there would have been had the rates not changed since 1982. The reduction in disability rate was greater for older black Americans than for the population as a whole. Similar trends were seen in other studies (Survey of Income and Program Participation, Medicare Current Beneficiary Survey, National Health Information Survey) over the same or nearly the same time period.

A study called Instrumental Activities of Daily Living suggests that fewer older people are having difficulty with routine care activities such as household chores and errands, although the number who have severe personal care disability (e.g., difficulty with bathing, dressing, and eating) has not changed. Analysis of data from the Health and Retirement Study indicates that severe cognitive impairment in older Americans declined from six percent in 1993 to four percent in 1998.

Researchers believe that a decline in disability reflects improvements in physiological health, better therapies, and improved coping strategies. Efforts are underway to understand long-term economic consequences of the decline in disability.

- New Therapies: The Working Group noted that many NIH-supported studies have reached the exciting point where potential targets for new therapies have been identified, opening the door for practical approaches to disease treatment and prevention. Areas where potential new targets for development of pharmacological drugs have been identified include Alzheimer's disease, ischemic brain and heart, some post-surgical difficulties, hepatitis C, conditions relating to cholesterol transport, osteoporosis, osteoarthritis, malaria, and sleeping sickness.
- ► Spinal Cord Injuries: A life-threatening consequence of upper cervical spinal cord injury is the interruption of respiratory pathways. Currently, mechanical ventilators provide the primary means of treating spinal cord-injured patients who can not breathe on their own, leading to a sense of isolation and a loss of independence.

Recently, however, investigators demonstrated the recovery of breathing function in spinal cord-injured rodents through the administration of theophylline to activate alternative respiratory motor pathways. Theophylline significantly increases the speed at which the brainstem reestablishes communication with the diaphragm following spinal cord injury, and this therapy has ramifications for both the survival and the quality of life for spinal cord-injured patients.

New Instruments and Technologies: The Assessment Working Group noted that the new or improved instruments and technologies in reported in FY 2001 not only offered insight into important and fundamental biological processes, but they also paved the way for better diagnostics,

prevention, and treatment for human diseases.

Some of these technologies continue to be built upon advances from FY 2000. One prominent example is the use of microarray technology to analyze gene activity of thousands of genes simultaneously to identify those implicated in cancers and other genetic disorders.

Another advance that was deemed significant was in the area of communications. NIH was able to use information technologies effectively to provide scientific data to a wider audience of researchers, as well as health information to the general public.

#### Protecting Human Subjects in

Research: The Office for Human Research Protections (OHRP) at OPHS provides oversight against non-compliance with research subject protections and educates the scientific community regarding the importance of protecting research subjects through their website, newsletters, town hall meetings, etc. Since 1990, OHRP has initiated 725 investigations. In addition to conducting investigations, OHRP leads the Human Subjects Research Subcommittee, of the Committee on Science of the National Science and Technology Council, in promoting effective inter-agency partnerships.

FDA's Bioresearch Monitoring (BIMO) Program inspects drug sponsors, clinical investigators, and contract research organizations and monitors institutional review boards and non-clinical/analytical laboratory facilities to ensure that the rights and welfare of human subjects who participate in clinical drug trials are protected and to verify that data collected by the regulated industry are accurate. FDA is the

only government agency with an active program of on-site inspections and the necessary expertise to evaluate the conduct of these studies. FDA completed 683 BIMO inspections in FY 1999, 697 in FY 2000, and 553 in FY 2001. The number of inspections conducted and completed each year is dependent on the number of investigations of new drugs or applications received.

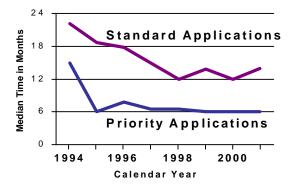
Oversight of Scientific Misconduct Cases: The Office of Research Integrity (ORI) at OPHS investigates cases of scientific misconduct and educates the scientific community regarding the importance of research integrity. In FY 2001, ORI completed 78 percent of the 18 scientific misconduct cases within eight months of receiving final decision from institution, exceeding their target of 70 percent. The average ORI processing time for the 18 cases was seven months. Nine of the 18 closed cases resulted in misconduct findings and the imposition of administrative actions.

## PROVIDING FASTER ACCESS TO DRUG THERAPIES

New Drug Applications (NDA): A major objective of the human drugs program is to reduce the time required for FDA's review of all drugs. Emphasis is given to the review of new drugs intended to treat serious or life-threatening diseases such as AIDS, AIDS-related diseases, and cancer; and those products that demonstrate the potential to address unmet medical needs. The timely performance of high-quality drug reviews in recent years reflects the importance of managerial reforms and additional resources provided from user fees under the Prescription Drug User Fee Act (PDUFA).

As a result, review times are decreasing. The graph illustrates that approval time in

### Approval Times for New Drug Applications



months for priority applications has decreased from 15 months in 1994 to six months in 2001, and approval time for standard applications have decreased from 22.1 months to 14 months. Americans now enjoy quicker access to new drug therapies such as Gleevec, treatment for a chronic type of leukemia or Xeloda and Taxotere, which combined help in the treatment of breast cancer. Approval time represents the total review time at the Agency plus industry response time to the Agency's requests for additional information. Of the 29 priority NDA submissions, 28, or 97 percent were reviewed within six months (target 90 percent). Of the 92 standard NDA submissions, 89, or 97 percent were reviewed within 12 months (target 90 percent).

Generic Drug Applications: It is estimated by the Congressional Budget Office "that the purchase of generic drugs reduced the cost of prescriptions (at retail prices) by roughly \$8 to \$10 billion in 1994". A generic drug product is one that is comparable to the reference listed drug product in dosage form, strength, route of administration, quality, performance

characteristics, and intended use. FDA met its goal for FY 2000 acting on 55.6 percent of original applications within six months after the submission date. This is an increase of more than 27 percent over FY 1999. Of these applications, several represent the first time a generic was approved for a product.

