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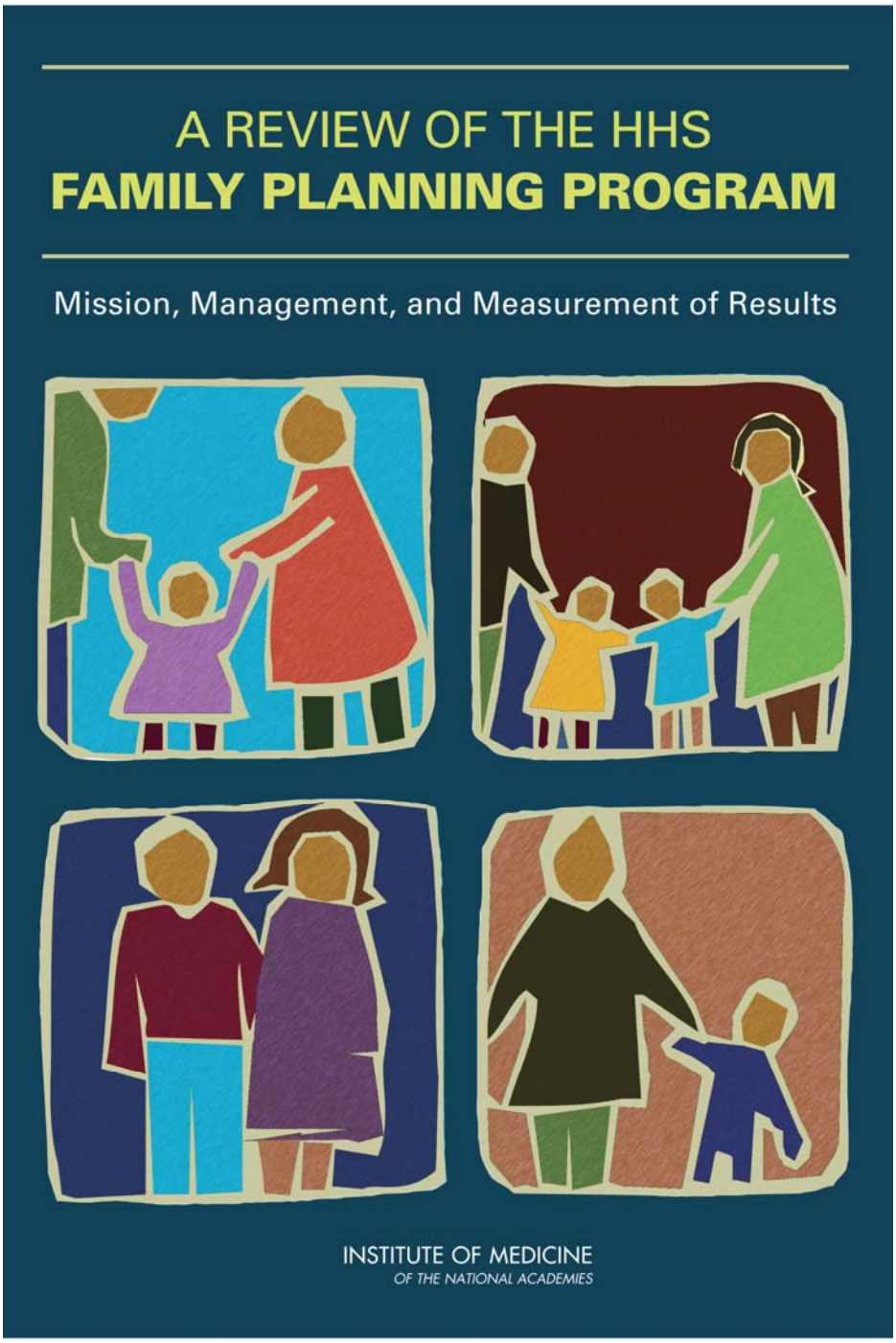

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A REVIEW OF THE HHS FAMILY PLANNING PROGRAM

Mission, Management, and Measurement of Results

Adrienne Stith Butler and Ellen Wright Clayton, *Editors*

Committee on a Comprehensive Review of the HHS Office of Family Planning Title X Program

Board on Health Sciences Policy
Board on Children, Youth, and Families

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Willing is not enough; we must do."
—Goethe

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This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We wish to thank the following individuals for their review of this report:

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Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the conclusions or recommendations nor did they see the final draft of the report before its release. The review of this report was overseen by **Susan C. Scrimshaw** and **Kristine M. Gebbie**. Appointed by the National Research Council and Institute of Medicine, they were responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authoring committee and the institution.

Preface

On January 22, 2009, President Obama called for greater efforts to "prevent unintended pregnancies … and support women and families in the choices they make." In so saying, he signaled his understanding that the ability to control conception is essential "to ensuring that our daughters have the same rights and opportunities as our sons…." More generally, adequate spacing of childbearing benefits the health of children and the socioeconomic well-being of their families, which in turn strengthens society. Family planning has been cited as one of the greatest public health achievements of the 20th century, and has been used by countless individuals both within the United States and internationally. Even so, contraception remains a sensitive topic in some communities and many modern methods of family planning are expressly forbidden by some religious traditions. Moreover, in recent years, some of the nation's cultural disagreements—its "culture wars—have involved the availability and use of contraception, especially by minors and by unmarried individuals. As this report is being completed, there is more public dialog about the need to help individuals and couples plan their families through expanded access to affordable contraception, but the whole area remains sensitive.

In this context, the resilience of Title X, the only federal program devoted exclusively to family planning, is remarkable in many ways. The program, which is directed primarily at the poor and near poor, was born in 1970 out of a conviction that all people, not just the wealthy, should be able to plan their families. President Richard Nixon showed a particular interest in family planning and in a message to the Congress in July 1969 wrote: "It is my view that no American woman should be denied access to family planning assistance because of her economic condition. I believe, therefore, that we should establish as a national goal the provision of adequate family planning services within the next five years to all those who want them but cannot afford them." From the beginning, Title X has awarded its funding on a competitive basis and to a wide variety of both public and private entities.

