

# **MISSING: Information About Women's Lives**

## **Executive Summary**

### **OVERVIEW**

With weekly headlines about suppressed information, slanted scientific panels, and altered research reports, the National Council for Research on Women joins a growing chorus of researchers, scientific experts, policymakers, and journalists in a call to concerned citizens to protest and reverse decisions that diminish the amount and quality of information available to us all. These decisions, we believe, cannot be left unchecked.

MISSING concentrates on missing information – information that directly affects women's lives. Vital data has been deleted, buried, altered, or has otherwise gone missing from government websites and publications. Taken cumulatively, these actions are serious for women and need to be addressed. As the report shows, such distortions and omissions have debilitating consequences for peoples' health and livelihoods. They also deny researchers critical facts and impede our ability to craft solutions and develop strategies to address the pressing challenges of our times.

Americans share a proud legacy of trusting the federal government to assemble information needed to advance women's rights and well-being. As data on women disappears, an important, non-partisan tradition of government is being destroyed.

MISSING concentrates on four key areas that affect women and girls where priorities have changed, funding has been cut, research findings distorted, important social differences masked, and critical committees and programs dismantled. The report makes clear the following has gone MISSING:

- Accurate and Science-Based Information on Women's Health
- Accurate and Reliable Information on Women's Economic Status
- Scientific Objectivity and Expertise
- Information to Help Protect and Advance Women and Girls

### **MISSING:**

#### **Accurate and Science-Based Information on Women's Health**

Information routinely posted on government websites, such as critical health data for women, is withdrawn or altered without explanation.

- A **Centers for Disease Control and Prevention (CDC)** fact sheet that focused on the advantages of using condoms to prevent sexually transmitted disease was revised in December 2002 to cast doubt on the effectiveness of

condoms, calling evidence on condom use and transmission of HIV and other STD's "inconclusive."

- Contrary to broad medical consensus, information on the **National Cancer Institute (NCI)** website was changed in 2002 to state that studies about the link between abortion and breast cancer were inconsistent. After an outcry by members of Congress, the **NCI** posted the panel's actual finding: abortion is not associated with an increased breast-cancer risk.
- Information on a **Health and Human Services (HHS)** website has been distorted, and performance measures to test the effectiveness of abstinence programs have been altered, in order to make abstinence-only approaches to pregnancy prevention appear more successful than they have been otherwise proven to be.<sup>i</sup>
- The **Union of Concerned Scientists (UCS)** has charged that officials distorted the **CDC's** science-based performance measures to test the effectiveness of sex education programs to prevent HIV and other STDs and used "measures designed to obscure the lack of efficacy of abstinence-only programs."<sup>ii</sup>
- The **Centers for Disease Control (CDC)** now requires review and approval of all HIV health education materials by federal rather than local officials thereby delaying the delivery of important health information to people who need it and seems to be applying a political rather than an educational test to the materials.
- The executive summary of the **National Healthcare Disparities Report**, a Congressionally mandated report card on racial, ethnic, and socioeconomic disparities in healthcare, downplayed major inequities in diagnosing and treating such conditions as hypertension, diabetes, and HIV – all of enormous importance to the health of women of color. After strong public objection, the decision to water down the report was reversed.

## **MISSING:**

### **Accurate and Reliable Information on Women's Economic Status**

A look at various public websites indicates that information accumulated over decades under both Republican and Democratic administrations, including a wide variety of helpful factsheets that analyze women's status and rights, is no longer available.

Department of Labor (DOL) and Census Bureau websites emphasize good news and underplay problems that prevent full and equal participation of women in the workforce. Without solid data on wages and information on job rights, women will

not have the necessary knowledge to overcome barriers that limit their advancement and their contributions to the nation's economy.

- A major resource for working women, the **Department of Labor's Women's Bureau**, an agency charged by Congress with providing information on women's economic status and rights, is now nearly silent on those issues.
- A valuable **Department of Labor** publication on the rights of women workers once distributed by the Women's Bureau, *Don't Work in the Dark—Know Your Rights*, is no longer available.
- An ongoing series of **Department of Labor** "Fact Sheets" on women workers, widely used by researchers and the media, has been curtailed, limiting information on rights in the workplace.
- A much-used **Department of Labor Handbook on Women's Workers** is scheduled for re-release, but as of March 2004, no date was available for its publication.
- The **Census Bureau** touts the ratio of women's earnings as compared to men – 76 cents for every \$1 – as "an all-time high." In reality, the disparity in wages has remained nearly constant with less than 1% change in the ratio in recent years, and was characterized in 2000 as a lack of pay equity.

