

The Point: SHARP News

The current economic crisis is affecting health care consumers and providers across the nation. States are trimming budgets at the same time that unemployment and the need for safety net services are going up. Deepening state budget crises are impacting AIDS Drug Assistance Programs (ADAPs) and funding for testing, prevention, and services. As these problems continued to develop at the state level, Congress passed national healthcare reform legislation that will help expand access to care in both the near- and long-term.

Against this backdrop, State Healthcare Access Research Project (SHARP) researchers and community partners held community focus group meetings, advocacy planning and training meetings, and legislative events in the first three months of 2010. We thank everyone who has participated in and helped organize and facilitate SHARP meetings, responded to emails and phone calls, and provided information on access to healthcare and support services for people living with HIV/AIDS in Alabama, Arkansas, Illinois, Los Angeles County, Louisiana, Mississippi, North Carolina, and South Carolina. What follows is a summary of developments and SHARP activities in the current SHARP states.

Find us online! *SHARP state reports and executive summaries, as well as this newsletter, are posted on the Treatment Access Expansion project website as they become available. View and download the reports and summaries at http://www.taepusa.org/SHARP_library.html.*

SHARP State Updates

Alabama

Community partners, supporters, and media representatives attended a reception on January 14th in Birmingham to launch the SHARP Alabama report. Kathie Hiers from AIDS Alabama and Amy Rosenberg from SHARP spoke of the work already accomplished in completing the report, and of using the report as a framework for ongoing advocacy efforts. Alabama state representative Patricia Todd capped off the celebration with an announcement of breaking news—Governor Bob Riley, after always zeroing out HIV funding in the state budget in years past, had requested \$7.7 million for HIV/AIDS programs this year.

As part of the implementation phase of Alabama SHARP, SHARP director Robert Greenwald and researcher Amy Rosenberg met with members of the AIDS Service Organization Network of Alabama (ASONA) in Mobile on February 11 to discuss next steps for healthcare access advocacy. Members shared information about past advocacy and program successes and began to prioritize which SHARP recommendations to focus on in the coming months.

More than 150 HIV/AIDS advocates from around the state converged on the state capitol in Montgomery for AIDS Media (Advocacy) Day on February 24th. Advocates distributed the SHARP report and executive summary to state legislators; many legislators also participated in the program. Advocates educated legislators about the importance of HIV education, prevention, testing, care and service programs, and urged greater state commitment and resources to fight HIV/AIDS. As of press time, the state budget still contained an HIV line item, including a \$5 million increase for ADAP.



The State Healthcare Access Research Project (SHARP) is conducted by Harvard Law School and the Treatment Access Expansion Project in collaboration with Bristol-Myers Squibb's BMS) WithInSight Initiative. BMS has no review or editorial discretion as to content.

Arkansas

Little Rock was the site for the 4th Regional HIV/AIDS Conference from March 3rd–5th, entitled “Taking Action Together: A New Era in HIV Care.” Organized by Michelle Smith and the team at Jefferson Comprehensive Care System, Inc. (JCCSI), the conference drew hundreds of participants from Arkansas, Louisiana, Mississippi, and Tennessee. Arkansas governor Mike Beebe welcomed conference attendees; SHARP’s own Robert Greenwald gave the dinner keynote address, updating participants on health care reform and federal efforts to improve access to care for people living with HIV/AIDS. Amy Rosenberg facilitated a lively “Consumer Speak Out” session and also presented with Patrick Packer, Executive Director of the Southern AIDS Coalition, on “Successes, Challenges, and Opportunities for Healthcare Access in the South.”