# IMPROVE THE WELL-BEING AND SAFETY OF FAMILIES AND INDIVIDUALS

#### PROTECTING CHILDREN AND YOUTH

Child Abuse and Neglect: ACF, in partnership with state and local governments administers the Child Abuse and Neglect program which is designed to emphasize both prevention and intervention. The performance goal is to decrease the percentage of children with substantiated reports of maltreatment that have a repeated substantiated report of maltreatment within six months. For FY 1998-2000 performance appears constant at eight to nine percent, although this data will be somewhat unstable since reporting is voluntary. Nonetheless, ACF is seeking to improve performance and has established goals of seven percent for FY 2002 and FY 2003.

Child Welfare: ACF, in partnership with state and local governments, administers programs which help children while they are living with their own families and find placements for those who cannot safely return to their homes. Programs such as Foster Care and Independent Living provide safe and stable environments for those children who cannot remain safely in their own homes. The Child Welfare Services and Promoting Safe and Stable Families programs provide services to children and families with a focus on protecting children and strengthening families. Key performance measures for these programs are: maintain the percentage of children who exit care through reunification within one year of placement at 67 percent and, for children who have been in care less than 12 months, increase the percentage that had no more than two placement settings (FY 2000 performance is 58 percent; FY 2003 target is

62 percent). These performance measures reflect efforts to focus on outcomes in child welfare. They are also being used in the Annual Child Welfare Outcomes report and the Child and Family Services Reviews and failure to meet the standards associated with them can result in a State being found not in conformity with the State plan requirements for titles IV-B and IV-E of the Social Security Act. The National Resource Centers funded by ACF are offering technical assistance to states to help improve service delivery and compliance with state plan requirements.

Adoption: ACF, in partnership with state and local governments, administers programs which, when a child cannot be reunified with his/her family, strive to place the child permanently with an adoptive family. The Adoption Assistance, Adoption Incentives and Adoption Opportunities programs have worked in concert with state and local initiatives to provide incentives and focus on children with special needs.

The success of these programs is demonstrated by the unprecedented increases in the number of children adopted from foster care. In FY 2000, 50,000 children in the foster care system were adopted, nearly doubling the FY 1995 total of 26,000 and exceeding the performance target of 46,000. In addition, the percentage of children who exit the foster care system through adoption within two years of placement increased to 20 percent, but fell short of the targeted 27 percent, and the median length of time until adoption is slowly declining. It is expected that as longer-term cases are cleared out of the system, the waiting time for children to be adopted will continue to decrease.

ACF will strive to continue to improve performance as there are currently estimated to be 134,000 children in the foster care system who cannot return safely to their own homes. By FY 2003, ACF has established the goal of placing 58,500 foster care children with adoptive parents. This will be challenging since most of these children are school-aged, in sibling groups, or have a physical, mental or emotional disability.

# ENABLING THE ELDERLY TO LIVE WITH INDEPENDENCE AND DIGNITY

Older Americans Act Community-based Services: The Older Americans Act focuses on those elders at risk of losing their independence. AoA, in partnership with states, Area Agencies on Aging and over 25,000 service provider agencies (the Aging Network) provides numerous services to older Americans including information and assistance, outreach, transportation, meals, home health, and adult day care. In order to provide a greater range of services and increase access among the elderly population, the Aging Network has successfully leveraged funds from a number of funding sources. In fact, for every dollar AoA contributes, the network was able to leverage \$1.90 in FY 1998-FY 2000 from various charitable and other organizations. Finally, the Aging Network, striving to serve the most vulnerable elderly, has steadily increased the number of home-delivered meals provided. In FY 1999, the Aging Network served 134.6 million meals, exceeding their target of serving 119.0 million. Preliminary FY 2000 data indicates that the Network has increased the number of meals provided, serving 142.4 million but short of the target, 155.0 million. Also, in FY 2000, the number of congregate meals served was increased to 116.0 million. exceeding the target of 113.1 million meals.

#### Long-term Care Ombudsman

Program: This longstanding AoA program has enabled residents of long term care facilities and their families to be informed "long-term care consumers" and facilitates the resolution of problems regarding care and conditions in long term care facilities. Thousands of paid and volunteer ombudsmen working in every State have made a dramatic difference in the lives of long-term care residents. Over the past five years, AoA has resolved or partially resolved at least 70 percent of complaints. FY 2000 performance was 74.1 percent, which exceeded their target of 70 percent.

Caregiver Research: While some of the care for older people is provided by home health agencies or nursing homes, much of it is provided informally at home by family and friends. In 1997, the economic impact of informal caregiving was estimated at \$196 billion, compared to \$32 billion for home health care and \$83 billion for nursing home care. Many informal home caregivers deal with complex and demanding care requirements.

NIH studies have contributed to increased understanding of stressors and predictors of bad outcomes, and have identified predictors of family dynamics that are responsive to interventions. Maintaining the health of the care providers as well as the care recipient is considered crucial to successful informal home care. Currently funded work is investigating how to encourage caregivers to reach out and obtain services and support that might be helpful to them.

### STRENGTHEN AMERICAN FAMILIES

INCREASING ECONOMIC SELF-SUFFICIENCY OF LOW-INCOME FAMILIES

Welfare Reform - Temporary Assistance for Needy Families (TANF): A primary goal of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 is to move recipients of welfare to work and self-sufficiency. Congress established work participation performance standards and a High Performance Bonus incentive system to facilitate this goal. There are positive results to report, demonstrating the early success of the program. Welfare rolls have fallen to historic lows; from over 12 million in August 1996 to 5.4 million in June, 2001. For FY 2000, all states met the Congressionally established work participation rate of 40 percent, consistent with ACF's performance goal. Also, in FY 2000, 76 percent of states with two-parent work-participation programs met the Congressionally established 90 percent work participation standard. The performance goal was that 100 percent of states would meet the participation standard, however, a 90 percent two-parent work participation is extremely rigorous. The Administration's reauthorization proposal will replace these two standards with a single participation standard for all cases with adults.

