



MISSISSIPPI MOVING FORWARD

PROGRESS AND CHALLENGES IN STATE RESPONSE TO HIV



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SUMMARY

Mississippi has one of the nation's highest rates of HIV infection and deaths from AIDS. In March 2011, Human Rights Watch published *Rights at Risk: State Response to HIV in Mississippi*, which found the state's response to HIV conflicted with human rights and sound public health policy.

The report, released at the first annual conference of people living with HIV in Mississippi, focused on how harsh socio-economic conditions in the state placed people at high risk of acquiring HIV. It also showed how Mississippi's harmful laws and policies undermined the lives of people with HIV, and how its efforts to address its HIV epidemic—including failure to invest in HIV prevention, care, and services, and a lack of accurate and complete sex education—were inadequate and sometimes misguided.

Since then, Mississippi has made progress in meeting the challenges of HIV, aided by civil society engagement and an HIV community that, together with its allies, continues to grow in size and political strength. State government has also since undergone important changes. Under the leadership of a new director of the STD/HIV Office, the Mississippi State Department of Health (MSDH) for the first time in its history sought and obtained significant state and federal funding to strengthen health services, housing, and other services critical to protect the lives and health of people living with HIV. MSDH is reaching out to more people with HIV, consulting the community on its policies, and taking steps to protect confidentiality and human rights in its interactions with people living with HIV.

However, much remains to be done. Mississippi must focus on housing and re-entry from prison for people with HIV, and embrace evidence-based sex education in its public schools. Most urgently, however, it must expand Medicaid under the Affordable Care Act (ACA)—a move that will significantly increase the number of people living with HIV who can access medical care, and will enable many more Mississippians to be tested for HIV and linked more directly to treatment. Moreover, expanding the health care sector will add jobs and bring new tax revenue to the state. The Mississippi legislature should approve Medicaid expansion in 2013; it is an opportunity the state cannot afford to waste.

RECOMMENDATIONS

To the Mississippi State Legislature

- Authorize expansion of Medicaid eligibility and services under the Affordable Care Act
- Approve the Mississippi State Department of Health budget request for 2013 for HIV and prevention of sexually transmitted disease (STD)
- Increase state funding for HIV-related services including housing and transportation
- Authorize the establishment of a state inter-agency Council on Homelessness as proposed by the Mississippi Continuum of Care

To the Mississippi State Department of Health

- Continue efforts to maximize federal and state support for HIV prevention, care and services, including housing and transportation
- Increase the transparency of the planned changes to the Housing Opportunities for Persons with AIDS (HOPWA) program and include people living with HIV/AIDS and other key stakeholders in this process
- Continue efforts to ensure adequate training for disease intervention specialists (DIS) regarding confidentiality and privacy obligations under domestic and international human rights laws
- Ensure that programs intended to identify and locate persons with HIV who are not in care are conducted with respect for privacy, confidentiality, and other fundamental human rights and are designed with the participation of people living with HIV
- Review the discharge planning programs for prisoners at the Mississippi Department of Corrections and take steps to ensure linkage to care and other essential services upon re-entry to the community
- Support the implementation of evidence-based sex education curricula in the public schools that is inclusive of lesbian, gay, bisexual, and transgender (LGBT) youth

To the Mississippi Department of Corrections

- Review the discharge planning programs for prisoners at Parchman, Leakesville, and Pearl prisons and take steps to ensure linkage to care and other essential services upon re-entry to the community

BACKGROUND

HIV in Mississippi

Nearly 10,000 people are living with HIV in Mississippi, almost half of whom have been diagnosed with AIDS.¹

This number does not include the approximately 2,000 people who have HIV but are unaware of their status.²

Overall, the epidemic in Mississippi has remained relatively stable since 2000, but the state ranks 7th in the United States in terms of the rate of HIV infection and 9th in terms of the rate of AIDS diagnosis.³ In Mississippi, 41

percent of people diagnosed with HIV were diagnosed with AIDS less than a year later. This late diagnosis is a contributing factor to a death rate from AIDS in Mississippi that is nearly double the national average.⁴

Only one in three people living with HIV in Mississippi is in treatment.

Source: Mississippi State Department of Health, STD/HIV Office 2012-2015 Jurisdictional Plan

The following diagrams provide information on the HIV epidemic and health services in Mississippi.

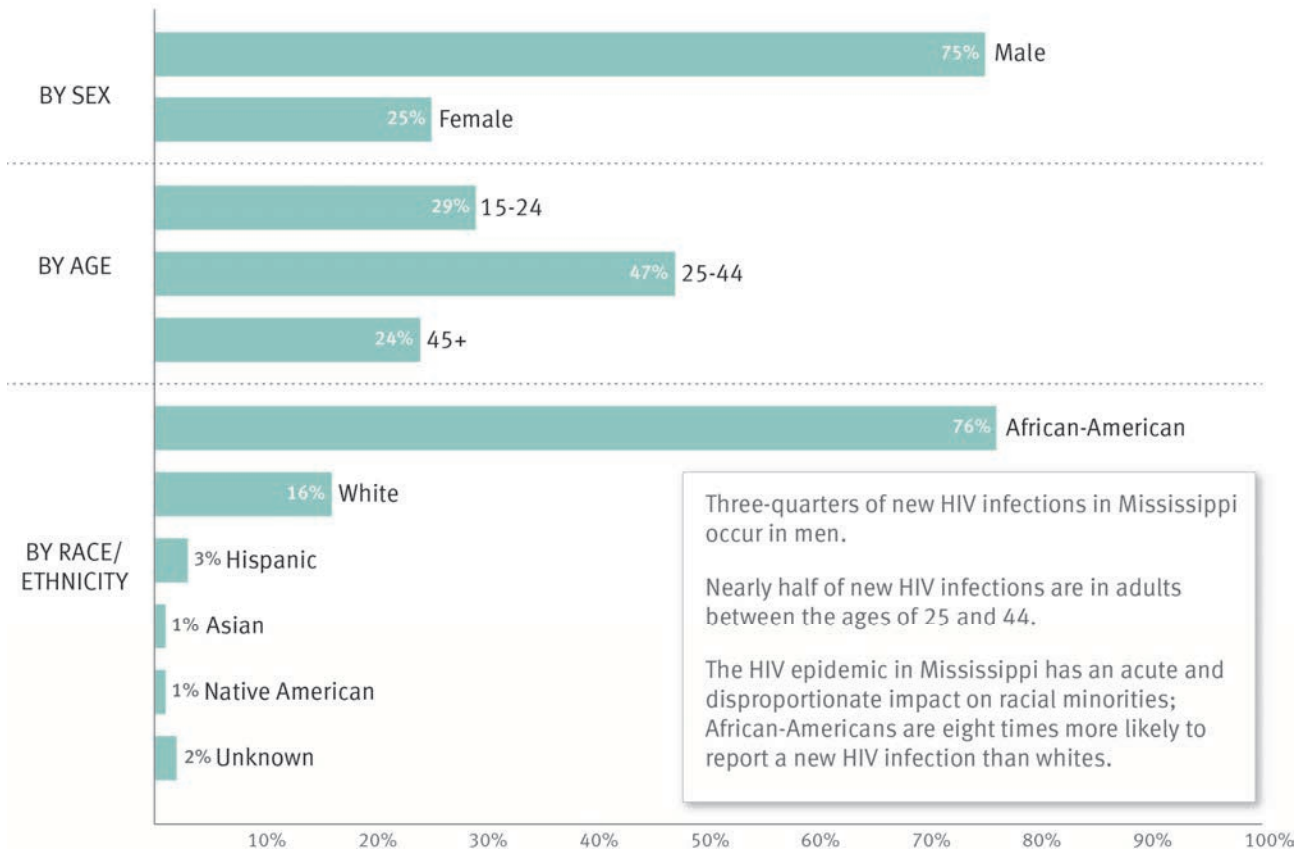
¹ Mississippi State Department of Health, "Mississippians Living with HIV Disease in 2011," http://msdh.ms.gov/msdhsite/_static/resources/4769.pdf (accessed February 22, 2013)