## **MISSING: Scientific Objectivity and Expertise**

When evidence-based research is jettisoned to make room for politically motivated suppositions, good public policy suffers. Members of advisory and peer review panels have been chosen or excluded based on ideological stands rather than expertise.

- Two advisory committees advised the **Federal Drug Administration (FDA)** to sanction the contraception known as Plan B as a non-prescription drug. After the hearings, conservative groups renewed campaigns to block approval. Political pressure seems to have blocked information that young women need to prevent unwanted pregnancies and diminish the need for abortions.
- Only extraordinary public outcry prevented the appointment of Dr. W. David Hager to chair the **FDA's Reproductive Health Drug Advisory Committee**. Hager is known for prescribing prayer as a treatment for premenstrual syndrome and refusing to prescribe birth control pills to unmarried women. He remains a member of the committee.<sup>iii</sup>

- A list compiled by the right-wing Traditional Values Coalition of more than 150 researchers and 200 grants in the fields of high-risk sexual behavior, STDs, and adolescent sexual behavior has forced **National Institute of Health (NIH)** officials to ask researchers to defend the public health benefits of their projects, causing the NIH to have to re-justify research that has already been peer-reviewed, approved and funded.

## **MISSING:**

### **Information to Help Protect Women and Girls**

Agencies and councils that monitor governmental efforts on behalf of women and offices designed to assure that the concerns of women are addressed in policy development have disappeared. Studies mandated by Congress on the problems that victims of domestic violence face – specifically workplace and insurance discrimination – languish in extensive review processes and are not released in a timely fashion.

- The **Office of Women’s Initiatives and Outreach in the White House** and **The President’s Interagency Council on Women** – both designed to assure that the concerns of women are addressed in policy development – were disbanded.
- Defense Secretary Donald Rumsfeld tried to terminate a 53-year-old panel, the **Defense Advisory Committee on Women in the Services (DACOWITS)**. The committee was resuscitated after an outcry by Representative Heather Wilson (R-NM), the only congresswoman who is a veteran, but with a new mission – to focus on issues such as health care for servicewomen and the effects of deployment on family life, but not issues of equity and access.<sup>vi</sup>
- Under the 2000 **Violence Against Women Act**, the Attorney General is required to conduct a national study of discrimination against domestic violence victims in the issuing or administration of insurance policies. The report to Congress was due in October 2001 and, as of March 2004 the report has still not been published. Data in this report would support legislation introduced last fall to address insurance discrimination and workplace issues.
- In February 2004, a newly appointed official of the **U.S. Office of Special Counsel** removed references to sexual orientation from a website designed to educate government employees about their rights. The official said he ordered the references removed because he was unsure if federal law protected workers discriminated against because they were lesbians, gay men, or bisexuals. Elaine Kaplan, who served as Special Counsel from 1998 to 2003, told the *Washington Post*: “It seemed to us that this was well-

established law. Part of the job of the agency is to educate employees about their rights.”<sup>vii</sup>

- The Title X funding appropriation bill for fiscal year 2004 allows the **Health and Human Services** department to collect the names of health providers that offer abortion services with their non-Title X dollars – the first step, providers fear, toward a domestic gag rule that would force them to choose between government support or withholding vital information from their patients. Also, in a lawsuit initiated by doctors protesting the abortion ban legislation of 2003, the Department of Justice subpoenaed the medical records of women, not party to the lawsuit, who have had procedures now criminalized under the ban.<sup>viii</sup>

## **CONCLUSION: A Call for Accountability and Action**

The combined effect of the decisions and actions outlined in this report are deeply troubling for American women – and for their families and communities. The pattern is unfortunately all too clear: cutting vital information, stacking scientific panels, defunding agencies, withholding data, raising doubts, spreading misinformation, holding back studies, silencing voices for women, spinning data, abandoning information resources, privileging ideology over science, inhibiting health providers, censoring researchers. The cumulative effect is a devastating loss of reliable, accessible, research-based information on at least three critical issues to women’s lives – health, employment, and violence.

The American public – women and men – has good reason to question whether they can trust that the information and analysis they receive from Washington is complete, accurate, and based on solid science. As this report documents, misinformation – or the lack of information – has a direct and harmful effect on women’s lives.

The National Council for Research on Women joins others in the research and science community in calling on concerned citizens to protest this pattern of loss. Help the Council identify other instances of information gone missing by sending them, or sites where good information is still available, to its Misinformation Clearinghouse at [www.ncrw.org](http://www.ncrw.org). We must challenge officials and elected representatives to confront this issue and ensure the unimpeded flow of solid, unbiased, and complete information.

Accurate, trustworthy, science-based information and data matter, and we should be able to count on our government to provide it.