TANF, is administered by ACF in partnership with State and local governments. While ACF continues to project gains in employment and wages, it will be increasingly challenging to achieve these goals. The economy will have an impact on goal achievement. In addition, there is concern that the remaining TANF population may have more barriers to employment than those TANF beneficiaries

who have already successfully obtained employment.

Child Care: The Child Care and Development Fund (CCDF) was established under the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 to help working low-income families achieve and maintain economic self-sufficiency and to improve the overall quality of child care. Administered by ACF, in partnership with state and local governments, CCDF unified federal child care programs. The number of children served through the CCDF increased from 1.51 million in FY 1998 to 1.87 million in FY 2000. While this performance falls short of the target for FY 2000 (1.97 million) it is, nonetheless, a substantial increase in the number of children served by CCDF subsidies. Other encouraging performance indicators are: the percentage of eligible children receiving CCDF subsidies has increased from 10 percent in FY 1998 to 12 percent in FY 2000, and the number of families working or pursuing training with the support of CCDF subsidies has increased from 0.8 million in FY 1998 to 1.04 million in FY 2000. While performance trends are encouraging, it will be a continuing challenge to provide quality child care to additional eligible children. In FY 2003, ACF projects that 2.2 million children will receive CCDFsubsidized child care, increasing the percent of eligibles receiving services to 14 percent.

### INCREASING PARENTAL RESPONSIBILITY AND INCOME SUPPORT

**Child Support Enforcement:** The mission of ACF's Child Support Enforcement(CSE) program (established under Title IV-D of the Social Security Act) is to assure that assistance in obtaining support is available to children by establishing paternity and support obligations, locating parents, and enforcing support obligations. Working in partnership with state and local governments, CSE broke new records in nationwide collections in FY 2001, reaching \$18.9 billion. The government collected a record \$1.6 billion in overdue child support from Federal income tax refunds for tax year 2000. More than 2.1 million families benefitted from these tax collections. In addition, a program to match delinquent parents with financial records located more than 1.5 million accounts with a value in excess of \$3.1 billion. The number of paternities established or acknowledged reached almost 1.6 million in FY 2000. Of these, over 689,000 were established through in-hospital acknowledgment programs and 867,000 were established through the CSE IV-D program.

The GPRA performance measures used by ACF are the same as those enacted by the Child Support Performance and Incentive Act of 1998 in the development of the performance-based incentive formula. The measures are: statewide paternity establishment percentage; percentage of IV-D cases with support orders; IV-D collection rate for current support; IV-D arrearage cases paying; and total dollars collected per \$1 of expenditures. Reporting program performance for FY 1999 and FY 2000 for these performance measures can be misleading since the performance targets were established using data collected under an older reporting system with data

definitions which differ from those employed by the current system implemented in 1999. For example, program performance for FY 2000 includes the following: paternity establishment for children born out of wedlock was 95 percent (target 96 percent). Regardless of the percentage, a record 1.6 million paternities were established. Other FY 2000 performance information includes: 62 percent of IV-D cases have support orders; the IV-D collection rate for current support is 56 percent, paying cases among IV-D arrearage cases are 57 percent and the cost effectiveness ratio has increased to \$4.21. As the IV-D caseload increases. maintaining or achieving modest increases in these percentage performance levels will be a challenge.

Head Start: Head Start is a national program administered by ACF that provides developmental education, health, nutrition and social services to America's low-income children aged three to five and their families through 1,525 community-based organizations. One of the cornerstone goals of the program is to strengthen families as the primary nurtures of their children and another is to ensure well-managed programs that involve parents in decision making.

In FY 2001, Head Start programs employed 55,900 parents (29 percent of employees). The performance target was 30 percent and historical data from FY1998-2000 indicate that the percentage of employees who are parents ranges from 29 to 31 percent, averaging slightly under 30 percent. It is important to note, however, that while the percentage decreased slightly, the actual number of parents employed by the Head Start programs increased from 50,000 in FY 2000 to 55,900 in FY 2001.

The Family and Child Experiences Survey (FACES) also shows that Head Start parents report a high level of satisfaction with the program; over 80 percent indicate they are "satisfied" or "very satisfied" for each of eight major program areas.

In addition, FACES yielded results in FY 2000 indicating that 66 percent of Head Start parents read to their children three times a week or more. The performance target for FY 2002/2003 is 70 percent. To enhance family literacy services, including new efforts to encourage parents to read to their children, Head Start recently awarded a grant to the National Center for Family Literacy.

# REDUCE REGULATORY BURDEN ON PROVIDERS, PATIENTS, AND CONSUMERS

## STREAMLINING THE REGULATORY DEVELOPMENT PROCESS

Reducing Administrative Burden for **Research Institutions:** OHRP (Office of Human Research Protection) at OPHS developed a simplified Assurance system for institutions conducting federally supported or conducted human subject research. The new Assurance system, called a federal-wide Assurance, can significantly reduce the administrative burden on individual institutions, OHRP, as well as other Federal Departments and Agencies. Reduction in burden is gained by: 1) the increased simplicity of the form and process, 2) increased approval period of the Assurance for most institutions (from a project by project approval to an approval period of three years), and 3) acceptance of an OHRP approved federal-wide assurance by other Federal Departments and Agencies of the Common Rule, thus removing the need for duplicate effort on the behalf of other Departments and Agencies.

Regulation of Medical Devices: FDA is working with stakeholders to develop more streamline performance standards as guides in the design of safer and more effective medical products and to enhance the quality of regulatory decision making. Use of standards also helps to expedite reviews of pre-market notifications and in certain cases, fill a standard void. For example, there is standardized protocol for the cleaning of devices prior to sterilization but not one for after use of device. FDA worked with the Association for the Advancement of Medical Instrumentation (AAMI) to initiate standards

development in that area. The AAMI Sterilization Standards Committee has initiated the development of such a protocol. When completed, this protocol will be useful to hospitals and others who clean medical devices prior to their being placed back into service. FDA recognized 30 standards in FY 2001 and 117 standards in FY 2000 for a cumulative total of 597 at the end of the year. FDA works closely with standards organizations like AAMI and the International Standards Organizations (ISO) to improve its use of consensus standards.