At the same time, the program has been under enormous pressure almost from its inception. The population in need has grown enormously in both numbers and diversity in the intervening years. Moreover, the number and efficacy of contraceptive and diagnostic technologies have also grown, as have their prices. While Title X was not incorporated into state block grants in the early 1980s, in part to protect family planning from local politics, funding in inflation-adjusted dollars for the program has leveled off or declined since 1980, demonstrating the lack of strong support for the program on the national level. Congress has amended the program on several occasions, initially expanding services to adolescents and then requiring providers to encourage teens to talk with their parents, adding services for infertility, and clarifying that Title X providers are not exempt from state child abuse reporting requirements. The position of the Deputy Assistant Secretary for Population Affairs was unfilled for three years between 2000 and 2009 and had two different occupants in the last three years alone. The requirements for services to be offered by Title X providers have changed frequently over the years, often without a clear rationale and usually without additional funding.

Finally, the program has long been buffeted by this country's deep divisions about abortion. Even though Title X has never paid for abortions, abortion issues can still affect the provision of family planning services. For example, those who support women's right to choose abortion worry that they are unable to provide—and that women will not be able to obtain—the advice they need under rules that limit disclosure. Those clinicians who oppose abortion feel that they are "promoting" abortion even to mention the procedure and may decide not to provide family planning at all if forced to provide abortion counseling or referral. The separation of abortion from family planning services can be particularly problematic. Indeed, the woman who has just terminated an unwanted pregnancy might be particularly receptive to contraception, and the inability to use Title X funds to address this issue at the time of abortion represents a major lost opportunity. Given the passion aroused by competing views about how family planning ought to be provided, it is hardly surprising that Title X has for years been hunkered down against political and fiscal gales.

Against this backdrop of limited funding and controversy, the Committee on a Comprehensive Review of the HHS Office of Family Planning Title X Program was convened by the Institute of Medicine. The Committee was composed of members with a broad range of expertise and perspectives regarding Title X, some favorable and others critical of the program. The committee's evaluation encompassed the goals of the program, its administration and management, and whether it is serving its target populations. To conduct the evaluation, the committee examined numerous documents, held five meetings and three public workshops, made 16 site visits, and commissioned two papers. The detailed and in-depth information and stakeholder views thus obtained served as the basis for a series of recommendations, presented in this report, for building on and enhancing the successes achieved by the Title X program.

The committee's work could not have been completed without the tireless efforts of its members and the extraordinary support of Marnina Kammersell, Thelma L. Cox, and especially Adrienne Stith Butler, our Senior Program Officer and the staff director of this study. To all of them, I extend my personal gratitude for the important work that they have completed so well. It is my hope, shared by the committee, that the new administration will use our findings and recommendations to strengthen services for family planning and reproductive health, thereby improving the lives of our nation's families and promoting equality of opportunity for women, in particular.

Ellen Wright Clayton, M.D., J.D.
Chair
Committee on a Comprehensive Review of the
HHS Office of Family Planning Title X Program

Acknowledgments

Several individuals and organizations made important contributions to the study committee's process and to this report. The committee wishes to thank these individuals, but recognizes that attempts to identify all and acknowledge their contributions would require more space than is available in this brief section.

To begin, the committee would like to thank the sponsors of this report. Funds for the committee's work were provided by the U.S. Department of Health and Human Services, Office of Family Planning (OFP). The committee thanks Susan B. Moskosky, Director of the Office of Family Planning and David M Johnson, who served as project officer, for their assistance during the study process.

The committee gratefully acknowledges the contributions of the many individuals who assisted the committee in its work. The committee found the perspectives of many individuals and organizations to be valuable in understanding the Title X program. It thanks those who participated in the committee's meetings by providing important information at its open workshops. Participants included a variety of stakeholders; Title X grantees, delegates, and regional program consultants; and state and federal government representatives. Appendix A lists each of these individuals and their affiliations. As part of its review, the committee visited several sites that receive Title X funding in order to gather information about the role of Title X clinics in providing reproductive health services. These visits helped the committee understand the experiences of local administrators and service providers. In addition to clinic visits, several individuals with knowledge of the program, including central office staff, grantees, and regional program consultants were interviewed by The Lewin Group (see Appendix J) for its assessment of the administration and management of the Title X program. Appendixes F and J provide findings from these visits and interviews. The committee greatly appreciates the time and information provided by all of these knowledgeable and dedicated individuals.

Finally, the committee would like to thank the authors whose paper contributions added to the evidence base that the committee examined. These include Julie Wolcott and Colleen Hirschkorn, The Lewin Group; and Kimberly D. Gregory, Cedars-Sinai Medical Center.

Contents

Summary

ABSTRACT

Family planning is one of the most significant public health achievements of the twentieth century. The ability of individuals to determine their family size and the timing and spacing of their children has resulted in significant improvements in health and in social and economic well-being. The Title X federal family planning program provides these critical services to those who have the most difficulty obtaining them. Title X is a valuable program that successfully serves its target audience: low-income individuals and adolescents. In 2006, clinics supported by the program provided care to almost 5 million women, men, and adolescents, 67 percent of whom had incomes at or below the federal poverty level, and 61 percent of whom were uninsured. While the program's core goals are apparent, a secondary set of changing priorities has emerged that has not been established through a clear, evidence-based strategic process. Funding for the program has periodically increased in actual dollars, but has not kept pace with the increased costs of contraceptives, supplies and diagnostics, greater number of people seeking services, inflation, the increased costs of salaries and benefits, infrastructure expenses, or insurance. The management and administration of the program generally support the achievement of its core goals, but several aspects of the program's structure could be improved to increase the ability of Title X to meet the needs of its intended population. At the same time, the extent to which the program meets those needs cannot be assessed without a greater capacity for long-term data collection. The committee recommends several specific steps to enhance the management and improve the quality of the program, as well as to demonstrate its direct contribution to important end results, such as reducing rates of unintended pregnancy, and infertility.