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- <sup>i</sup> Politics and Science web page.  
[http://www.house.gov/reform/min/politicsandscience/example\\_abstinence.htm](http://www.house.gov/reform/min/politicsandscience/example_abstinence.htm) :  
[www.house.gov/reform/min/politicsandscience](http://www.house.gov/reform/min/politicsandscience).
- <sup>ii</sup> Union of Concerned Scientists. (2004, February). *Scientific Integrity in Policymaking: An Investigation into the Bush Administration Misuse of Science*  
[.http://ucsusa.org/documents/RSI\\_final\\_fullreport.pdf](http://ucsusa.org/documents/RSI_final_fullreport.pdf)
- <sup>iii</sup> Boonstra, Heather. (2003, May). Critics Charge Bush Mix of Science and Politics Is Unprecedented and Dangerous. *The Guttmacher Report on Public Policy*, 6 (2).
- <sup>iv</sup> qtd. in Reppert, Barton. (2004, January 6). Politics in the Lab Hits US Scientific Integrity. *Christian Science Monitor*, Opinion, p. 11.
- <sup>v</sup> United Nations. (1995). Fourth World Conference on Women Platform for Action.  
<http://www.un.org/womenwatch/daw/Beijing/platform/index.html>
- <sup>vi</sup> Wolfowitz, Paul. (2002, October 18). Remarks prepared by Deputy Secretary of Defense for delivery at the Women in Military Service for America Memorial, Arlington VA. *Department of Defense*. <http://www.defenselink.mil/speeches/2002/s20021018-depsecdef2.html>
- <sup>vii</sup> qtd in Barr, Stephen. (2004, February 18). Gay Rights Information Taken Off Site. *Washington Post*, Section A, p. 17.
- <sup>viii</sup> Lichtblau, Eric. (2004, February 12). Defending '03 Law, Justice Department Seeks Abortion Records. *New York Times*, Section A, p. 1.
- <sup>ix</sup> Lifetime, Television for Women. (2004, January 22). Conducted as part of the advocacy campaign: *Our Lifetime Commitment: Every Woman Counts*
- <sup>x</sup> Center for the Advancement of Women. (June: 2003). *Progress and Perils: New Agenda for Women*. <http://www.advancewomen.org/report/index.php>
- <sup>xi</sup> Melbye, Mads, et al. (1997, January 8). Induced Abortion and the Risk of Breast Cancer. *New England Journal of Medicine*, 336 (2), 81-85.
- <sup>xii</sup> Kaiser Family Network (2002, December 19). Democratic Lawmakers Accuse Bush Administration of Political Bias in Deleting Information from New CDC Condom Fact Sheet. *Daily Reproductive Health Report*.  
[http://www.kaisernetwork.org/daily\\_reports/rep\\_index.cfm?DR\\_ID=15185](http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=15185)

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- <sup>xiii</sup> Politics and Science web page.  
[http://www.house.gov/reform/min/politicsandscience/example\\_abstinence.htm](http://www.house.gov/reform/min/politicsandscience/example_abstinence.htm) :  
[www.house.gov/reform/min/politicsandscience](http://www.house.gov/reform/min/politicsandscience).
- <sup>xiv</sup> Block, Jennifer. (2003). Sex, Lies and Duct Tape. *Conscience*.  
<http://www.catholicsforchoice.org/conscience/archived/Jennifer%20Block.htm>
- <sup>xv</sup> Kaiser Family Network (2002, December 19). Democratic Lawmakers Accuse Bush Administration of Political Bias in Deleting Information from New CDC Condom Fact Sheet. *Daily Reproductive Health Report*.  
[http://www.kaisernetwork.org/daily\\_reports/rep\\_index.cfm?DR\\_ID=15185](http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=15185)
- <sup>xvi</sup> Union of Concerned Scientists. (2004, February). *Scientific Integrity in Policymaking: An Investigation into the Bush Administration Misuse of Science*  
[.http://ucsusa.org/documents/RSI\\_final\\_fullreport.pdf](http://ucsusa.org/documents/RSI_final_fullreport.pdf)
- <sup>xvii</sup> Union of Concerned Scientists. (2004, February). *Scientific Integrity in Policymaking: An Investigation into the Bush Administration Misuse of Science*  
[.http://ucsusa.org/documents/RSI\\_final\\_fullreport.pdf](http://ucsusa.org/documents/RSI_final_fullreport.pdf)
- <sup>xviii</sup> See Pear, Robert, (2004, February 21). Taking Spin Out of Report that Made Bad into Good. *New York Times*, Section A, p. 16
- <sup>xix</sup> Vedantam, Shankar. (2004, January 14). Racial Disparities Played Down: At Request of Top Officials, Report on Health Care Differs From Draft. *Washington Post*, Section A, p. 17.
- <sup>xx</sup> *ibid.*
- <sup>xxi</sup> Herdt, Gilbert, (2004, February 6). Letter to the Editor. *New York Times*, Late Edition, Section A, p. 26.
- <sup>xxii</sup> Lichtblau, Eric. (2004, February 12). Defending '03 Law, Justice Department Seeks Abortion Records. *New York Times*, Section A, p. 1.
- <sup>xxiii</sup> Herbert, Bob. (2003, November 3). Editorial: The Big Chill at the Lab. *New York Times*, Section A, p. 19.
- <sup>xxiv</sup> Waxman, Henry, Letter to Health and Human Services Director Tommy Thompson. Politics and Science web page.  
[http://www.house.gov/reform/min/pdfs\\_108/pdf\\_inves/pdf\\_admin\\_nih\\_hit\\_list\\_oct\\_27\\_1\\_et.pdf](http://www.house.gov/reform/min/pdfs_108/pdf_inves/pdf_admin_nih_hit_list_oct_27_1_et.pdf) .
- <sup>xxv</sup> Kolata, Gina. (2004, February 14). FDA to Delay Its Decision on Morning-After Pill, *New York Times*, Section A, p. 12.