# MAXIMIZING COLLABORATION WITH HHS STAKEHOLDERS

**Regulation of Animal Drugs:** The Animal Drugs and Feeds Program at FDA informs and assists product sponsors throughout the approval process starting with pre-submission conferences. The focus is to inform and assist firms in complying with the new legislation and to streamline the product review process through phased review. Instead of waiting until all stages of product development are completed before contacting FDA, phased review helps industry sponsors stay on course throughout the drug development process by communicating requirements (or standards or criteria) for approval at each stage of development. Pre-submission conference tracking was established in FY 1999. FDA met their goals in FY 2000 and FY 2001, conducting pre-submission conferences with 75 percent (target 73 percent) of product sponsors in FY 2000 and 80 percent (80 percent) in FY 2001.

### PERFORMANCE DATA COLLECTION

#### MEASURING PROGRAM PERFORMANCE

Sound information is essential to HHS' mission of enhancing the health and wellbeing of Americans. For every HHS strategic goal – whether providing for effective health and human services or fostering sustained advances in medicine and health – reliable and readily available information is necessary for planning, decision making, and measuring results. The Department plays an essential role in producing data for decision-making for health and human services programs, both as a direct producer and as a partner in data collection with the states, grantees, and other governmental agencies.

Generally, for the initial implementation of GPRA, our programs' choice of performance goals was driven by the existing capabilities of systems designed to track the health of the general population, support broad planning objectives, and provide services. Historically, programs and operating components have relied upon data for program management, policy decision making, and intervention development. GPRA reinforced the perspective of data for decision making and encouraged staff throughout HHS to reflect and refine our data systems. As a result, our programs work extensively with their partners in program implementation and data collection - state, local, and tribal governments, grantees, and Medicare contractors – to identify enhancements to these systems that would improve the timeliness, completeness, and accuracy of our data and enable us to move to more sophisticated measures of performance.

Key challenges include:

- ► Data systems need to produce data on a more timely basis and with a frequency relevant to the periods over which performance is being measured.
- As the health system continues to change, current data collections may not continue to produce needed data.
- ► A major challenge in selecting annual performance goals is that many of the interventions for complex chronic diseases or social problems require years of focused efforts to realize significant progress.
- ► The majority of HHS programs are implemented at the state and local level, and obtaining reliable, systematic data at these levels is crucial in order to monitor program implementation, performance, and outcomes.
- ► Data systems need to produce information with sufficient quality and precision to detect what may be relatively small changes in key performance goals.
- ► Major changes in complex data collection systems take time.

Efforts are underway in HHS at the program, operating component, and department level to enhance the data that is available to our programs and partners for planning, decision making, and measuring results. These efforts include developing new data collections, enhancing current data collections, eliminating data collections that are no longer relevant, combining reporting where possible, and building capacity to collect data at the state and local level.

The HHS Data Council, which includes representatives from all of HHS' operating

and staff components, provides oversight for these activities and serves as a department-wide forum for data issues. To facilitate its work, the Council has established a Data Strategy Committee to identify current and emerging needs for data, assess current HHS data capabilities to address these needs, and develop recommendations for a multi-year data strategy. Subcommittees of this group work to coordinate efforts to improve HHS data in particular topic areas. Most HHS components also have a data group that coordinates and addresses data needs.

This analysis begins with examples from the broad range of HHS data collection systems and how they currently support program planning and performance measurement in the Department. We also review efforts that are underway in HHS at the program, operating component, and department level to enhance the data that is available to our programs and partners for planning, decision making, and measuring results. Finally, we look at activities by the HHS Office of Inspector General to review our performance data, and we discuss the status of final reporting on our FY 1999 through FY 2001 performance goals.

### HHS NATIONAL, POPULATION-BASED DATA COLLECTION

HHS' national, population-based data collections provide statistics on morbidity and mortality for a wide-range of diseases and the underlying causes or risk factors for these diseases. CDC's National Center for Health Statistics (NCHS), the nation's principal health statistics agency, is responsible for collecting much of this data. In addition to providing data to HHS programs with data for planning and measurement, these national data systems provide data for the broad public health and health policy community.

These national, population-based data systems support program planning by allowing HHS programs to identify and track health problems and identify potential interventions. The data are also used to report on performance goals that assess changes in the national population, as a benchmark for evaluating programmatic achievements in the subsets of the national population the program serves, and as a means of verifying and validating programmatic and state-level data collections.

The following are examples of HHS' national, population-based data collections and how they are used by HHS programs to measure performance.

Behavioral Risk Factor Surveillance System (BRFSS): BRFSS collects state-level information on health behaviors related to the leading preventable causes of death, including physical inactivity, injury, weight control, alcohol consumption, tobacco use, and HIV/AIDS. It also collects data on preventive health practices such as mammography use. CDC uses BRFSS data to report on a performance goal to increase the percentage of diabetics who receive an annual eye exam and annual foot exam and OPHS, to reduce injurious suicide attempts among youth grades 9-12.

Youth Risk Behavior Surveillance System (YRBSS): YRBSS is a biennial, national, school-based survey that measures risk behaviors that contribute to the leading causes of mortality and morbidity among youth and adults in the United States: behaviors that contribute to unintentional and intentional injuries; tobacco use; alcohol and other drug use; sexual behaviors that contribute to HIV infection, other sexually transmitted diseases and unintended pregnancy; dietary behaviors; and physical activity. CDC and OPHS use YRBSS data to report on performance goals that reduce the percentage of teenagers who smoke, increase the percentage of high school students who have been taught about HIV/AIDS prevention in school, and increase the percent of adolescents who abstain from sexual intercourse or use condoms if currently sexually active.