² Mississippi State Department of Health, STD/HIV Office, "2012-2015 Jurisdictional Plan," p. 29. http://msdh.ms.gov/msdhsite/_static/resources/5116.pdf (accessed February 22, 2013).

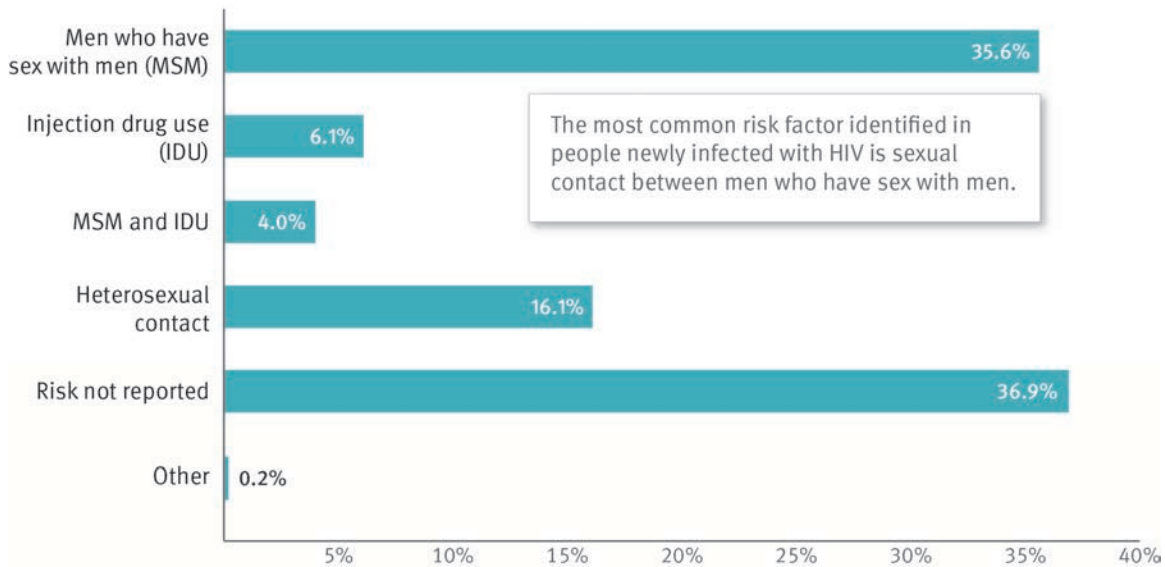
³ US Centers for Disease Control, "HIV Surveillance Report 2010, Table 1a," http://www.cdc.gov/hiv/surveillance/resources/reports/2010report/pdf/2010_HIV_Surveillance_Report_vol_22.pdf#Page=17 (accessed January 27, 2013.); Kaiser State Health Facts, "Estimated Rates(per 100,000) of AIDS Diagnosis, All Ages, 2010," <http://www.statehealthfacts.org/comparemactable.jsp?ind=513&cat=11&sub=120&yr=138&typ=1&sort=a&rgnhl=26> (accessed January 27, 2013).

⁴ Kaiser State Health Facts, HIV, Mississippi, <http://www.statehealthfacts.org/comparecat.jsp?cat=11&rgn=26&rgn=1> (accessed November 2, 2012).

HIV CASES IN MISSISSIPPI, 2011



PEOPLE LIVING WITH HIV IN MISSISSIPPI: EXPOSURE CATEGORIES



Source: Mississippi State Department of Health STD/HIV Office, HIV Disease 2011 Fact Sheet Mississippi

STATE RESPONSE TO HIV IN MISSISSIPPI: AN UPDATE

Progress Since 2011

Mississippi has made progress in several key areas since 2011.

The state has increased funding for HIV care and services, and is working to improve respect for confidentiality and awareness of human rights among its disease intervention specialists, state public health workers who often are the first points of contact with newly infected individuals. Sex education has improved, with nearly half the state's school districts moving from an abstinence-only to an "abstinence-plus" curriculum; a significant number have adopted evidence-based curricula for preventing pregnancy and sexually transmitted diseases. A new program run by the Mississippi Center for Justice has strengthened the availability of legal services for people living with HIV in Mississippi.

Increased State Funding for HIV Programs

Prior to 2012, the state of Mississippi relied almost exclusively on federal funds to provide HIV services and care. For more than a decade, the state provided less than \$1 million a year for HIV programs despite clear evidence, often provided by its own state agencies, that its limited and incomplete federal programs failed to reduce infection rates or meet Mississippians' urgent needs. Moreover, the *Rights at Risk* report described how the state failed to maximize the federal benefits it could receive for housing, medical care, and support services vital for people living with HIV.⁵

In 2012, Mississippi's percentage of national HIV cases for the first time reached 1 percent, triggering federal guidelines that require states to provide matching funds to continue core federal funding for HIV services.⁶ Community advocates feared that a substantial matching requirement would force the closure of vital programs. People living with HIV—many for the first time speaking publicly about their own status and challenges—joined the Mississippi

⁵ For example, Mississippi's limited Medicaid contribution failed to take advantage of a very favorable federal matching rate of nearly 3 to 1 for every dollar spent, and in the area of housing the state failed to apply for competitive grants available for people living with HIV.

⁶ US Health Resources and Services Administration, "HIV Programs," Ryan White Part B, Grants to States and Territories," <http://hab.hrsa.gov/about/hab/partbstates.html>, accessed December 20, 2012.

State Department of Health to successfully advocate for the legislature to appropriate \$2.5 million in matching funds. This was a significant victory, marking the first time in three decades of the epidemic that Mississippi had provided more than \$1 million dollars annually to address HIV.⁷

The legislature will be considering an even larger request for HIV services from the MSDH for fiscal year 2013-14. Dr. Mary Carrier, chief public health officer for the state of Mississippi, has submitted a budget request for \$3.5 million for HIV care and services, plus \$366,000 designated for treatment of sexually transmitted diseases other than HIV.⁸ Approval of this funding request by the legislature is essential to maintain the federal funding of HIV treatment at its current level, and to maintain current STD testing services at public health clinics. In Mississippi, gonorrhea, chlamydia and syphilis rates are among the highest in the nation, and these diseases increase one's risk of acquiring HIV.⁹ The state's request for funding to ensure adequate treatment for these conditions should be approved without delay.