Just prior to the Regional Conference, and again on March 18th, Arkansas community partners met with Amy Rosenberg to finalize the SHARP report and plan for its release. We have been invited by the Joint Public Health Committee of the Arkansas General Assembly to present on the SHARP report at the Committee’s session on April 20th. Coming together under a new name—Arkansas HIV Community Advocates (AHCA)—the coalition decided on speakers and topics for the presentation to legislators, as well as planning a press conference following the legislative event to release the SHARP report publicly. AHCA is a broad-based coalition, including consumers, community-based healthcare and services providers, government officials, industry representatives, faith leaders, and academics—all dedicated to improving access to care and services and to seeking a greater commitment from the state for HIV programs (currently Arkansas provides no state funding for HIV care).

In some good news, careful and active management of the ADAP program by the Arkansas Department of Health (ADH) has meant that the income eligibility level for the program has returned to 200% of the federal poverty level (FPL), from 150% FPL (though still below the 500% FPL eligibility level from early 2009), and that individuals on the ADAP waitlist have been able to be enrolled in the program. As of April 1, there was no one on Arkansas’s ADAP waitlist.

On April 20th, AHCA held a press conference in the rotunda of the state Capitol building. Speakers included those living with HIV/AIDS, representatives from the Arkansas HIV/AIDS Minority Task Force, the Minority Health Commission, the Department of Health, and Rep. Gene Shelby, the vice chair of the General Assembly’s Joint Committee on Public Health. Following the press conference, AHCA presented the SHARP report findings and recommendations to members of the Joint Committee on Public Health, and responded to legislators’ questions. Legislators indicated their desire for more information on improving healthcare access, and AHCA and the SHARP team are currently following up on several of their questions and requests.

Illinois

Advocates in Illinois hosted an advocacy training meeting, legislative breakfast, and advocacy day in Springfield on February 23rd and 24th. The Illinois Alliance for a Sound AIDS Policy (IL ASAP) trained advocates from around Illinois on state budget issues, SHARP report recommendations, and how to speak effectively to elected officials. As part of the advocacy training, Amy Rosenberg briefed the ASAP attendees on the Illinois SHARP report, and then presented the report’s key findings and recommendations the following morning to state legislators and other government officials. Following the well-attended legislative breakfast, ASAP advocates headed to the Capitol to educate their representatives about some of the opportunities to improve healthcare access identified in the SHARP report.

One of the opportunities discussed in the Illinois SHARP report is to expand the funding sources for the state’s successful HIV case management model. Currently, the system relies solely on Ryan White funding; advocates want to explore Medicaid reimbursement for case management. As part of this, Illinois partners are drawing on the experience of other SHARP states that have Medicaid-funded targeted case management, such as Alabama and Arkansas. Obtaining Medicaid reimbursement for case

management for eligible clients would free up some Ryan White funds to help more people access services.

Los Angeles County

After preliminary meetings in late 2009, SHARP staff member Amy Rosenberg and Harvard Law students Dan Fields and Matt Siegler met with SHARP community partners in Los Angeles on March 25th and 26th. The SHARP LA County report is focusing specifically on healthcare access issues for Latinos. Amy, Dan, and Matt met with client services and treatment education staff at AIDS Project Los Angeles and Bienestar, as well as meeting with the LA County AIDS Director, Mario Pérez, and the Office of AIDS Policy and Programs medical director, Dr. Jennifer Sayles, to get their perspectives on barriers to accessing care faced by the County's Latino population. A SHARP team will be returning to Los Angeles on April 15th and 16th to hold discussion groups with people living with HIV, including groups for Latina women, transgender individuals, and gay men. The SHARP team is also working on setting up meetings with healthcare providers, staff from Medi-Cal, and state legislators representing LA County.

Louisiana

At the January 21st meeting of the Louisiana Commission on HIV/AIDS and Hepatitis-C, ASOs in Louisiana heard that further cuts were expected in the state budget for the Office of Public Health and the HIV/AIDS program, and that the ADAP faced a budget shortfall of millions of dollars. These budget problems and other challenges and opportunities for access to healthcare and services were top issues for discussion at SHARP focus group meetings in January, February, and March with providers, consumers, and agency representatives in New Orleans, Shreveport, Baton Rouge, and Lafayette. SHARP researcher Dorothee Alsentzer and Harvard Law students Rebecca Harlow and Maggie Francis note that providers and consumers around the state have identified common themes, including among others, barriers to care in (and after release from) parish jails, housing and transportation, Medicaid case management reimbursement rates, and inadequate sex education curricula.