National Household Survey on Drug **Abuse (NHSDA):** The recently expanded NHSDA provides both national and state estimates of the incidence and prevalence of drugs, alcohol and tobacco, use patterns, age at first use, risk factors, treatment and disability. The data chart progress by age, gender, ethnicity, and rural/urban service setting (at the state and national levels). SAMHSA uses data from NHSDA to track the track success of the nation as a whole in improving effective substance abuse and mental health services, and to inform in program planning while the agency works with grantees reach consensus on a set of goals to measure program performance and develop a system to collect and report program-level data.

National Health Interview Survey (NHIS): NHIS interviews over 100,000 persons each year to monitor a broad range of health issues. CDC uses NHIS data to report on a performance goal to increase the use of smoke detectors in homes, and OPHS a goal to increase physical activity. HRSA uses NHIS and the National Hospital Ambulatory Medical Care Survey (NHAMCS) indicators in HRSA surveys that monitor various indicators of care in the Health Centers, including performance goals related to mammography and pap smear rates. Data from the HRSA surveys are then benchmarked to national estimates obtained through NHIS and NHAMCS. In addition,

CMS uses NHIS as a secondary data source for its mammography, adult immunization, and diabetes goals.

National Health and Nutrition
Examination Survey (NHANES): This survey enables sophisticated laboratory and examination centers to move around the U.S. to obtain standardized medical information from direct physical examination, diagnostic procedures, and lab tests. CDC uses NHANES data to report on a performance goal to reduce the number of children with elevated blood lead levels.

National Hospital Discharge Survey (NHDS): NHDS obtains information on hospitalizations, surgery, procedures, and other information from a representative sample of hospital discharge records. CDC uses NHDS data to report on a goal to reduce the incidence of pelvic imflamatory disease, and HRSA uses NHDS data to report on a performance goal to reduce hospitalizations for ambulatory care sensitive conditions.

National Immunization Survey (NIS): CDC utilizes the NIS, a telephone-based survey of U.S. households, to provide data to report on performance goals related to childhood and adult immunization. CMS, HRSA, and IHS use the NIS, which provides state-level data, and the National Health Interview Survey, which provides national data, to benchmark and to validate programlevel data.

Medicare Current Beneficiary Survey (MCBS): MCBS is an on-going personal-interview survey of a rotating panel of 16,000 Medicare beneficiaries. The sample is nationally representative of the Medicare population, and MCBS can be linked to Medicare claims data. Sampled beneficiaries are interviewed every four months to acquire

continuous data on services, costs, payments, and insurance coverage. CMS will use data from the MCBS to report on its performance goals to improve beneficiary understanding of basic features of the Medicare program, improve the effectiveness of dissemination of Medicare information to beneficiaries, and increase adult immunization. CMS also uses MCBS data to check the consistency of data from the Medicare Consumer Assessment of Health Plans Study (CAHPS), which is used to assess beneficiary satisfaction with health plans.

# National Survey on Child and Adolescent Well-Being (NSCAW):

NSCAW, a large national longitudinal study, follows a representative sample of children who enter the child welfare system assessing their social, emotional, cognitive and functional status, as well as service needs and services provided for children and their families at 12 months (baseline) and at 18 months. Follow-up interviews will be conducted from start of study with 6100 children, their caregivers their caseworkers and their teachers. ACF will use this data to gain a better understanding of performance goals related to foster care and adoption.

Enhancing and coordinating HHS' national population-based data collections is key to addressing HHS' data needs, and is a prime focus of the HHS Data Council. Under the auspices of the HHS Data Council, a number of significant improvements have been made in HHS data systems and in HHSwide data planning and integration. These improvements include the HHS Survey Integration Plan, a comprehensive, department-wide plan for addressing critical needs for race and ethnicity data, an HHSwide inclusion policy for race and ethnicity data, and HHS wide data improvement initiatives in health system data. The Council has also developed a web-based directory of

all of the major data collection systems within HHS with links to programs. In addition, the Health Insurance Portability and Accountability Act (HIPAA) administrative simplification initiative can be considered a successful model of public-private sector collaboration on national data objectives.

Each year, new data needs arise and a number of critical data gaps remain. To address these issues in an overall strategic framework, the Council has established a Data Strategy Committee to identify current and emerging needs for data, assess current HHS data capabilities to address these needs, identify opportunities for cost efficiencies, and develop recommendations for a multiyear data strategy and plan reflecting a broad coordinated approach to data planning, investment and decision making in HHS. Through the Data Strategy Committee, AHRQ, ASPE, NCHS, and CMS are working on a master plan for addressing the need for data on long-term care, including expansion of long-term care data to include assisted living facilities as well as nursing homes, and expansion of CMS's Medicare Current Beneficiary Survey (MCBS) to get better information about persons transitioning from one site of care to another. AHRQ also is working with CMS to use their Minimum Data Set (MDS) to develop quality indicators and disparity measures for two congressionally mandated reports.

The types of improvements to HHS national, population-based data collections that have been identified and are being pursued include:

• Developing new data collections, reprioritizing or redesigning existing HHS surveys (e.g., integration of related efforts, content revisions, etc) to include new data elements and content, and eliminating data collections that are no longer relevant.

- Developing new tools or approaches, including new sampling techniques, diagnostic approaches, and web-enabled survey administration, etc., to make surveys more responsive and efficient.
- Developing new approaches for making survey data available to users without jeopardizing confidentiality.
- Providing funding to other Departments, states, private entities, or foundations to build on existing data collection mechanisms (e.g., supplementing an ongoing survey conducted outside HHS).
- Increasing sample size to provide state, county or community level data to improve the usefulness of these data to states for planning and measurement.
- Expanding data collection to include all states in order to provide accurate national data. For example, at the current time, the only source of data for state estimates of teenage sexual behaviors is the Youth Risk Behavioral Survey (YRBS), which is conducted every two years by the states and CDC. In 1999, 41 states and four territories participated in the survey, limiting its usefulness in preparing national statistics.
- Increasing frequency of data collections. For example, the Youth Risk Behavior Surveillance System (YRBSS) is conducted every other year.
- Reducing lag time between data collection and reporting.