In 2012, the Mississippi legislature appropriated \$2.5 million in state funds for HIV services, the first time in the history of three decades of the epidemic that Mississippi provided more than \$1 million annually for HIV.

In 2012, Mississippi secured significant funding from a new federal initiative designed to address severe health disparities, high morbidity, and social determinants of health such as poverty, unstable housing, and lack of health insurance that combine to increase HIV risk among racial and ethnic minorities.

Mississippi will receive \$3.5 million over the next three years from the US Department of Health and Human Services, which it plans to use to increase HIV testing, improve linkage of the newly tested to treatment, and help people to stay in care and stick to medication regimens by providing peer support and case management to assist with barriers that people are encountering such as transportation and other issues.

⁷ AIDS has been reportable in Mississippi since 1983 and HIV since 1988. Mississippi State Department of Health, STD/HIV Office, "State of Mississippi 2010 STD/HIV Epidemiologic Profile," p. 4, http://msdh.ms.gov/msdhsite/_static/resources/3591.pdf (accessed February 21, 2013).

⁸ Human Rights Watch telephone interview with Joy Sennett, Director of the Office of Communicable Diseases, Mississippi State Department of Health, November 15, 2012.

⁹ Mississippi State Department of Health, "Mississippi STD Facts 2011."

Mississippi's proposal for this funding called attention to the social, economic and racial dimensions of the state's HIV epidemic, acknowledged the need for greater community-based and peer participation in state response, and planned improved coordination between HIV and other social service providers in order to leverage as many resources as possible.

The state's proposal also acknowledged external critiques and recommendations for improved response, including those made in the Human Rights Watch report.¹⁰ Mississippi's prompt and successful application for this funding is an example of the proactive approach to maximizing federal dollars for HIV taken by the new leadership in the state STD/HIV Office of the Department of Health.

The STD/HIV Office plans additional structural changes that should improve delivery of health care services to people living with HIV.¹¹ These include building the capacity of HIV case managers to perform and coordinate medical management for clients, assisting with scheduling medical and support service appointments, and helping with transportation problems in order to improve clients' ability to stay in care and adhere to medication regimens.

The STD/HIV Office also plans to use the new federal funds for a peer counseling program, an innovative model that employs HIV-positive persons to help others stay in care and adhere to medication.¹²

Improved Training for Disease Intervention Specialists

In Mississippi, one third of people with HIV do not receive regular medical treatment.¹³ Many face barriers such as transportation, unstable housing, and fear of stigma and discrimination.

¹⁰ Mississippi State Department of Health, "PS12-1210 MAI HIV Prevention Application" on file with Human Rights Watch.

¹¹ See, Mississippi State Department of Health, STD/HIV Office, 2012-2015 Jurisdictional Plan.

¹² Ibid; see e.g., Leeman, J. et al, "Implementation of Antiretroviral Adherence Interventions: a Realist Synthesis of Evidence, *Journal of Advanced Nursing*, 2010 September 66:(9) 1915-30; Jane M. Simoni et al., "An RCT of Peer Support and Pager Messaging to Promote Antiretroviral Therapy Adherence and Clinical Outcomes among Adults Initiating or Modifying Therapy in Seattle, WA, USA," *JAIDS*, 2009, vol. 52, no. 4, pp. 465-473; Amy R. Knowlton et al., "Informal care and reciprocity of support are associated with HAART adherence among men in Baltimore, MD, USA," *AIDS & Behavior*, 2011, vol. 15, no. 7, pp. 1429-1436; Tom Decroo et al., "Are Expert Patients an Untapped Resource for ART Provision in Sub-Saharan Africa?," *AIDS Research and Treatment*, 2012, pp. 1-8; Michael L. Scanlon & Rachel C. Vreeman, "Current strategies for improving access and adherence to antiretroviral therapies in resource-limited settings" *HIV/AIDS - Research and Palliative Care*, 2013, vol. 5, pp. 1-17.

For several years, the actions of the Mississippi State Department of Health posed additional barriers to seeking and continuing medical care. MSDH disease intervention specialists are responsible for conducting interviews with persons infected with HIV, following up with sexual partners, and ensuring that disease data is accurately reported to state and federal health authorities. Human Rights Watch and others found that some DIS workers failed to protect patient confidentiality and were disrespectful of—and sometimes harassed or threatened—those newly diagnosed with HIV.¹⁴

Since DIS workers are often a person’s first point of contact with the public health department after receiving positive HIV test results, they play a critical role in linking newly infected persons to care, and encouraging continued interaction with public health and treatment services. The poor conduct of some workers contributed to Mississippi’s poor record of retaining people in HIV care and services. As Sheila R., a 40-year-old woman living with HIV, told Human Rights Watch in 2011:

They came to my house and banged on the door, told me I would be prosecuted if I didn’t show up for my interview. They scared me to death.¹⁵

Responding to complaints from people living with HIV and their advocates, the MSDH has since taken several steps intended to strengthen anti-discrimination and confidentiality and ethics obligations among all staff, including disease intervention specialists. The department has conducted trainings in confidentiality requirements under the Health Insurance Portability and Accountability Act (HIPAA), developed an internal code of ethics, and provided “sensitivity trainings” intended to improve interaction with people living with HIV and lesbian, gay, bisexual, and transgender persons. State officials have consulted federal civil rights offices for guidance in improving these programs.¹⁶

¹³45 percent of those living with AIDS and 65 percent of those living with HIV are not in treatment. Mississippi State Department of Health, STD/HIV Office 2012-2015 Jurisdictional Plan, p. 44.

¹⁴ Human Rights Watch, *Rights at Risk: State Response to HIV in Mississippi*, March 2011, <http://www.hrw.org/reports/2011/03/09/rights-risk-o>; State Health Access Research Project of Harvard Law School (SHARP), “Mississippi State Report,” 2010.

¹⁵ Human Rights Watch interview with Sheila R., Canton, Mississippi, August 27, 2010.

¹⁶ Human Rights Watch telephone interview with Dr. Nicholas Mosca, director of STD/HIV Office, Mississippi State Department of Health, Jackson, Mississippi October 24, 2012.

Mississippi should continue to ensure compliance with legal and ethical obligations as the role of DIS workers is expanded in coming years. Mississippi's recent successful federal grant application proposes that DIS workers participate in an inter-agency team designed to identify people who are not in HIV treatment and bring them into care.