The Title X Family Planning Program is the nation's only federal program devoted exclusively to providing family planning services. Through grants to public and nonprofit private entities, Title X funds support the provision of comprehensive family planning and related health services. These services help women and men maintain reproductive health; avoid unintended pregnancies; and determine the number, timing, and spacing of their children—all of which contribute to the health and the social and economic well-being of women, men, children, and families. By law, priority is given to low-income individuals.

The program was created in 1970 and is authorized under the Public Health Services Act, which provides for family planning services, training, research, and information and education. At least 90 percent of the program's funds must be used for family planning services. The budget for fiscal year 2008 was $300 million.

The program is administered by the Office of Family Planning (OFP) within the Office of Population Affairs (OPA) in the Department of Health and Human Services' (HHS) Office of Public Health and Science. OFP develops Title X priorities, policies, and performance measures and oversees all family planning grants. It allocates funds to 10 Regional Offices, which make awards to grantees in states and territories through a competitive process. The Regional Offices monitor program operations through site visits, comprehensive program reviews, and extensive data collection, and facilitate communication between OFP and grantees.

STUDY CHARGE

In 2005, the Title X program participated in the Program Assessment Rating Tool (PART) process, which was developed and is carried out by the Office of Management and Budget (OMB). One of OMB's findings was that while several evaluations of the Title X program had been conducted, none of them had been broadly based, independent, and of sufficient quality and scope. To fill this gap and assess the overall impact of the program, OFP asked the Institute of Medicine (IOM) to provide an independent evaluation of the Title X program. The specific charge to the committee was as follows:

> The HHS Office of Family Planning (OFP) has requested that the Institute of Medicine provide a critical review of the Title X Family Planning Program. The review will assess the administration and management of the program including whether the program is serving its intended target populations. The committee will also consider the extent to which the Title X program needs to reexamine the scope of its services, objectives and operational requirements of the program.
>
> Specifically, the committee will review and address the following questions:
>
> - Has OFP used the PART process (including identified goals, objectives and justification) to reflect relevant goals, outcomes, and processes needed to successfully implement and manage the Title X Program?
> - Does the overall Title X Program meet relevant past, existing, and foreseeable future needs of the targeted population, using accepted medical, family planning, recognized and professional standards and reproductive health practices (based on the existing legislation, regulations, and guidance)?
> - How do Title X Program goals and objectives contribute to those of HHS?
> - To what extent is the Title X Program complimentary versus duplicative of other public or private funding sources (e.g. Medicaid, community health centers)?
>
> As part of this review and assessment, the committee will consider Title X documentation including legislation, regulations, previous program evaluations (such as those conducted by the Government Accountability Office, Office of the Inspector General, and Research Triangle Institute), guidance documents (Program review tool, Title X guidelines, Program Instructions), data management (Family Planning Annual Report guidance), Service Delivery Improvement

RFAs (past and present final reports), and the PART Evaluation (level of contribution to improving service delivery).

During the committee's deliberations, four focus areas emerged that served to structure this report: (1) why family planning matters, whom the Title X program is intended to serve, and what those individuals need; (2) whether the program goals are clear and consistent and to what extent they have been achieved; (3) whether the management and administration of the program further the achievement of its goals; and (4) whether the data collected on the program are adequate for monitoring and evaluation purposes.

FINDINGS, CONCLUSIONS, AND RECOMMENDATIONS

The Importance of Family Planning

According to the Centers for Disease Control and Prevention (CDC), family planning is one of the 10 greatest public health achievements of the twentieth century (CDC, 1999). The ability to time and space children reduces fetal, infant, and maternal mortality and morbidity by preventing unintended and high-risk pregnancies (World Bank, 1993). Unintended pregnancy is associated with an increased risk of morbidity for the mother and with health-related behaviors during pregnancy, such as delayed prenatal care, tobacco use, and alcohol consumption, that are linked to adverse effects for the child (IOM, 1995). In addition to preventing unintended pregnancies, the effective use of latex condoms can reduce the transmission of sexually transmitted diseases (STDs). The availability and appropriate use of contraception can also reduce abortion rates, since a large percentage of unintended pregnancies (about one-half in 2000) result in abortion (AGI, 2003; Finer and Henshaw, 2006). Moreover, couples who are able to plan their families experience less physical, emotional, and financial strain; have more time and energy for personal and family development; and have more economic opportunities. There is also ample evidence that family planning services are cost-effective (Amaral, 2007; Frost et al., 2008; Jaffe and Cutright, 1981).

In 2002, nearly three-quarters of women of reproductive age in the United States (more than 64 million women aged 15–44) received family planning services (Mosher et al., 2004). Nonetheless, the rate of unintended pregnancies in the United States remains high. In 2001, 49 percent of pregnancies were unintended, a rate unchanged since 1994 (Finer and Henshaw, 2006). While unintended pregnancies occur in all age and racial/ethnic groups, they are more likely among adolescents, women in their early 20s, and poor and minority women (Finer and Henshaw, 2006). Notably, the United States has high rates of unintended pregnancy compared to other developed countries. For example, the percentage of unintended pregnancies in France is 33 percent and in Scotland 28 percent (Trussell and Wynn, 2008).

Population in Need of Title X Services

As noted, Title X targets low-income individuals; the 1978 amendment to Title X emphasized expanding services to adolescents. When the program was established in

1970, there were approximately 6.4 million adults aged 18–44 living below the federal poverty level in the United States; by 2007, that number had risen to nearly 14 million. In 1970, there were 20.1 million adolescents aged 13–17 in the United States; in 2006, there were 21.4 million. Population projections suggest that these groups will continue to grow through 2025, as will their need for care. Racial and ethnic minorities are an important population served by Title X since they are more likely to live in poverty than white Americans. Of course, not all individuals in these target populations need family planning services (because, for example, they are not sexually active or wish to become pregnant).