Senator Mary Landrieu helped the state avoid an even bigger fiscal crisis by introducing and successfully defending the inclusion of a provision to maintain the federal matching percentage for Louisiana's Medicaid program. The much-maligned "Louisiana Purchase" contained in the federal healthcare reform legislation in fact means that Louisiana's FMAP will *not* drop from 72 to 63 percent as scheduled in 2010. The continued level of federal funding will help the state maintain Medicaid services. This provision will also help other states affected by natural disaster in the future.

On March 30th SHARP community partners meeting in Lafayette, consumers, providers, and advocates actively participated in legislative strategy development and advocacy training facilitated by David Munar and Jessica Terlikowski of the AIDS Foundation of Chicago. The meeting, which also served as a Louisiana AIDS Advocacy Network (LAAN) town hall event, culminated in the decision to push the Louisiana Legislature to adopt a resolution in support of Congressional authorization of \$126 million in emergency federal supplemental ADAP funds for FY 2010. LAAN held an HIV/AIDS Legislative Awareness Day in Baton Rouge on May 3rd to raise awareness around that request and educate lawmakers about the impact of recent budget cuts on HIV/AIDS services across the state.

Mississippi

SHARP team member Imbi Ichile has been researching the state profile section of the Mississippi SHARP report, assembling epidemiological data, demographic and economic information, and information about Mississippi's different healthcare programs. SHARP staff met with community partner Robin Webb of A Brave New Day at the recent Regional HIV/AIDS Conference in Little Rock to discuss ideas for conducting SHARP in Mississippi, and plan to visit the state later this spring.

North Carolina

In late January, North Carolina's ADAP program announced that it would close to new enrollees (with the exception of pregnant women), begin a waiting list effective immediately, and make significant

cuts to the ADAP formulary (elimination of all medications except antiretrovirals). This followed a period of unprecedented growth in demand for ADAP services. Community advocates from the statewide North Carolina AIDS Action Network (NCAAN) began working immediately on the state, federal, and private industry levels to find resources to address the shortfall in ADAP funding. On February 25th and 26th, SHARP director Robert Greenwald, SHARP researcher Amy Rosenberg, and Harvard Law students Jee Lee and Colleen Kelly held meetings with 80+ community partners in Raleigh and Charlotte to facilitate discussion and strategic planning to respond to the ADAP crisis. Also attending were key North Carolina Division of Public Health staff, including the head of the Communicable Disease Branch Evelyn Foust, AIDS Director Jacquelyn Clymore, and ADAP Director Sally Kohls. Jacquelyn Clymore presented an ADAP update at both the Raleigh and Charlotte meetings, with information about how the crisis happened, efforts to address it, and resources needed to operate ADAP for the rest of this state fiscal year and next.

In response to advocacy efforts, North Carolina Secretary of Health and Human Services Lanier Cansler released \$7 million in funding to support ADAP through March. NCAAN continues to work closely with Health Department staff and to advocate intensively for resources needed for ADAP and other HIV programs. NCAAN has developed many advocacy materials, including fact sheets, sample letters to the editor, and a postcard campaign. NCAAN has weekly advocacy conference calls and maintains an active listserv.