Medical providers will notify the MSDH of persons who have not undergone viral load or CD4 count¹⁷ testing within six months of their HIV diagnosis. These names will then be provided to a team comprised of case managers, DIS workers, and peer counselors who will be trained to engage them in care. DIS workers will be primarily responsible for “locating and interviewing” individuals who are not in care, as they “have the skills and proficiency to locate partners and contacts of infected individuals through investigative processes, including field visits, to arrange for physical examination, diagnosis and medical treatment as necessary.”¹⁸

Given the history of some DIS workers' problematic interaction with persons with HIV, including a failure to respect confidentiality, this expansion of DIS workers' scope of work raises concerns. The Mississippi State Department of Health states that protocols for this effort will be developed with the assistance of the US Centers for Disease Control and Prevention and the Health Resources Services Administration. MSHD also states that it is important that this program emphasize the need for respect for privacy, confidentiality, and other fundamental human rights, and that content be developed with the participation of people living with HIV.

The official document used by the Mississippi State Department of Health to inform newly infected persons about the public health laws that apply to persons living with HIV posed a significant human rights problem as well. This form erroneously stated as a “requirement” the “necessity of not causing pregnancy or becoming pregnant.”¹⁹ After challenge by the American Civil Liberties Union of Mississippi and others, that form has been revised to eliminate language suggesting that it was illegal for persons with HIV to become pregnant or to father a child.

¹⁷ CD 4 cells or T-lymphocytes in the blood are counted to determine the progression of the HIV virus within the body. See, http://www.aidsinfonet.org/fact_sheets/view/124 (accessed February 16, 2013).

¹⁸ Mississippi State Department of Health, “PS12-1210 MAI HIV Prevention Application”, p. 12.

¹⁹ A copy of the form is included in the appendix of Human Rights Watch, *Rights at Risk: State Response to HIV in Mississippi*, March 2011, <http://www.hrw.org/reports/2011/03/09/rights-risk-o>

Moving Toward Evidence-Based Sex Education in Mississippi

In 2010, Mississippi ranked first nationally in gonorrhea case rates, number two in chlamydia case rates, and number three in rates of primary and secondary syphilis. Most of these cases were in young people 15-24 years old.²⁰

Mississippi leads the nation in teen pregnancy rates with a rate 20 points higher than the national average.²¹ HIV cases among 15-19 year olds have nearly tripled since 2001.²² Yet for decades the state continued to cling to abstinence-based education that its own state department of health deemed “ineffective.”²³ In February 2011, the legislature passed House Bill 999 requiring that all school districts provide some type of sex education, which was a significant step forward. However, the bill limits the curricula that schools can offer to “abstinence” or “abstinence-plus.”²⁴

Mississippi’s “abstinence-plus” curriculum expands the ability to provide information about HIV transmission and contraception, but still requires that abstinence be taught as the “state standard,” prohibits condom demonstrations or availability in schools, and requires that all students who participate in these sessions receive written parental permission. The “abstinence-plus” curriculum must still inform students that “a mutually faithful relationship in the context of marriage is the most healthy option” for avoiding sexually transmitted disease.²⁵ In a state where gay marriage is constitutionally barred, this effectively denies LGBT youth any assurance they have “healthy options” for sexuality.

Still, health education advocates are encouraged by the opportunity for broader discussion, and the state has shown flexibility in implementing “abstinence-plus” curricula.

To date, 74 of 152 school districts in Mississippi have adopted an “abstinence-plus” curriculum. Of these, 35 have implemented curricula that have been approved as “evidence-based” by the US Department of Health and Human Services.²⁶ According to Jamie Bardwell, director of the Women’s Fund of Mississippi and an advocate for comprehensive sex education, the evidence-based curricula allow for greater diversity in gender and sexuality among the students. “Mississippi sex education law is not perfect, but there is progress,” she said.²⁷

²⁰ Mississippi State Department of Health, “Sexually Transmitted Diseases 2011 Fact Sheet.”

²¹ US Centers for Disease Control, “Numbers of Births and Birth Rates for Teenagers Aged 15-19 By State 2007-2010,” http://www.cdc.gov/nchs/data/databriefs/db89_tables.pdf (accessed November 2, 2012); Mississippi teen birth rate is 55 and US is 34.2 per 1000 population, US Centers for Disease Control, “Teen Births,” http://www.cdc.gov/nchs/data/databriefs/db89_tables.pdf (accessed November 2, 2012).

²² Mississippi State Department of Health, STD/HIV Office, 2012-2015 Jurisdictional Plan, p. 10.

²³ State of Mississippi, “2010 STD/HIV Epidemiologic Profile,” p. 9.

²⁴ HB 999, Mississippi State Legislature, signed into law by Governor Haley Barbour March 16, 2011.

²⁵ Ibid.

²⁶ Human Rights Watch email communication with Scott Clements, Director, Healthy Schools Program, Mississippi Department of Education, November 30, 2012; Human Rights Watch telephone interview with Jamie Bardwell, director of Women’s Fund of Mississippi, Jackson, Mississippi January 25, 2013.

²⁷ Human Rights Watch telephone interview with Jamie Bardwell, director of Women’s Fund of Mississippi, Jackson, Mississippi January 25, 2013.

In an effort to improve outreach to newly infected persons, the STD/HIV Office is also preparing two new brochures intended to inform them of their rights and responsibilities as a person living with HIV in a non-threatening and factually accurate manner. Dr. Nicholas Mosca, director of the state's STD/HIV Office, explained the state's new approach: "This is a know-your-rights pamphlet designed for those who are not irresponsible but who just might be scared."²⁸ Mosca is consulting with the Mississippi Center for Justice, Human Rights Watch, and other legal advocates to develop appropriate language.

Human Rights Challenges for People with HIV in Mississippi

Despite these important advances, Mississippi state officials must take action to address unmet needs that continue to exacerbate the HIV epidemic in the state. People living with HIV urgently need adequate housing, and the prison discharge planning system that links HIV-positive prisoners to care has raised concern among advocates that prisoners are not being discharged with adequate plans for re-entry to the community. Most importantly, the Mississippi legislature must authorize Medicaid expansion under the Affordable Care Act in the 2013 session.

Inadequate Housing for People Living with HIV

Adequate housing is a fundamental right, crucial to dignity, survival, and the ability to protect one's health.²⁹ Housing is particularly important for HIV prevention and for the health of people living with HIV. Homeless individuals living with HIV die at a rate five times higher than those who are housed.³⁰ In addition, stable housing supports healthy outcomes for people with HIV as it promotes adherence to medication and increases access to mental health and other support services.³¹

²⁸ Human Rights Watch telephone interview with Dr. Nicholas Mosca, director, STD/HIV Office, Mississippi State Department of Health, Jackson, Mississippi October 24, 2012.

²⁹ Universal Declaration of Human Rights, G.A. Res. 217, UN GAOR, 3d session, pt. 1, article 25 (1), UN Doc. A/810 (1948); International Covenant on Economic, Social and Cultural Rights (ICESCR), adopted December 16, 1966, GA Res. 2200A (XXI), UN GAOR (no. 16) at 49, UN Doc. A/6316 (1966), 99 UNTS 3, entered into force January 3, 1976, signed by the US on October 5, 1977; Committee on Economic, Social and Cultural Rights, General Comment No. 14, Highest Attainable Standard of Health, UN Doc. E/C.12/2000/4, adopted August 11, 2000, para. 21.