Barriers to Obtaining Services

Women and men may experience a number of barriers when trying to obtain family planning services. These may include a lack of awareness of the availability of services, distance to a family planning provider, difficulty in arranging transportation, limited days and hours of operation, long waiting times to schedule an appointment or receive services, poor quality of care, concerns about confidentiality, and perceived or real cost barriers (Bertrand et al, 1995; Brindis et al., 2003). In addition, the increasing number of racial and ethnic minorities in the United States leads to a growing need for culturally appropriate care, especially for sensitive services such as family planning. A further barrier to obtaining services is the fact that 18 percent of the U.S. population (forty-seven million people) speak a language other than English at home and 8 percent of the population (twenty-one million Americans) have limited English proficiency (Flores et al., 2005).

Increased Complexity and Cost of Providing Services

In the 38 years since the establishment of Title X, the health care system and overall social environment have changed in ways that have dramatically increased the complexity and cost of providing family planning services to the targeted groups. In 2007, 15.3 percent of Americans were uninsured (DeNavas-Walt et al., 2008). Among women aged 15-44, 20.8 percent lacked health insurance in 2005 (The Guttmacher Institute, 2007). In addition, millions of adults are underinsured (Schoen et al., 2008), and employer-based insurance plans often do not cover basic family planning services (Klerman, 2006), although this situation has improved in the last decade.

The birth control pill, the intrauterine device (IUD), the male condom, and sterilization were the primary contraceptive methods available when Title X was enacted. New methods have since become available, including improved oral contraceptives, injectables, introduction of two new IUDs, and the contraceptive patch and ring. These safer and often more effective contraceptives are often more costly than earlier methods (Sonfield et al., 2008). Discontinuation rates of the various contraceptive methods vary enormously and the more expensive long-lasting reversible methods have much higher continuation rates. Moreover, technologies such as improved Pap smears for the detection of cervical cancer, DNA-based tests for chlamydia, and STD/HIV tests cost more than earlier tests (Dailard, 1999).

The need for the Title X program to deal with STDs has also grown. The diagnosis and treatment of STDs is an essential component of comprehensive reproductive health care and helps reduce rates of infertility—a problem Title X was directed to address by

the 1978 amendment. The prevalence of STDs has changed dramatically. In particular, rates of detecting infection with chlamydia, which may be associated with subsequent infertility, have steadily increased. HIV was nonexistent at the time Title X was enacted; today more than 1.2 million people in the United States are living with HIV/AIDS. As part of providing preventive health services, Title X clinics must offer STD and HIV/AIDS prevention education, screening, and referral.

Conclusions

The following conclusions emerged from the committee's review of the literature on the role and history of family planning in the United States:

> *The provision of family planning services has important benefits for the health and well-being of individuals, families, communities, and the nation as a whole.*
>
> *Planning for families—helping people have children when they want to and avoid conception when they do not—is a critical social and public health goal.*
>
> *The federal government has a responsibility to support the attainment of this goal. There is an ongoing need for public investment in family planning services, particularly for those who are low income or experience other barriers to care.*

Program Goals

Clarity and Consistency of the Goals

The stated mission of the Title X program is to provide grants to public or nonprofit private entities "to assist in the establishment and operation of voluntary family planning projects which shall offer a broad range of acceptable and effective family planning methods and services (including natural family planning methods, infertility services, and services for adolescents)." The Program Guidelines add that Title X will "provide individuals the information and means to exercise personal choice in determining the number and spacing of their children" (OFP, 2001).

In establishing the program in 1970, Congress made clear that one major goal was to decrease the adverse health and financial effects of inadequately spaced childbearing on children, women, and their families. There was also concern at the time that the United States and the world faced serious risks due to unfettered population growth (Nixon, 1969). The program was designed to address this challenge by dramatically expanding voluntary family planning services. The federal government's continuing recognition of the contribution of family planning and reproductive health to the public well-being is evidenced by their inclusion in the nation's top health priorities as outlined in the HHS Strategic Plan and Healthy People 2010.

The program's operations are defined by (1) Program Guidelines that indicate required services, (2) annual program priorities and key issues, and (3) performance

measures developed in response to the PART review. The Program Guidelines identify the clinical services that must be provided by all projects funded under the program, as well as criteria by which the quality of care is to be measured, thereby ensuring uniformity in all regions. Each Title X clinic must offer an array of 13 services, ranging from physical examination to reporting of child abuse. This expansive list poses problems, however. Most providers and program administrators wish to offer the broadest range of services possible for Title X clients, many of whom have no other source of care (Gold, 2007). Given the limited funds made available, however, all these services likely cannot be provided at a high level of quality and may not be available to all who want and need them, nor are they all appropriate for every client.

OFP disseminates an annual program announcement informing the field about the availability of funds and identifying program priorities and key issues. While the key issues have remained quite stable for the past several years, the program priorities have continually changed and expanded. The committee learned that there is no clear process for establishing these priorities and issues, nor is there an organized system for evaluating salient research findings or seeking guidance from researchers or providers about emerging needs and how the program should adapt to meet them. Many grantees therefore feel that the shifts in priorities are politically driven rather than being based on evidence or on assessments of needs or ways to improve service delivery and outcomes.

OFP developed three long-term measures for the PART process for use in assessing the program's progress in achieving its goals (OMB, 2005):

1) Increase the number of unintended pregnancies averted by providing Title X Family Planning services, with priority for services to low-income individuals;
2) Reduce infertility among women attending Title X Family Planning clinics by identifying Chlamydia infections through screening of females ages 15-24; and
3) Reduce invasive cervical cancer among women attending Title X Family Planning by providing Pap tests.

The committee concluded that the first two measures relate directly to the program's stated mission. Although less central to the program's mission, the third is worthwhile since many Title X clients have no other means of receiving these services (Gold, 2007); however, it places an additional burden on providers already dealing with very limited resources.