#### VITAL STATISTICS

The *National Vital Statistics System* is based on a partnership between federal and state agencies, and provides data on births, including teen births, access to prenatal care, maternal risk factors, infant mortality, causes of death, and life expectancy. Vital statistics

are often the most complete and continuous public health information available at the national, state, and local levels.

HRSA's Maternal and Child Health Bureau uses Vital Statistics data to report on performance goals related to infant mortality rates, including racial disparities in these rates, use of prenatal care, low birth weight babies, and teen birth rates. OPHS uses this data to report on a performance goals to reduce births to teens, mothers who smoke during pregnancy, the annual rate of suicide, and increase prenatal care. CDC uses this data to report on a performance goal to reduce fire-related deaths.

To improve the quality and timeliness of these data, CDC provides technical assistance to the States and works with the States to standardize data elements and develop consensus on uniform conventions for coding and data processing. CDC has reduced lag for reporting final data from this system, reporting final 1998 birth data in 15 months, a 17 percent reduction from the baseline of 18 months. In addition, preliminary 2000 vital statistics data were released in July 2001, just seven months after data collection and two months earlier than anticipated.

Current technology in place in States, hospitals, and funeral homes greatly limit efforts to make this data available in real time for performance monitoring, public health intervention and research. Further, this technology limits the ability to rapidly adapt vital records to reflect new needs and approaches such as OMB's revised classification of race and ethnicity. CDC is working with the States to move toward fully automated, web-based systems that capture data at the source and facilitate

improved data quality, rapid editing and processing, and rapid distribution of data to users.

#### SURVEILLANCE SYSTEMS

Disease Surveillance Systems: These systems rely on case reports from physicians, hospitals, or other sources to identify incident cases of diseases. Specific diseases are often required to be reported to state health agencies under state authorities. CDC works with states to collect and report this data at the national level. The following are examples of these systems and how they are used to measure performance:

- The *National Nosocomial Infectious*Surveillance System receives reports from a selected group of hospitals on the incidence and characteristics of hospital-acquired infections. Data from this system alerted health authorities to the emergence of antibiotic-resistant strains of bacteria. This led CDC to develop specific recommendations regarding the use of antibiotics and performance goals to measure an improvement in the appropriate use of antibiotics.
- ► Examples of other disease surveillance systems that provide data for performance goals include, HIV/AIDS Surveillance System, STD Surveillance System, Foodborne Outbreak Reporting System, Sentinel Surveillance for Chronic Hepatitis C, U.S. Sentinel Physician Surveillance for Influenza, and Group B Streptococcal Disease Surveillance, part of the Active Bacterial Core Surveillance.
- ► Through its National Electronic Disease Surveillance System (NEDSS) project, CDC is building a national integrated surveillance system to enable rapid reporting of disease trends. This system creates public and private health care sector linkages to increase

the volume, accuracy, completeness, and timeliness of the data. In addition, this new system provides local health departments with Internet access to permit rapid sharing of information on infectious disease outbreaks or bioterrorist incidents.

Through NEDSS, CDC is also developing and implementing national data standards for surveillance and reporting; providing technical infrastructure support for states and local communities; and establishing local, state, and regional demonstration projects that create linkages between the public health and health care systems. These efforts are increasing the speed and reliability of data collection.

CDC has five performance goals related to the development of NEDSS, including electronic reporting of laboratory records and enhancing security to allow transmission of data over the Internet. A key activity related to NEDSS has involved the creation of a Secure Data Network (SDN). The SDN provides for a secure Internet connection and gateway facility. Through a system of tools, policy requirements, and procedures, the SDN enabled 80 percent of surveillance systems to implement the transmission of case-level surveillance data electronically in FY 2001.

Adverse Event Reporting Systems: The FDA Adverse Event Reporting System (AERS) is an Oracle-based computerized information system designed to support the Agency's post-marketing safety surveillance program for all approved drug and therapeutic biologic products. FDA uses AERS to report on its performance goal to expedite processing and evaluation of adverse drug events, which allows for electronic periodic data entry and acquisition of fully coded information from drug companies.

#### NON-HHS DATA COLLECTION

Outside data sources used for performance measurement in HHS include:

- The National Council on Quality
  Assurance's (NCQA) Health Plan Employer
  Data Information Set (HEDIS®), an annual
  survey of individual managed care plans.
  This is the national standard for plan-based
  measurement for care delivered to enrollees
  in managed care organizations. Measures
  exist for both Medicaid and
  Medicare+Choice managed care. CMS uses
  data from HEDIS® and from the National
  Health Interview Survey to validate data
  extracted from its National Claims History
  File (NCH) for a performance goal on
  diabetics receiving biennial retinal eye exams.
- ▶ Data to report on CDC's performance goal related to the consumption of folic acid among women of reproductive age is collected under contract with the March of Dimes Birth Defects Foundation. The data is collected using a pool of respondents that is statistically significant and large enough to allow for appropriate generalization of the data to a national level.
- ACF's Head Start program uses the National Center for Education Statistics' National Household Education Survey (NHES) and Early Childhood Longitudinal Study (ECLS) as a national comparison with information performance goals related to the Family and Child Experiences Survey (FACES). NHES utilizes a home-based data collection method to collect information on early childhood education and school readiness and early childhood program participation. ECLS, which-includes both a kindergarten and birth cohort, provides national data on children's status at birth and various points thereafter; children's transitions to non-parental care, early education programs and school; and

- children's experiences and growth through the fifth grade. Additionally, it will provide data to test hypotheses about the effects of a wide range of family, school, community and individual variables on children's development, early learning, and early performance in school.
- AoA utilizes data from the Census Bureau's *Current Population Survey* as a benchmark for its service targeting performance goals.