³⁰ North American Housing and HIV Research Summit VI, *Evidence into Action: Housing is HIV Prevention and Care*, September 2011; Buchanan, D., et al, "The Health Impact of Supportive Housing for HIV-Positive Patients: A Randomized Controlled Trial," *American Journal of Public Health*, 2009, 99:3 pp. 675-91.

³¹ North American Housing and HIV Research Summit VI, *Evidence into Action*, p6; Aidala, A. et al, "Housing Need, housing assistance and connection to medical care," *AIDS and Behavior*, 2007, 11 (Supp. 2) S101-115.

Nationwide, many people living with HIV face severe housing problems. The US National AIDS Housing Coalition estimates that at least half of people living with HIV in the US face housing instability or experience homelessness.³² Although the federal Housing Opportunities for People Living with AIDS program reaches 60,000 households with housing assistance, 140,000 households are estimated to need it, leaving a substantial gap in this essential service to be filled by the states.³³ This shortfall is exacerbated in southern states by an outdated funding formula that neglects regions in which new infections are rising.³⁴ HOPWA funds are limited and their inadequacy must be understood in the context of the dramatic housing shortage statewide, as one in five Mississippians live below the federal poverty level.³⁵ Low-income housing in Mississippi is a rare commodity and much of what does exist is substandard.³⁶ Housing availability declined drastically in the aftermath of Hurricane Katrina in 2005, and recovery efforts are still slow.³⁷

“Housing is the greatest unmet need among people living with HIV.”

—Mississippi Development Authority (MDA)

Recent studies indicate that 25 percent of people who rent in Mississippi are “extremely low income” (ELI) and that acute housing shortages exist for ELI renters in 70 of Mississippi’s 82 counties.³⁸ According to Kathy Garner, director of AIDS Services Coalition in Hattiesburg, “There is a real shortage of affordable housing for poor folks in Mississippi, and the problem is getting worse, not better. People with HIV are part of a pretty bleak overall picture.”³⁹

³² US National AIDS Housing Coalition, “Breaking the Link Between Homelessness and HIV,” February 2011.

³³ AIDS Housing Opportunity Act (42 USC 12901) as amended by the Housing Community Development Act of 1992, 24 CFR 574; US National AIDS Housing Coalition, “Breaking the Link Between Homelessness and HIV”.

³⁴ US Department of Housing and Urban Development, “HOPWA Funding Allocation”, http://portal.hud.gov/hudportal/HUD?src=/program_offices/comm_planning/aidshousing/programs/formula/ (accessed November 5, 2012); for an analysis of federal funding formulas for HIV in relation to the South, see Southern AIDS Strategy Initiative, Duke Center for Health Policy and Inequalities Research, “HIV Epidemic Reaches Crisis Proportions in the Last Decade,” January 2012.

³⁵ Ibid.

³⁶ Mississippi Development Authority, 2010-2015 Mississippi Consolidated Plan for Housing and Community Development,” May 7, 2010.

³⁷ See, e.g., Mississippi Center for Justice, “Advancing the American Dream: Protecting and Improving the Fair Housing Act on the 5 Year Anniversary of Hurricane Katrina,” Testimony before the US House of Representatives Committee on the Judiciary, July 29, 2010.

³⁸ National Low Income Housing Coalition, State Housing Profile Mississippi, 2012.

³⁹ Human Rights Watch telephone interview with Kathy Garner, executive director, AIDS Services Coalition, Hattiesburg, Mississippi, December 3, 2012.

“There is a real shortage of affordable housing for poor folks in Mississippi, and the problem is getting worse, not better.

People with HIV are part of a pretty bleak overall picture.”

—Kathy Garner,
AIDS Services
Coalition

The state of Mississippi has identified significant shortfalls in short-term, long-term, and emergency housing for the HIV population. The Mississippi Development Authority has declared that “housing is the greatest unmet need among people living with HIV,” and estimated that more than 3,500 people with HIV will have unmet housing needs by 2015.⁴⁰

In Mississippi, however, the state provides no funding for housing services targeted to people living with HIV. All funding for HIV-related housing assistance comes from the federal government, which leaves thousands of people with HIV unstably housed or homeless.⁴¹ HOPWA programs in Mississippi currently serve approximately 1,000 people, and there are approximately 70 beds dedicated to transitional housing for persons with HIV out of a total population of 10,000.⁴²

In Mississippi, HOPWA program funds are issued to the Mississippi Development Authority and administered by the Mississippi State Department of Health. Human Rights Watch and researchers from the State Health Access Research Project (SHARP) at Harvard Law School documented weaknesses in program administration, including poor recordkeeping and reporting and failure to maximize potential federal benefits. In 2010, Mississippi erroneously noted a “zero” need for HIV housing assistance in required reports to the federal government, jeopardizing its ability to receive grant monies under the HOPWA program.⁴³

Mississippi’s program was not designed to take advantage of HOPWA funds for medium or long-term rental assistance, offering only short-term assistance for a 21-week period.

⁴⁰ Mississippi Development Authority, “2010-15 Mississippi Consolidated Plan for Housing and Community Development”, May 2010, p. 90.

⁴¹ State Health Access Research Project of Harvard Law School (SHARP), “Mississippi State Report,” 2010, pp. 62-65; Mississippi Development Authority, “2010-15 Mississippi Consolidated Plan for Housing and Community Development,” May 2010, p. 90.

⁴² Mississippi Development Authority, *Consolidated One Year Action Plan for Housing and Community Development 2012*, p. 9; Email communication with Kathy Garner, executive director, AIDS Service Coalition, Hattiesburg, Mississippi, January 21, 2013.

⁴³ Ibid.

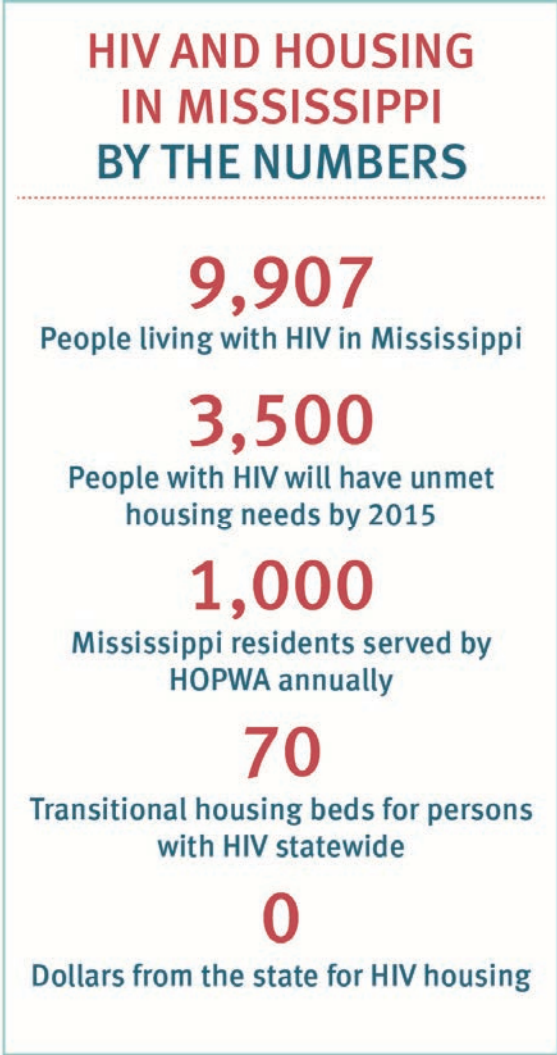
Housing was not well integrated into other essential services for people with HIV, such as drug dependence or mental health programs.⁴⁴