Achievement of the Goals

Title X has achieved a great deal in providing family planning services to its target population—low-income individuals and adolescents. Grantees provided care to 5 million family planning users in 2006—67 percent living at or below 100 percent of the federal poverty level[1] and 90 percent below 200 percent of that level (RTI International, 2008). In addition, 61 percent of clients were uninsured, 21 percent had public health insurance,

[1] For a family of four, the 2009 poverty guideline (also known as the federal poverty level) is $22,050 (HHS, 2009).

and just 8 percent had private insurance (insurance status for 10 percent was not reported). In terms of age, almost one third (32%) of users were aged 20 to 24 years, followed by those 15 to 19 (24%) and those aged 25 to 29 (19%) (RTI International, 2008).

With regard to the above three performance measures, it is difficult to measure unintended pregnancies averted, cases of cervical cancer prevented by providing Pap tests, and reductions in infertility due to identifying chlamydia infections as a direct result of Title X services. The program can make a case that it contributes to these outcomes, but a direct effect cannot be demonstrated without building far greater capacity for long-term data collection. The desirability of establishing such a system needs to be weighed against the costs involved.

While the Title X program provides only a portion of the funds for Title X clinics, it has a special and unique role. The program covers services that other payers do not. These include the direct provision of contraceptives and other pharmaceuticals to patients, and client education and counseling. In addition, Title X covers clients who do not qualify for other coverage and cannot afford services, as well as expenses associated with program development and service delivery that other sources (such as Medicaid, section 330 programs, and Maternal Child Health Block Grants), do not reimburse, such as overhead and infrastructure, staffing and staff training, supplies, and needs assessments and reporting.

Title X providers feel pressure to offer more and more comprehensive family planning services and comply with new program priorities without additional resources. This situation creates a tension between providing broad preventive care to fewer clients and targeting more limited services to a greater number.

Conclusions and Recommendations

The committee's findings on the clarity, consistency, and achievement of the goals of the Title X program support the following conclusions:

> *While the program's core goal and contributions to the broader goals of HHS are clear, its operational priorities have fluctuated over time without a clear rationale or grounding in science. This situation has created confusion among the program's grantees about the relative importance of the program's priorities and where to invest the limited resources available.*
>
> *The program has not engaged sufficiently in long-term strategic planning. Such planning is needed to produce directives that are evidence based and age appropriate, and to cover increasing costs.*
>
> *Although data do not currently exist to permit a comprehensive evaluation of the program, it has clearly delivered care to millions of people despite very limited resources. More funds will be needed, however, to serve the growing number of individuals of reproductive age who lack the means to obtain family planning care and to keep up with changes and improvements in technologies.*

Based on the above conclusions, the committee offers the following recommendations:

Recommendation 3-1: Reassert family planning as a core value in public health practice. The Department of Health and Human Services (HHS) and Congress should recognize and support the Title X program as the leading voice for the nation's family planning effort, especially because the program's benefits apply not only to individuals and families, but also to communities and the nation.

Recommendation 3-2: Reassert and commit to the original goals of the Title X program. HHS should reassert the original mission of the Title X program—helping individuals plan for pregnancy if they so desire, as well as avoid unintended pregnancy. HHS, OPA, and their leadership, as well as Title X grantees, should be clearly dedicated to this mission and the goals of the Title X program, supportive of family planning as a critical public health intervention, committed to evidence-based practice, and knowledgeable about the field of family planning and reproductive health.

Recommendation 3-3: Develop and implement a strategic plan. OFP should develop and implement a multiyear, evidence-based strategic plan that (a) reflects the mission of the Title X program and an understanding of its target population, as well as the field of family planning and reproductive health; (b) provides a vision for coordination, leadership, and evaluation; (c) addresses the family planning needs of individuals over the full reproductive lifespan; and (d) specifically references its evidence base. OPA's operation and ongoing management of the program should be guided by this plan and linked to ongoing evaluation.

Management and Administration

The committee examined a number of issues related to the management and administration of the Title X program: the adequacy of its funding, costs of the drugs and diagnostics Title X clinics must maintain under the Program Guidelines, the challenge for clinics of managing multiple funding sources, the need to review and update the Program Guidelines, the importance of ensuring transparency in program decisions and improving communication with grantees, workforce needs, and the trade-off between the benefits and burdens of local review of informational and educational materials.

Funding

As is true for much of the nation's health care system, funding for the Title X program is severely constrained (Figure S-1). Shortly after the program was established,

Congress dramatically expanded its funding, which peaked in 1980. Since then, however, funding has increased in actual dollars but has not kept pace with the increased costs of contraceptives, supplies and diagnostics, greater number of people seeking services, inflation, the increased costs of salaries and benefits, infrastructure expenses, or insurance. Grantees identify funding and rising costs of supplies as their greatest challenges (Sonfield et al., 2006).

Each region receives a core allocation of regular service funds by the Central Office, based on a historical formula that measures each region's need according to three data sets—the Guttmacher Institute's Women in Need of Contraceptive Services and Supplies (The Guttmacher Institute, 2008b), census data, and the Bureau of Primary Care's Common Reporting Requirements. The methodology for regional allocations was last examined in 2003–2004 at the request of the Acting Assistant Secretary of Health. At that time, OFP determined that the allocations continued to reflect the need in each region accurately. According to the testimony of Title X grantees before the committee, grantees are largely unaware of how funding allocations are determined and are concerned about the lack of transparency, inequities in the allocations, and the data that are used.

Costs

Under the Program Guidelines, every Title X clinic must "maintain an adequate supply and variety of drugs and devices to effectively manage the contraceptive needs of its clients." Clinics report that this is one of the strengths of the program (Gold, 2008), but that increased costs have limited the types of contraceptives they can maintain. For example, many clinics cannot afford the cost (for both the product and related clinic services) of IUDs, implants (Implanon), and a number of other contraceptives, despite their long-term effectiveness, reliability, relatively fewer side effects, and client preferences. For cervical cancer screening, many clinics must use regular Pap tests because of the higher cost of the newer liquid-based test, which can modestly improve detection of cancers but also greatly improve detection of pre-cancers, and reduce the number of tests that need to be repeated (ACS, 2006). The same is true of the recently developed test for human papillomavirus (HPV) and the vaccine to prevent it.