#### **PROGRAM EVALUATIONS**

Evaluations conducted by HHS are generally used to evaluate program effectiveness, develop performance measurements, assess environmental impacts on health and human services (i.e., external factors affecting program performance), and improve program management. The results of these evaluations are used by HHS programs to inform the performance planning process, assist in the interpretation of performance data, and as in the example below, to report on performance goals. Examples include:

- ► HRSA's Community Health Center Effectiveness, which compares data from CMS's State Medicaid Research Files on Health Center Medicaid users and National Hospital Discharge Survey for the general population to assess the effectiveness of care at the Health Centers. This study provides data to report on a goal to reduce the rates of hospitalizations for ambulatory care sensitive conditions in the Health Center's Medicaid population and enables HRSA to benchmark against care provided elsewhere.
- ► A 1996 AoA evaluation of nutrition programs for the elderly, which addressed

nutrition outcomes for program participants, has significantly influenced the ongoing assessment of these programs and has contributed to AoA's current efforts to develop performance outcome measures. State and area agencies on aging routinely measure the nutritional risk of elderly program participants, and AoA's Performance Outcome Measures project includes the measurement of changes in nutritional risk over a six-month period for new clients.

# HHS OFFICE OF INSPECTOR GENERAL AUDITS AND REPORTS

The following are two examples of HHS programs that have used the HHS Office of Inspector General's (OIG) audits and reviews to assess program performance and report on performance goals.

- ► CMS uses OIG's annual estimate of the Medicare fee-for-service error rate as a basis for setting performance goals and for measuring performance. The payment error rate is computed by the OIG as part of their *Chief Financial Officer's Act* audit.
- ► HRSA's *National Practitioner Data Bank* uses data from user surveys conducted by the OIG to report on a performance goal measuring the impact of query information from the database on decision making by licensing boards, hospitals and other health care entities, and professional societies.

# INTERNAL MANAGEMENT INFORMATION SYSTEMS

Recently CDC combined historical workforce data with training data to establish a large data warehouse, the *Workforce Information Zone* (WIZ). WIZ provides managers with a real-time tool to analyze changes in workforce demographics, retirement eligibility, accessions, separations,

and much more. Besides providing comprehensive historical reporting capabilities, the system also employs multiple regression analysis to forecast future workforce size and series demographics. WIZ provides data to report on CDC's performance goals to reduce the time it takes to classify positions and the time involved in referring candidates to fill positions.

#### **ADMINISTRATIVE SYSTEMS**

In addition to developing its own information systems, HHS relies on partnerships with state and local agencies, health plans, and providers to collect and manage data. Generally, these data come from administrative data collections. A significant number of HHS programs rely on these data to measure performance.

Administrative data systems are generally maintained by HHS' state and local partners as part of providing services under a grant or contract. These data are the byproduct of processes such as program enrollment, eligibility determination, claims processing, payment, and service provision. For example, the HHS grantees who manage service delivery programs maintain administrative systems that provide ongoing data on clients, services, and populations served. HHS programs have used these systems to provide data to report on goals measuring program performance. HHS grantees report these data on either a voluntary or mandatory basis. To facilitate benchmarking program performance to national data from population-based data collections, these programs frequently use Healthy People 2010, NHIS, and HEDIS indicators as program performance goals. Several examples of administrative data systems and how HHS programs currently

use these systems to measure performance follow.

- ► The Medicare *National Claims History File* (NCH) is a 100 percent sample of Medicare fee-for service claims, which have been validated for completeness and consistency.
- ► HRSA's HIV/AIDS Bureau has developed and is pilot testing a *Cross-Titles Data Report*. This report will replace the administrative data reports required by each of the main Titles of the Ryan White CARE Act, streamlining reporting for programs which participate in more than one Title and reducing the number of data elements which programs must report on.
- ► IHS' Resource and Patient Management System (RPMS) collects data for each inpatient discharge, ambulatory medical visit, and dental visit and for community health service programs including health education, community health representatives, environmental health, nutrition, public health nursing, mental health and social services, and substance abuse. IHS uses these data to report on performance goals related to clinical services and prevention activities.
- ► The IHS *Diabetes Audit* is an annual medical record review that assesses diabetes care conducted in more than 75 percent of the IHS and tribal facilities, representing care to nearly 70,000 American Indian and Alaskan Native people with diabetes. The Audit provides data for four IHS performance goals that are key to reducing mortality and morbidity in diabetics. IHS has an initiative underway to automate the Audit by extracting the data from IHS' electronic patient records system.

Because administrative data systems provide program-level data, they are key to HHS' ability to measure program performance. In fact, these systems provide data to report on a significant portion of

HHS' performance goals. Frequently, our programs' initial choice of performance goals were limited by the capabilities of these systems. Since these data are collected by HHS' partners who implement HHS programs – state, local, and tribal governments, grantees, and Medicare contractors – HHS programs have worked in partnership with these organizations to implement enhancements to these systems.

The types of improvements that have been identified and are being pursued include:

- Working with program partners to achieve consensus on a set of performance goals that best measures program performance and then ensuring that a system is in place to collect and report these data. These efforts include enhancing current data collections, developing new data collections, eliminating data collections that are no longer relevant, and combining reporting for programs where possible.
- Assisting the states in building the state and local data collection infrastructure needed to enable timely and accurate data reporting and ensure that all states can report data, and providing technical assistance to states and grantees to improve data quality
- Developing common definitions, data elements, standards, and uniform coding so that the data can be reliably used and aggregated.
- Addressing confidentiality, policy, security, and technical issues to enable clinical information systems to provide real-time data on quality of care measures.
- Developing the legal, regulatory, and technical means that facilitate data sharing across organizations.

- Addressing issues related to verifying and validating data provided by states and grantees.
- Working with states and grantees to move from voluntary to mandatory collection of performance data under the Paperwork Reduction Act.
- Automating data collection and reporting to reduce the time needed to report aggregated national data and providing program performance data via the Internet to facilitate its use.