Following the release of the Human Rights Watch and SHARP reports in 2011, the state STD/HIV director requested technical assistance from the US Department of Housing and Urban Development (HUD) to review and evaluate the state's HOPWA program. The state's HOPWA program did not comply with federal regulations in several respects. For example, the state failed to meet the requirement that it offer case management services to HOPWA recipients, a federal mandate intended to ensure both an individual housing plan and coordination with other available HIV support services.⁴⁵ The state was also mixing Ryan White and HOPWA funding in an impermissible manner. In October 2012 the HOPWA program was temporarily suspended due to these violations, resulting in a freeze of all new applications and applications for renewal.⁴⁶

⁴⁴ Human Rights Watch, *Rights at Risk: State Response to HIV in Mississippi*, New York, March 2011, <http://www.hrw.org/reports/2011/03/09/rights-risk-o>; State Health Access Research Project of Harvard Law School (SHARP), "Mississippi State Report," 2010, pp. 62-65.

⁴⁵ 24 CFR 574.310, US Department of Housing and Urban Development, HOPWA regulations.

⁴⁶ Human Rights Watch interview with Dr. Nicholas Mosca, director, State STD/HIV Office, Mississippi State Department of Health, Jackson, MS, October 24, 2012.



Source: Mississippi State Department of Health, “Mississippians Living with HIV Disease in 2011; Mississippi Development Authority, “2010-15 Mississippi Consolidated Plan for Housing and Community Development”; Mississippi Development Authority, *Consolidated One Year Action Plan for Housing and Community Development 2012*

The suspension lasted only a month, and the program accepted new applications as of November 1, 2012. According to Mosca, state STD/HIV director, MSDH is in the process of restructuring the program to improve service and capacity. Specifically, case management services will be improved by supporting community-based organizations to assist clients with applications for the HOPWA program. The 21-week short-term emergency assistance program will be limited to those facing imminent eviction or foreclosure, while other funds will be made available to increase options for medium and long-term assistance. Greater efforts will be made to collaborate with other housing providers for low-income persons in the state such as the state’s three Continuum of Care coalitions that receive HUD funding for homelessness prevention and low to moderate-income housing.⁴⁷ Many of these goals are reflected in the state’s HOPWA plan for 2013 and in the STD/HIV Office “Jurisdictional Plan” for 2012-2015.⁴⁸

⁴⁷ Ibid.

⁴⁸ Mississippi Development Authority, *Consolidated One Year Action Plan for Housing and Community Development 2012*, p. 91; Mississippi State Department of Health, *STD/HIV Office 2012-2015 Jurisdictional Plan*, p. 70.

Unfortunately, the program’s suspension and the shifts in eligibility have occurred with inadequate communication with the community—a lack of transparency that has caused stress and anxiety for people living with HIV. During the period of suspension, rumors circulated that the HOPWA program had been terminated, and since it resumed operation, Human Rights Watch has received reports of people being told by state social workers and MSDH simply that “unless you are being evicted you cannot apply for HOPWA” without any further explanation, referrals or assistance.⁴⁹ Key stakeholders including organizations now providing housing for people living with AIDS have not been informed of the plans for restructuring HOPWA.⁵⁰

Acute housing shortages exist for “extremely low income” renters in 70 of Mississippi’s 82 counties.

Clearly, MSDH must improve administration of the HOPWA program. However, improving access to affordable housing for people living with HIV in Mississippi will not be an easy task without additional state funds. As a matter of public health and human rights, Mississippi should supplement HOPWA funding. Indeed, the state should provide increased funding for low income housing in general. All people, including those living with HIV, have the right to basic shelter that is essential for their health and, indeed, their survival. In 2012, HIV and housing advocates in Mississippi urged the legislature to approve their proposal for an inter-agency Council on Homelessness, a low-cost measure that would improve coordination and planning for housing services provided by the state to low and moderate-income people including persons with HIV. This effort was unsuccessful, but should be reconsidered and passed by the legislature in 2013.⁵¹

⁴⁹ Human Rights Watch telephone interview with Richard W., Indianola, Mississippi, February 7, 2013; Human Rights Watch email communication with Kathy Garner, AIDS Services Coalition, Hattiesburg, Mississippi. February 8, 2013.

⁵⁰ Human Rights Watch email communication with Kathy Garner, executive director, AIDS Services Coalition, Hattiesburg, Mississippi. February 8, 2013.

⁵¹ House Bill 153 died in Committee in the 2012 legislative session.

Mississippi Center for Justice: Providing Legal Services for People with HIV

In September 2011, Marni von Wilpert joined the Mississippi Center for Justice (MCJ) on a two year grant from the Skadden Fellowship Foundation. Marni's mission is to support the center's Health Law Division by providing legal services to people living with, or families affected by, HIV.

Marni focuses on issues related to employment discrimination, housing discrimination, access to health care, confidentiality, and privacy. She has represented individual clients, but finding them has proved to be more difficult than she expected. Marni explained:

I thought when I started this HIV legal representation project that there would be a line outside of people wanting to press their cases. But I realized that most people living with HIV, as well as medical providers and social workers, had no idea that the problems they were encountering were legal issues or that legal remedies were available. So much of my first year has been focused on education on legal rights.⁵²

The MCJ has published "know your rights" pamphlets that address the rights of persons with HIV in housing, employment, and confidentiality. Marni and Linda Rigsby, director of the health law project at MCJ, have met with professional health associations in Mississippi to provide information concerning their legal obligations toward persons with HIV.

Despite these advances, Marni remains shocked at the degree of stigma that prevents people with HIV in Mississippi from seeking medical or legal assistance:

In the Delta, the stigma is so terrible. Recently, I was working with a young man who knew he had HIV but would not start taking any medication. He was afraid his family would find out he had the disease. He died without ever starting the drugs that could have saved his life.⁵³

⁵² Human Rights Watch interview with Marni von Wilpert, Staff Attorney, Mississippi Center for Justice, Indianola, Mississippi, November 27, 2012.

⁵³ Ibid.