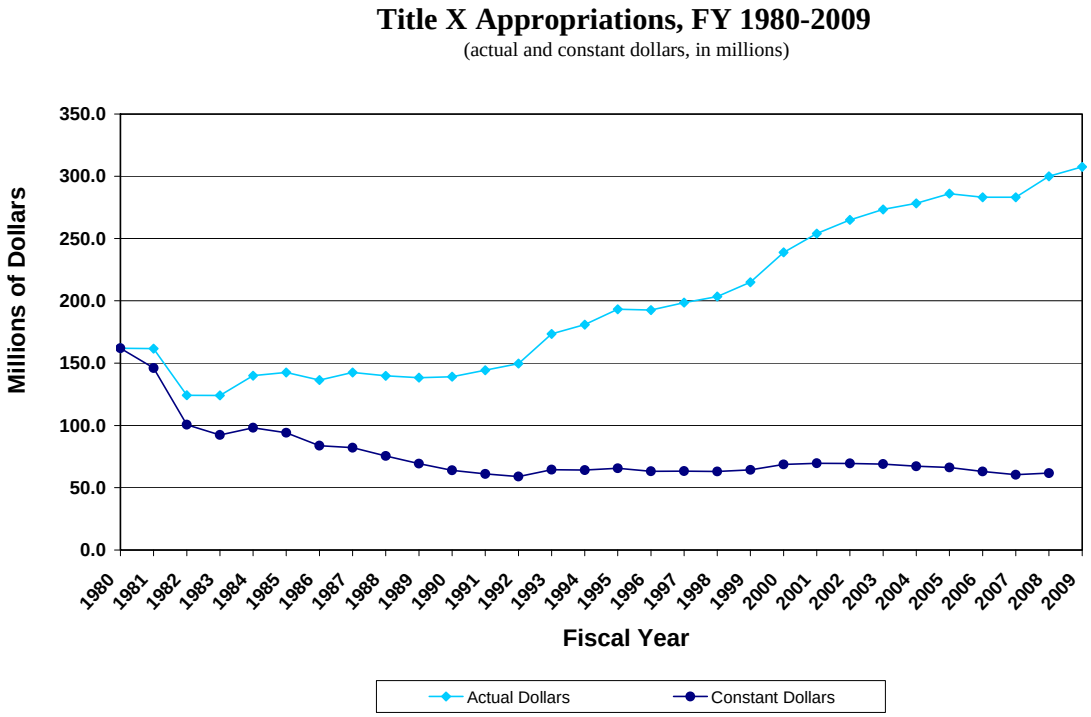

FIGURE S-1 Estimated funding for Title X when adjusted for inflation.
SOURCE: Sonfield, 2009. Reprinted with permission from unpublished Guttmacher memo.

Many Title X clinics obtain contraceptives through the Office of Pharmacy Affairs' 340B drug pricing program, consortia, cooperatives, other groups (such as Planned Parenthood Federation), or state governments that negotiate discounted prices for bulk purchases. Coordinating or consolidating these purchasing sources could help alleviate the cost problem by maximizing the benefits of volume purchasing. Models for such in the Federal government include those used by the Veterans Administration and CDC (for example, the Vaccines for Children program).

Continuity of Products

Some Title X clinics have reported problems with maintaining continuity of products because the 340b program revises the list of available drugs quarterly and often obtains products with short expiration periods. Clinics must constantly monitor the list of available drugs and determine whether drugs being used by clients need to be changed, which disrupts continuous and hence effective use. This poses a burden for both providers and clients. Continuity of products is also compromised by the multiple funding sources noted above.

Administrative Burden

Title X clinics bear a significant burden in budgeting for and managing their multiple sources of funding, a burden exacerbated by the multiple funding cycles for the awarding

of grants within the Title X program. Coordination of patient fees and record-keeping and reporting requirements for the numerous federal programs involved and establishment of a single funding cycle could reduce this administrative burden, as well as associated costs. Similarly, patient fee schedules and record keeping requirements vary across federal programs and create burdens for clinics receiving Title X funding and other funds (e.g. 330 funding).

Program Guidelines

As discussed above, some of the services required under the Program Guidelines may not be appropriate for all clients. The cancer screening requirements, for example, apply to all clients regardless of age or risk factors. Thus, for example, adolescents must have breast, rectal, and pelvic examinations and Pap smears within 6 months of becoming a Title X client, even though relevant abnormalities are rarely found in adolescents. Ensuring that the Program Guidelines are evidence based could improve the delivery of services under Title X.

Transparency and Communication

The lack of transparency regarding decisions by the Central Office and Regional Program Coordinators (RPCs) in the awarding of funds to grantees is a program challenge. OFP communicates regularly with RPCs, who in turn communicate with grantees; some internet resources are available as well. Nonetheless, grantees often do not receive the information they desire about program decisions, nor do they feel that they have adequate input into many decisions or that their concerns reach the Central Office.

Grantees and delegates also would like more regular feedback on their performance and more constructive advice on how to improve. Some find the comprehensive program review process strenuous and overly focused on small details. Grantees also would like more opportunities to learn from other grantees about successful approaches that might be replicated.

Staffing

Staffing is a pressing concern for many grantees and delegates and is likely to become even more so given the shortage of and competition for trained medical personnel in most areas of the country, as well as the impending retirement of many nurses and nurse practitioners who staff the clinics, the increasing cost of salaries and benefits, the need for and cost of continued professional training (Murray, 2002; HHS, 2007), and efforts to revise state licensure laws to require more advanced training for practitioners (National Council of State Boards of Nursing, 2008). The need to increase the pool of qualified professionals has been an ongoing problem for the program and will become greater with the growing need for Title X services by increasingly diverse populations.