ADAP Alert! *Several SHARP states are facing growing ADAP crises. The following resources are available to help state advocates stay abreast of recent developments and link to supporting materials for ADAP campaigns:*

- ✓ *AIDS Connect: find several states' ADAP advocacy documents in one centralized location at <http://aidsconnect.net/content/blog/state-crisis-adap-advocacy-across-country>*
- ✓ *NASTAD ADAP Alert: up-to-date information on the number of individuals on ADAP waiting lists as well as programs with cost containment measures. Available at http://nastad.org/InFocus/InfocusResultsDetails.aspx?infocus_id=319*

South Carolina

As South Carolina's 2010 legislative session opened, the budget contained zero dollars for the state's ADAP program. As a result, there is now a waiting list for South Carolina's ADAP. As of March 26th, 13 people were on the waiting list. In conjunction with the SC HIV/AIDS Care Crisis Task Force, state advocates are launching a campaign to protect ADAP and prevent further funding cuts at the state level. The Task Force organized a letter-writing campaign and a rally at the State House in March to protest the cuts. At the same time, SHARP researcher Dorothée Alsentzer and Harvard Law students Peter Chang and Colleen Kelly held focus group meetings and one-on-one interviews with providers, consumers, and agency representatives in Spartanburg, Greenville, Greenwood, Columbia, Charleston, North Charleston, and Ridgewood to draw into focus the successes, challenges, and opportunities for access to care and services in South Carolina. SHARP community partners have identified stigma, transportation, housing, MH/SA services, inadequate sex education curricula, and incarceration-related issues as some of the major challenges facing people living with HIV/AIDS in the Palmetto State.

SHARP Community Partners Awarded NAF Southern REACH Grants

The National AIDS Fund announced its Southern REACH grantees in February. Congratulations to SHARP community partners who were awarded grants to build capacity and implement HIV/AIDS advocacy efforts!

- **Alabama:** AIDS Alabama, Birmingham
- **Arkansas:** Brothas & Sistas, Little Rock
- **Louisiana:** NO/AIDS Task Force, New Orleans
- **Mississippi:** A Brave New Day, Pearl
- **North Carolina:** Alliance of AIDS Services-Carolina, Raleigh
- **South Carolina:** South Carolina HIV/AIDS Council, Columbia
- **Regional:** Southern AIDS Coalition, Birmingham

Policy Advocacy Trainings Available

SHARP is very pleased to offer our community partners policy advocacy trainings from the experts at AIDS Foundation of Chicago (AFC). Trainings cover the areas of general advocacy (“Advocacy 101”), operations, communications, political strategy, and grassroots mobilization, and can be tailored to your particular needs and time requirements. See the complete list of training topics at the TAEP website (www.taepusa.org). For more information, contact Dorothee Alsentzer (617.390.2556, dalsentzer@law.harvard.edu) or Amy Rosenberg (617.390.2677, arosenbe@law.harvard.edu).

SHARP at IAC! *SHARP will present a poster at the International AIDS Conference, July 18-23, in Vienna, Austria. Check out the IAC at <http://www.aids2010.org/>.*

Coming Up

May 13, 2010 (Thursday)

HIV/AIDS Legislative Lobby Day in Columbia, South Carolina

Lead: South Carolina HIV/AIDS Care Crisis Task Force

Contact: Bernita Streater (bernita8277@hotmail.com)

May 1, 2010 (Saturday)

AIDS Walk Charlotte, Charlotte, North Carolina

Lead: Carolina RAIN (Regional AIDS Interfaith Network)

Contact: Nathan Smith, n.smith@carolinarain.org, www.aidswalkcharlotte.org

May 1, 2010 (Saturday)

AIDSWalk+Ride, Raleigh, North Carolina

Lead: Alliance of AIDS Services-Carolina

Contact: www.aidswalkandride.org

May 25, 2010 (Tuesday)

HIV/AIDS Advocacy Day in Raleigh, North Carolina

Lead: Alliance of AIDS Services-Carolina

Contact: John Paul Womble (johnpaul.womble@aas-c.org)

Feedback Please!

We'd like to make *The Point: SHARP News* useful for you—please give us your suggestions for what you'd like to see included in future issues. Here's how to reach SHARP staff:

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