### MEASURING PERFORMANCE WITH STATES AND GRANTEES

The majority of data used to report on performance for HHS programs is collected and reported by HHS' partners who implement these programs – state, local, and tribal governments, grantees – and Medicare contractors. In these instances, HHS programs have worked with these organizations to achieve consensus on a set performance goals that best measure program performance and then enhance current data collection systems or developing new systems to collect and report the data. CMS' work to develop a childhood immunization goal for the Medicaid program highlights the potential as well as the challenges of enhancing these data collection systems.

### Centers for Medicare and Medicaid:

CMS, working in conjunction with the States, CDC, and the American Public Human Services Association (APHSA), has developed a three stage process to develop individual state baselines and methodologies for reporting on a performance goal on immunization coverage for two-year-old children enrolled in Medicaid. Because Medicaid is a state-run program and states have significant flexibility to set enrollment criteria, it is best for states to determine how

to measure their own immunization rates and to determine their own performance targets.

The methodologies chosen by individual states will depend on a number of factors, for example: the service delivery systems used in that state, the existence of functional state or regional registries, and the average duration a Medicaid beneficiary remains enrolled in the state program. Due to the various data collection and reporting methodologies likely to be used by individual states and differing definitions of children in the various states, immunization coverage levels will not be directly comparable across states. However, each state will measure its own progress, using a consistent measurement methodology. CMS and CDC are providing technical assistance to the States to develop their baseline methodology to measure immunization rates.

#### **DELIVERING INFORMATION TO USERS**

In addition to efforts to enhance HHS' data collection capabilities, HHS is working to enhance the capacity of HHS programs and the capacity of its partners to access and use data. The HHS Data Council has identified and is pursuing the following priorities:

- Providing easy access to health and human services information via the Internet,
- Enabling users through training and technical assistance,
- Building expertise to translate data into useful knowledge, and
- Developing improved analytic methods and tools.

HHS needs to develop improved analytic software and techniques for data linkage and analysis of linked files, and to develop new indicators, and analytic approaches as new topics and priorities emerge. HHS also needs to develop improved techniques to handle difficult problems such as with small geographic areas and small population subgroups.

#### DATA VERIFICATION AND VALIDATION

Data Discussions in the Performance Plans and Reports: For any given performance goal, the strengths and limitations of the data source used to report on the goal can vary, and the level of statistical reliability needed to assess goal performance and support decision making can also vary.

To assist the readers of the HHS' performance plans and reports, HHS programs have identified the data source, discussed the means used to verify and validate the data, and addressed any significant data issues for the performance goals in plans and reports. Many programs also discuss activities completed, underway, or planned that will enable the program to move to more sophisticated measures of performance and/or to improve the timeliness, completeness, and reliability of the data.

HHS Inspector General Review of Performance Data: The HHS Office of Inspector General's (OIG) work with regard to GPRA focuses on measures related to mission-critical issues and areas at high risk of fraud, waste, and abuse and includes assessments of data collection methods and controls over the systems that produce performance data.

The OIG reviewed ACF's Adoption and Foster Care Analysis and Reporting System

(AFCARS). The ACF performance measures pertaining to children in foster care and children adopted under the auspices of a state welfare agency are based on data from this system. Since states collect and transmit case management information to ACF through this system, OIG assessed the reliability of the AFCARS data submitted by two states for the first half of FY 1999. While some errors were noted in the information from both states, these errors did not affect the data used to develop ACF's performance measures or were not pervasive enough to affect reported measures. The OIG will also be doing additional work in AFCARS.

An OIG review of the OCR FY 1999 GPRA report found that the office did not accurately report performance results and did not have an adequate system for validating the information presented in its performance report. This conclusion was based on exceptions found in a judgmental sample of 63 of the 209 review or investigation cases used to prepare the performance report.

The OIG recommended that OCR issue guidance to its regional offices to ensure that performance results are accurately and consistently reported; enhance its data validation process to ensure that future performance results are reliable; and review and, where appropriate, clarify the explanations and descriptions of performance measures and reported results in future performance plans. In response, the office is taking steps to improve the accuracy and verification of data in future years ' reports.

Upcoming projects include a review of ACF 's use of State-supplied data for performance measurement. The OIG will determine whether ACF has taken adequate steps to validate State data used in one or more major programs.

### STATUS ON REPORTING ON FY 1999 - 2001 PERFORMANCE GOALS

The chart on the next page outlines the status of final reporting on HHS' FY 1999, 2000, and 2001 goals. Please note that the chart reports on performance targets for which we have final data; many performance goals have multiple targets.

### STATUS OF FINAL REPORTING ON PERFORMANCE GOALS

Operating or	FY 1999			FY 2000			FY 2001		
Staff Component	Targets	Reported as of 2/03		Targets	Reported as of 2/02		Targets	Reported as of 2/02	
AoA	18	18	100%	18	18	100%	23	2	9%
ACF	47	47	100%	52	42	81%	63	13	21%
AHRQ	46	46	100%	52	52	100%	54	54	100%
ATSDR	11	11	100%	25	25	100%	25	23	92%
CDC	110	109	99%	195	189	97%	217	165	76%
CMS	22	22	100%	40	38	95%	54	39	74%
DM	54	54	100%	56	53	95%	67	49	73%
FDA	70	70	100%	60	60	100%	64	46	72%
HRSA	68	61	90%	76	67	88%	95	31	33%
IHS	27	26	96%	34	29	85%	38	26	68%
NIH	86	86	100%	88	88	100%	90	90	100%
OCR	10	10	100%	19	19	100%	6	6	100%
OIG	6	6	100%	5	5	100%	8	8	100%
OPHS	13	12	92%	30	18	60%	28	16	57%
PSC	40	40	100%	41	41	100%	42	40	95%
SAMHSA	55	54	98%	157	145	92%	182	112	62%
TOTAL	683	672	98%	948	889	94%	1055	720	68%