Informational and Educational Materials

During the committee's site visits, in testimony provided by grantees and delegates, and in the Membership Survey of the National Family Planning and Reproductive Health Association (NFPRHA), several issues regarding informational and educational materials were raised. These issues include the manner in which materials developed by the OPA Clearinghouse are reviewed, the duplicative review by a delegate's advisory committee after review by the grantee responsible for the delegate, and delays or other problems in obtaining payment for materials ordered from outside sources. Grantees and delegates suggested that materials used in a related program might be distributed without additional review. Concerns were also expressed about the ability of the advisory committees (rather than professional health educators or public health personnel) to select culturally, linguistically, and literacy level–appropriate materials. Grantees and delegates indicated that some of the OPA Clearinghouse materials fail to meet those criteria—deficits that should be rectified at the Clearinghouse level.

Conclusions and Recommendations

The committee drew the following conclusions about the management and administration of the Title X program:

> *The management structure and administration of the program generally work well, but could be improved.*
>
> *Specific areas for improvement include overall funding levels, pharmaceutical and lab testing costs, birth control method availability, administrative burden, the evidence base for and flexibility of the Program Guidelines, transparency and communication, staffing shortages, and informational and educational materials.*

The committee offers the following recommendations for achieving these improvements:

> **Recommendation 4-1: Increase program funding so that statutory responsibilities can be met.** Title X should receive the funds needed to fulfill its mission of providing family planning services to all who cannot obtain them through other sources and to finance such critical supplemental services as infrastructure, education, outreach, and counseling that many other financing systems do not cover. Consistent with legislative intent, financing for the program must also support research and evaluation; training; and the development and maintenance of needed infrastructure, and the adoption of important new technologies.
>
> **Recommendation 4-2: Examine and, if appropriate, improve methods of funding allocation.** The Office of Family Planning (OFP) should carefully examine and, if appropriate, improve the system used to allocate funds from from

OFP to regions, regions to grantees, and grantees to delegates. The transparency of these funding processes should be improved so that program participants and the public are aware of how decisions about funding allocations at each level are made and what the process is to comment on them.

Recommendation 4-3: Improve the ability to purchase drugs and diagnostics at reduced prices by consolidating funding sources. OFP should work with the various public and private sources of funding for drugs and diagnostics for Title X clinics to develop a coordinated or consolidated purchasing program.

Recommendation 4-4: Improve the continuity of products provided to clients of Title X clinics. The 340B drug pricing program should revise its list of available drugs less frequently and make an effort to obtain drugs with longer expiration periods. Product continuity would also be enhanced by the consolidation proposed under recommendation 4-3.

Recommendation 4-5: Reduce the administrative burden on Title X clinics. OPA should work with other HHS agencies supporting family planning to coordinate patient fee schedules and record-keeping and reporting requirements. OPA should also adopt a single funding cycle, where possible, for the awarding of grants.

Recommendation 4-6: Adopt a single method for determining criteria for eligible services. The federal government should adopt a single method of determining criteria for eligible services (for example, which services are available at which percent of the Federal Poverty threshold), what copays if any are required, and how to report clients seen. The current inconsistencies create an atmosphere that discourages coordination of HRSA, CDC, and other programs with Title X.

Recommendation 4-7: Review and update the Program Guidelines to ensure that they are evidence based. OFP should review annually and update as needed the Program Guidelines in order to reflect new scientific evidence regarding clinical practice. In so doing, OFP should establish a mechanism for obtaining expert scientific and clinical advice in a systematic, transparent way. Expertise should be drawn from the clinical, behavioral, epidemiological and educational sciences. In addition, it is important to enhance the flexibility of Title X clinics, so that they can meet the needs of individual patients while simultaneously adhering to evidence-based guidelines and practices.

Recommendation 4-8: Increase transparency and improve communication. OFP should increase the transparency and communication of information at all levels of the program. Such information should encompass methods for allocating program funds, the process for establishing annual program priorities, suggestions for program improvements, lessons learned through research supported by Title X and other programs, and the ways data are used. This information should be disseminated both vertically and horizontally.

Recommendation 4-9: Assess workforce needs. With the help of an independent group, OFP and other agencies within HHS should conduct an analysis of family planning workforce projections for the United States, in general, and for the Title X program specifically. The study should assess current and future workforce training needs and the educational system capacity necessary for the future workforce that will be needed. The study should also identify ways in which these needs can be met and financed.

Recommendation 4-10: Assess the local review of informational and educational materials. OFP should assess whether the benefits of local review of all educational materials outweigh the burdens, including costs. OFP should develop processes that eliminate duplicative reviews, while also ensuring that consumers also have an opportunity for input either at the local or national level.

Data to Monitor and Evaluate the Program

The committee developed a framework (outlined in Figure S-2) that could serve as the foundation for a more integrated and comprehensive evaluation approach to guide Title X's future efforts by linking the program's evaluation to its stated goals and priorities.

CLIENT NEED	*STRUCTURE*	*PROCESS*		*OUTCOMES*
Predisposing Factors: ⇨	*Enabling Factors:* ⇨	*Health Behaviors* ⇨ *Services Received* ⇨		*Client Outcomes*
Client Characteristics	**System Characteristics**	**Process of Care: Client–Provider Encounter**	**Service Use Performance Indicators for Title X Priority Areas**	**Modeled Improved Clinical Outcomes**

FIGURE S-2 Conceptual framework for Title X evaluation.

Current Data Sources

OFP currently uses data from a variety of sources to monitor and evaluate the program. The primary source is the *Family Planning Annual Report* (FPAR), which is based on annual uniform reporting by all Title X grantees. Another main source is the Comprehensive Program Reviews (CPRs), which are conducted approximately every 3 years by OFP's Regional Offices. The Program Review Tool (PRT), used in the CPRs, includes questions on administration, financial management, clinical services, and outreach/information. In addition, Regional Offices conduct annual grantee monitoring site visits to follow up on issues identified in the CPR, grant application, and/or needs assessment. A final data source is the National Survey of Family Growth (supported in part by Title X), which examines reproductive behaviors, health, and family planning services received.