Inadequate Discharge Planning for HIV-Positive Prisoners

For more than two decades, the Mississippi Department of Corrections segregated HIV-positive prisoners in a separate housing unit at the Mississippi State Penitentiary (MSP) at Parchman.⁵⁴ In May 2010, the Mississippi Department of Corrections terminated this segregation policy, a significant advance in human rights resulting in part from advocacy by Human Rights Watch and the American Civil Liberties Union.⁵⁵

During the period of segregation, all health care and discharge planning services for the HIV-positive prisoners took place at the Parchman facility. With desegregation, some prisoners with HIV remained at Parchman while others were reassigned. As of October 2012, the population of 224 prisoners with HIV was housed as follows: 63 male HIV-positive prisoners at MSP, 64 males and 28 females at the Central Mississippi Correctional Facility (CMCF) at Pearl, Mississippi, and 69 males at the South Mississippi Correctional Institution at Leakesville, Mississippi. Each month, 1 to 3 prisoners with HIV are released from each of these three facilities.⁵⁶

Prior to desegregation, the discharge planning program at MSP contained the three most important elements of an effective re-entry system: early identification of prisoners about to be released, provision of adequate medications for transition to outside health care, and contact with a health clinic in order to arrange an appointment and transfer relevant medical records. These operations, consistent with national correctional health standards in the United States, are critical to ensuring there are no gaps in adherence to antiretroviral (ARV) medications, as interruption or inconsistency in ARV doses can result in poor health outcomes and development of resistance to the drugs in an individual's regimen.⁵⁷

Norma Evans is the site manager for Wexford Health Services, a private company that provides health care at MSP. According to Evans, prior to 2011, prisoners were identified six

⁵⁴ Human Rights Watch and ACLU, *Sentenced to Stigma: Segregation of HIV-Positive Prisoners in Alabama and South Carolina*, April 2010, <http://www.hrw.org/reports/2010/04/14/sentenced-stigma-0>

⁵⁵ Ibid.

⁵⁶ Human Rights Watch interview with Norma Evans, Site Manager, Wexford Health Services, Mississippi State Penitentiary, Parchman, Mississippi, November 27, 2012.

⁵⁷ See, e.g. National Commission on Correctional Health Care, "Administrative Management of HIV in Correctional Institutions," 2005; National Commission on Correctional Health Care, "The Health Status of Soon-To-Be- Released Inmates," Testimony to Congress, March 2002; Nunn, A, et al, "Linking HIV-positive jail inmates to treatment, care and social services after release," *Journal of Urban Health*, 2010 December 87(6): 954-68; Arriola, KRJ, et al, "Development and implementation of the cross-site evaluation of the CDC/HRSA corrections demonstration project", *AIDS Educ Prev.* 2002;14(3 Suppl A):107-118.

weeks prior to their release date and plans were made to discharge the prisoner with 30 days of medication and an appointment with the HIV clinic nearest their home. Often medical staff from the clinic near Parchman would come to the prison to meet the prisoner before he was released and discuss his condition and review his medical records. This procedure was confirmed by Kawanis Collins, an HIV program coordinator at the Magnolia Health Clinic near Parchman, who would regularly go to the prison to meet the person to be released. According to Collins, “In 2011, the Parchman program was running well and I was able to coordinate the care that the prisoners needed when they returned to our community.”⁵⁸

Since desegregation, however, the discharge planning process has not functioned as smoothly, particularly at Pearl and Leakesville. Mauda Monger, coordinator at the Delta Region AIDS Education Training Center at the University of Mississippi Medical Center, conducted trainings in discharge planning at all three prisons in the fall of 2012. According to Monger, MSP’s program is relatively stable because “they have been doing it so long, and they do not have much staff turnover at that site.”⁵⁹ Monger also found that when CMCF was only housing women, their discharge program was functioning fairly well. However, since men have been fully integrated into the system there, she now expressed concern about the discharge planning at Pearl.

At Pearl, since the men came in, it really is a disaster. They have high staff turnover, no one person designated to be the contact person with the clinics, and not a lot of motivation for the program. The process is a bit better at Leakesville and I have hope that it will continue to improve there, but at Pearl I am not so sure.⁶⁰

Discharge planning is essential to ensure that a prisoner’s treatment plan continues without disruption that can endanger the prisoner’s health and increase the chances of HIV transmission to sexual partners. Three releases a month from, at most, three prisons is a relatively small and manageable volume for prison health services.⁶¹ The Department of

⁵⁸ Human Rights Watch telephone interview with Kawanis Collins, program coordinator, Ryan White Part C Program, Magnolia, Mississippi, October 15, 2012.

⁵⁹ Human Rights Watch interview with Mauda Monger, local performance site coordinator/director, AIDS Education Training Center, University of Mississippi Medical Center, Jackson, Mississippi, November 29, 2012.

⁶⁰ Ibid.

⁶¹ North Carolina, for example, releases an average of 350 HIV-positive prisoners per year. For an examination of the efficacy of their HIV discharge planning programs, see, Wohl, D. et al, “Intensive Case Management Before and After Prison Release is

Health STD/HIV Office has made the “reinstatement of discharge planning” from the prisons a priority for 2012-2015. Human Rights Watch will continue to monitor the issue.⁶²

The Need for Medicaid Expansion under the Affordable Care Act

Mississippi has a key opportunity to expand HIV services by taking advantage of new Medicaid provisions under the Affordable Care Act. Medicaid is a joint state and federal program that provides coverage for medical care to certain low-income individuals (such as children, pregnant women, and individuals with disabilities).⁶³

In Mississippi and throughout the United States, the Medicaid program is a lifeline for many low-income people living with HIV. In Mississippi as well as nationally, nearly half of those living with HIV who are receiving regular medical care are on Medicaid.⁶⁴ Medicaid provides payment to doctors, hospitals, and pharmacies for the essential services and medications needed by people living with HIV.

However, Mississippi’s Medicaid program is currently limited to adults with children or adults who are aged or disabled, leaving many HIV-positive people without Medicaid coverage. States are also allowed to set eligibility limits and Mississippi’s are among the lowest in the nation, leaving many HIV-positive people living in poverty without Medicaid coverage.⁶⁵ The Affordable Care Act gives states the opportunity to expand their Medicaid programs with the federal government absorbing much of the expense, an opportunity Mississippi cannot afford to decline.

In Mississippi and nationally, nearly half of those living with HIV who are receiving regular medical care are on Medicaid.

No More Effective Than Comprehensive Pre-Release Discharge Planning in Linking HIV-Infected Prisoners To Care, “*AIDS Behavior*, 2011 February, 15 (2) 356-64.

⁶² Mississippi State Department of Health, STD/HIV Office 2012-2015 Jurisdictional Plan, p. 72.

⁶³ Centers for Medicare and Medicaid Services, “What is Medicaid?” <http://www.medicaid.gov/index.html>, accessed January 22, 2013.

⁶⁴ Kaiser Foundation, Medicaid and HIV: A National Analysis, October 2011; MSDH, Medical Monitoring Project, Mississippi 2010 MMP Fact Sheet, released April 6, 2012.

⁶⁵ In Mississippi a jobless family of four can have an income of only 24 percent of the federal poverty level, and a working family of four can have an income of 44 percent of the poverty level, ranking Mississippi 10th lowest in eligibility levels in the US. Kaiser Family Foundation, State Health Facts, “Medicaid Income Eligibility Limits as a Percent of Federal Poverty Level, 2012.” The current federal poverty guideline is \$11,170 per year for an individual and \$23,050 for a family of four, US Department of Health and Human Services, “2012 HHS Poverty Guidelines.”