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<sup>xxvi</sup> Planned Parenthood Federation of America. (2004, February 13). FDA Chooses Politics Over Science, Delays Decision on Emergency Contraception. [http://www.ppfa.org/about/pr/040213\\_FDA.html](http://www.ppfa.org/about/pr/040213_FDA.html)

<sup>xxvii</sup> Union of Concerned Scientists. (2004, February). *Scientific Integrity in Policymaking: An Investigation into the Bush Administration Misuse of Science*. [http://ucsusa.org/documents/RSI\\_final\\_fullreport.pdf](http://ucsusa.org/documents/RSI_final_fullreport.pdf)

<sup>xxviii</sup> Boonstra, Heather. (2003, May). Critics Charge Bush Mix of Science and Politics Is Unprecedented and Dangerous. *The Guttmacher Report on Public Policy*, 6 (2).

<sup>xxix</sup> Kennedy, Donald. (2003, January 31). An Epidemic of Politics. *Science*, Volume 299, No.5607, p. 625.

<sup>xxx</sup> For further analysis by the Institute for Women's Policy Research see [www.iwpr.org/pdf/C353.pdf](http://www.iwpr.org/pdf/C353.pdf).

<sup>xxxi</sup> Friedlin, Jennifer (2003, September 1). Lower Male Income Causes Tightest Wage Gap. *Women's Enews*. [www.womensenews.com/article.cfm/dyn/aid/1508/context/archive](http://www.womensenews.com/article.cfm/dyn/aid/1508/context/archive)

<sup>xxxii</sup> qtd in Jennifer Friedlin (2003, September 1). Lower Male Income Causes Tightest Wage Gap. *Women's Enews*. [www.womensenews.com/article.cfm/dyn/aid/1508/context/archive](http://www.womensenews.com/article.cfm/dyn/aid/1508/context/archive)

<sup>xxxiii</sup> qtd. in Morahan, Lawrence. (2002, February 28). Pentagon Lets DACOWITS' Charter Expire. *CNSNews.com*. <http://www.cnsnews.com/Pentagon/Archive/200202/PEN20020228b.html>

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<sup>xxxiv</sup> Wolfowitz, Paul. (2002, October 18). Remarks prepared by Deputy Secretary of Defense for delivery at the Women in Military Service for America Memorial, Arlington VA. *Department of Defense*. <http://www.defenselink.mil/speeches/2002/s20021018-depsecdef2.html>

<sup>xxxv</sup> qtd. in Morahan, Lawrence. (2002, February 28). Pentagon Lets DACOWITS' Charter Expire. *CNSNews.com*.

<sup>xxxvi</sup> Qtd in Barr, Stephen. (2004, February 18). Gay Rights Information Taken Off Site. *Washington Post*, Section A, p. 17.

<sup>xxxvii</sup> General Accounting Office, (2003, October). Women's Earnings: Work Patterns Partially Explain Difference between Men's and Women's Earnings.

<sup>xxxviii</sup> Sen, Amartya. (2000). *Development as Freedom*. New York: Random House,

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p. 57.

<sup>xxxix</sup> qtd in Glanz, James, (2004, February 19). Scientists Say Administration Distorts Facts. *New York Times*, Section A, p. 18.

<sup>xl</sup> Editorial, (2004, February 23). Uses and Abuses of Science. *New York Times*, Section A, p. 20.

<sup>xli</sup> Girls Inc. Fact Sheets are available for downloading from <http://www.girlsinc.org/ic/page.php?id=3.2>