How Data Collection Efforts Can Be Improved

The evaluation framework outlined above guided the committee's recommendations for evaluation strategies to improve the management and quality of the Title X program. The full framework (presented in the main text) lists data that are currently being collected in each of the framework's columns. The FPAR and CPR provide the most comprehensive information about the program, including key characteristics of the client population, critical system characteristics, and services performed. However, client-level data, such as knowledge and pregnancy intentions, are not obtained. Nor does OFP systematically collect data on key process and outcome variables. In addition, how Title X synthesizes and uses existing data for program planning is not clear to the committee or to grantees and delegates.

Conclusions and Recommendations

The committee's comparison of the data needed to monitor and evaluate the Title X program against the data actually collected supports the following conclusions:

> *The program does not collect all the data needed to fully monitor the program and evaluate its impact.*
>
> *A comprehensive framework for approaching program evaluation could ensure that all major aspects of the program are evaluated and the needs of clients are being met. Gathering these data will require innovative approaches – and new funding – to minimize the burden on providers.*

The following recommendations are made for meeting these data needs.

Recommendation 5-1: Fund and use a comprehensive framework to evaluate the Title X program. OFP should develop, fund, and use a comprehensive framework to evaluate the Title X program. The use of such a framework would allow OFP to evaluate the program on the full continuum from clinic performance and quality, to clinic management, to program outcome. It would also help in identifying the types of data needed for evaluation purposes.

Recommendation 5-2: Examine the data elements of the *Family Planning Annual Report* (FPAR). When revising the Program Guidelines (see recommendation 4-7), OFP should review and clarify data elements contained in the FPAR and where possible and useful, eliminate those that are unnecessary, particularly if additional elements are needed.

Recommendation 5-3: Collect additional data. In order to help fill gaps in the Title X Program's data collection systems, OFP should collect additional data in the areas of client needs, structure, process, and outcomes for use in evaluating the program's progress and its effectiveness in achieving its goals. Specifically, OFP should:

- **Collect additional data on client characteristics.** Use of other data sources, such as the CPRs, should be modified to enable collection of data that will supplement the FPAR data, for example, to obtain data on clients' knowledge about available contraceptive methods and pregnancy intentions.
- **Collect data on system characteristics.** Additional data are needed, for example, regarding the availability of interpreters to meet the needs of clients with limited English proficiency.
- **Collect data on the process of care.**
  - These data should include patients' perceptions of care. With expert consultation, selected CPR site visits could be structured to sample a limited number of clients for the purpose of obtaining generalizable results.
  - With expert advice, OFP should examine the three core outcome measures identified for the PART process in relation to evidence-based guidelines and national health priorities. After determining the most appropriate measures, OFP should develop related performance metrics for clinic service to establish quality improvement standards.
- **Conduct research to assess program outcomes.** OFP should expand research aimed at evaluating program results, such as the impact of the program on pregnancy planning and intention, decreased

infertility, outreach to those in need of services, and on the prevention of unintended pregnancy.

Recommendation 5-4: Examine Outreach and Education Evaluation. In order to assist ongoing quality improvement and effective expansion of community outreach and education, OFP should work with Grantees to develop and refine evaluation measurement tools for outreach and education that can be applied easily by delegates.

Recommendation 5-5: Obtain scientific input on evaluation efforts. OFP should expand its use of scientific expertise to strengthen its evaluation strategies and improve its evaluation research program, and consider expanding its use of national databases to evaluate program impacts.

Recommendation 5-6: Communicate evaluation findings. To ensure transparency and broad-based dissemination of information and ultimately improve care (see recommendation 4-8), OFP should enhance ongoing feedback and communication with grantees, delegates, clinics, and others about important evaluation findings and how they can help improve care and track progress toward reaching program goals.

CONCLUDING THOUGHTS

The committee has identified a variety of ways in which the Title X program could be improved. These include focusing on the program's core mission; undertaking a strategic planning process with a longer time horizon; implementing patient-focused, scientifically based clinical practices; and enhancing evaluation and communication. While there is room for improvement, it is also important to note that the program has successfully served thousands of low-income men and women and adolescents for almost four decades. Despite increasingly limited funds and varying levels of controversy and challenge, the dedication of federal agency staff, grantees, delegates, and clinic staff to the goals and clients of the program has remained strong and made it possible for the program to deliver essential services. The committee salutes their steadfast commitment to the overall goals of family planning in general and to the Title X program in particular.

Summary of Recommendations

Recommendation 3-1: Reassert family planning as a core value in public health practice.

Recommendation 3-2: Reassert and commit to the original goals of the Title X program.
Recommendation 3-3: Develop and implement a strategic plan.

Recommendation 4-1: Increase program funding so statutory responsibilities can be met.
Recommendation 4-2: Reexamine finding allocation methods.
Recommendation 4-3: Improve the ability to purchase drugs and diagnostics at reduced prices by consolidating funding sources.
Recommendation 4-4: Improve the continuity of products provided to clients of Title X clinics.
Recommendation 4-5: Reduce the administrative burden on Title X clinics.
Recommendation 4-6: Adopt a single Method for determining criteria for eligible services.
Recommendation 4-7: Review and update the Program Guidelines to ensure that they are evidence based.
Recommendation 4-8: Ensure transparency and improve communication.
Recommendation 4-9: Assess workforce needs.
Recommendation 4-10: Assess the local review of informational and educational materials.

Recommendation 5-1: Use a comprehensive framework to evaluate the Title X program.
Recommendation 5-2: Examine the data elements of the *Family Planning Annual Report* (FPAR).
Recommendation 5-3: Collect additional data.
Recommendation 5-4: Examine outreach and education evaluation
Recommendation 5-5: Obtain scientific input on evaluation efforts.
Recommendation 5-6: Communicate evaluation findings.

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