Mississippi has a key opportunity to expand HIV services by taking advantage of new provisions under the Affordable Care Act.

People with qualifying incomes will be eligible whether or not they have children or are disabled. States that do so will receive federal funds to cover most of the cost of this expansion until the year 2020. Specifically, the federal government will pay 100 percent of the expansion costs from 2014-16 and 90 percent of the costs until the year 2020 and thereafter.⁶⁸

In passing the Affordable Care Act of 2010, Congress modified the nation’s system for health care and health care insurance coverage.⁶⁶ The June 2012 decision by the Supreme Court upheld most of the ACA but left the issue of Medicaid expansion for the states to decide.⁶⁷ Under the formula established by the ACA, states may choose to expand Medicaid eligibility in 2014 to most persons with incomes 133 percent of the federal poverty level (about

Federal Payment for State Medicaid Expansion, by Year

2014-2016	100%
2017	95%
2018	94%
2019	93%
2020-	90%

A 2012 study by the Mississippi Institutions of Higher Learning University Research Center projects that approximately 311,000 adults will be newly enrolled in the program between 2014 and 2019 if Mississippi expands its Medicaid program under the Affordable Care Act.⁶⁹

These include the creation of more than 9,000 new jobs and the tax revenue that this will generate. The center’s report found that the “economic activity generated by new federal Medicaid dollars” could result in additional cost savings to state agencies such as the Department of Mental Health and Department of Health and increased revenues to

This expansion will cost the state a net amount of \$109 million by 2020, a number that takes into consideration not only additional costs but new revenues that will be seen by the state as a result of the expansion of the

⁶⁶ Patient Protection and Affordable Care Act, signed into law March 23, 2010 (Public Law No. 111-148); Health Care and Education Reconciliation Act, signed into law March 30, 2010 (Public Law 111-152).

⁶⁷ National Federation of Independent Business v. Sibelius, 567 U.S. ___ 2012.

⁶⁸ Title II, Subtitle (A), section 2001 of the Affordable Care Act

⁶⁹ Bob Neal, Mississippi Institutions of Higher Learning, “The Fiscal and Economic Impacts of Medicaid Expansion in Mississippi 2014-2025,” October 2012.

state agencies such as the Department of Transportation, Department of Agriculture, and Department of Environmental Quality.⁷⁰

In contrast, Mississippi's failure to expand Medicaid will come at a high price. The state will lose money that now goes to reimburse hospitals for uncompensated care, as the federal dollars that support these expenses will be gradually decreasing over time as the ACA is implemented, on the assumption that more people will have insurance coverage. The center's report states that this loss of an estimated \$261 million between 2014 and 2020 could put Mississippi's hospitals in a very difficult situation, forcing them to "increase prices, reduce services, or both."⁷¹ On the other hand, if Medicaid is expanded, the state will realize \$230 million in net savings on uncompensated care in the first five years.⁷²

Medicaid expansion will generate new tax revenue and an estimated 9,000 new jobs.

The center concludes that although there are challenges to paying for it in the short run, in the long term, a healthier workforce should result in a more productive workforce, leading to a healthier, more robust economy. In the long run (30 to 40 years) the benefits of increased access to health care might outweigh the costs.⁷³

The legislature is set to consider this important question in the 2013 session, and state lawmakers should act to expand Medicaid under the ACA. Indeed, with some of the highest HIV infection and AIDS death rates in the nation, Mississippi cannot afford to refuse this opportunity.

Medicaid's new program will cover people living with HIV *before* they become disabled from the disease, reducing their medical costs and permitting them to continue working and contributing to Mississippi's productivity and tax revenue. In addition, the evidence indicates that HIV-positive people who can reduce their viral loads to undetectable levels

⁷⁰ Ibid.

⁷¹ Ibid, p. 31.

⁷² Treatment Access Expansion Project, Harvard Law School, "Mississippi Medicaid Expansion Fact Sheet." In Mississippi as well as nationally, nearly half of those living with HIV who are receiving regular medical care are on Medicaid.

⁷³ Bob Neal, Mississippi Institutions of Higher Learning, "The Fiscal and Economic Impacts of Medicaid Expansion in Mississippi 2014-2025," October 2012, p. 21.

through medication are significantly less likely to transmit the virus to others.⁷⁴ “Treatment as prevention” is a major focus of global and domestic public health authorities such as the US Centers for Disease Control and Prevention.⁷⁵ But treatment as prevention only works if people with HIV are treated early and can continue to access medical and support services.

The Mississippi Center for Justice’s Health Law Project seeks to educate young people about the importance of health care reforms under the Affordable Care Act. “Building support for health care reform from the ground up can urge our legislators to expand Medicaid,” explained Meigan Thompson, community organizer at MCJ. Thompson told Human Rights Watch that she talks with young adults every day who need health insurance but have no understanding of what it costs or how it might be accessed. Many were covered by Medicaid until age 18 but now cannot afford private insurance. They remain without coverage for serious conditions such as asthma and sickle cell disease: “I explain to them that if Mississippi expands Medicaid as it has the option to do, the Affordable Care Act will provide coverage for them even with those medical conditions.”⁷⁶

Advocates for Medicaid expansion in Mississippi note that the opportunity for Medicaid expansion corresponds with and complements the Mississippi Economic Council’s recent designation of health care as a primary “economic driver” for the state economy. Plans for significantly expanding Mississippi’s health care sector were announced in a report released in January 2012 and endorsed by Governor Phil Bryant.⁷⁷ Governor Bryant opposes Medicaid expansion and the report makes no mention of the Affordable Care Act.

This is true despite the fact that the act will promote and provide significant funding for many of the goals outlined in the report, including addressing physician shortages in rural areas, creating jobs in the health care industry and reducing loss of productivity due to employee illness. As Ed Sivak, director of the Mississippi Economic Policy Center, said:

⁷⁴ Myron S. Cohen et al. “Prevention of HIV-1 Infection with Early Antiretroviral Therapy,” *New England Journal of Medicine*, vol. 365, pp. 493–505.

⁷⁵ US Centers for Disease Control, “Issue Brief: Prevention Benefits of HIV Treatment,” January 10, 2013, <http://www.cdc.gov/hiv/topics/treatment/resources/factsheets/tap.htm> (accessed January 26, 2013).

⁷⁶ Human Rights Watch interview with Meigan Thompson, community organizer, Mississippi Center for Justice, Indianola, Mississippi, November 27, 2012.

⁷⁷ Mississippi Economic Council, *Blueprint Mississippi 2012*, January 2012.

“We think there is no quicker way to realizing the goals of that report than expanding Medicaid.”⁷⁸

The Mississippi legislature should act quickly to expand Medicaid under the Affordable Care Act, for the health of its residents and the state’s economy.

⁷⁸ Human Rights Watch email communication with Ed Sivak, director, Mississippi Economic Policy Center, December 20, 2012.

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(front cover) Mississippi state sign near
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