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## **Summary of Activities and Accomplishments of the New Duke AIDS Policy Clinic 2011-2012**

### **May 21, 2012**

The Duke AIDS Policy Clinic (“Policy Clinic”) began in the fall of 2011. The Policy Clinic is an outgrowth of the established Duke AIDS Legal Project through which students have been providing direct representation to HIV positive clients in North Carolina since 1996 in cases involving benefits advocacy, discrimination, breaches of confidentiality, estate planning, and guardianship planning. The Duke AIDS Legal Project (“Legal Project”) is the only legal office in North Carolina focused exclusively on the legal needs of people living with HIV. Our work on individual cases, consultations, and educational workshops has grounded us and made us acutely aware of the larger issues affecting the HIV/AIDS community. In our direct legal representation students and faculty have:

- Handled numerous cases involving unauthorized disclosure of HIV status by medical providers, friends, or family members. While legal remedies are limited, in individual cases, we have stopped further disclosures, obtained apologies and staff HIV 101 training, obtained monetary damages, and forced medical providers to respond to their licensing bodies regarding disclosures.
- Represented many clients for whom HIV stigma led to discrimination in employment or public accommodations. As a result of the Legal Project’s representation, our clients have been reinstated, re-gained occupational licenses, obtained workplace policy changes and HIV 101 training, and received lost wages and additional damages.
- Counseled clients, medical providers and case managers about the limitations on forced disclosure of HIV status in employment and educational settings.
- Counseled clients and service providers about access to care issues including private health insurance, federal and state high-risk insurance coverage, pre-existing condition limitations, COBRA, Medicaid, Medicare, and the AIDS Drug Assistance Program (ADAP).
- Obtained Social Security Disability, Supplemental Security Income, Medicare, and Medicaid benefits for disabled persons living with HIV.

Students in the Duke AIDS Policy Clinic are working on an ambitious number of policy issues directly related to the ability of persons living with HIV to access care and treatment.

## I. FEDERAL POLICY WORK

A. **The Southern HIV/AIDS Strategy Initiative (“SASI”)**: In August of 2010, the Policy Clinic was awarded a Ford Foundation grant to develop research-based strategies aimed at securing federal resources for HIV prevention, care and treatment in nine targeted Deep South states (AL, FL, GA, LA, MS, NC, SC, TN, and [East] Texas.) We pulled together a Steering Committee of HIV/AIDS advocates, people living with HIV and their providers from throughout the Southeastern United States and SASI was born. SASI, led by the Duke Policy Clinic, contracted with the Duke Center for Health Policy and Inequalities Research to produce a comprehensive report, [“HIV/AIDS Epidemic in the South Reaches Crisis Proportions in Last Decade,”](#) which was released in December, 2011, and which took a close look at the nine southern states that have been particularly hard hit by the HIV epidemic. The Report documented that more people are living with and dying from HIV in the Southeast than in any other region of the country. (See [www.southernaidsstrategy.org](http://www.southernaidsstrategy.org).)

In December, 2010, SASI representatives met with Jeffrey Crowley, White House Director of the Office of National AIDS Policy, Dr. Ron Valdiserri, Deputy Assistant Secretary for Health, Infectious Diseases at the U.S. Department of Health and Human Services, and Christopher Bates, Executive Director of the Presidential Advisory Council on HIV/AIDS to share the report findings.

At the February, 2012 meeting of the Presidential Advisory Council on HIV/AIDS (PACHA), Dr. Valdiserri announced a new Southern Initiative. HHS will be awarding a total of \$43.5 million over three years to state health departments for initiatives aimed at reducing HIV among minority populations and at reducing HIV mortality rates. Dr. Valdiserri specifically credited the work of SASI and two other groups as having led the advocacy efforts for this initiative.

SASI is now calling on the White House, the Office of National AIDS Policy and the Department of Health and Human Services to convene a State of the South Task Force to recommend next steps in implementing the National HIV/AIDS Strategy in the Southeast, to identify collaborative opportunities across federal agencies aimed at addressing the growing HIV/AIDS epidemic in the Southeast, and to identify funding opportunities for projects aimed at evaluating best HIV prevention and care practices for the Southern U.S. In April, 2012, SASI representatives met with the White House and congressional leaders in Washington DC to advocate for the Task Force.

One of our policy clinic students mastered the contents of the SASI Research Report, helped to fine tune some of its findings, and created educational charts which are being used to educate a range of audiences from federal decision-makers to people living with HIV and their advocates. Our

student traveled with a faculty member to Ft. Walton Beach, Florida over her spring break to help conduct a workshop on SASI's work for women from the South who are living with HIV.

## II. NORTH CAROLINA POLICY WORK

**A. Confidentiality and Stigma:** HIV-related stigma is consistently identified as a barrier to care. Concerns about confidentiality causes patients to miss appointments, seek care at greater distances, miss medications and avoid getting tested for HIV altogether. Unfortunately, unauthorized disclosures of HIV status have had devastating consequences for our clients. They have been shunned by their families, refused a hug or touch, and forced to use separate dishes and utensils. They have been thrown out of churches and fired from jobs. They have faced community harassment as word of their HIV status spread.

Because it has been our experience that clients have frequently had their HIV status disclosed without their permission in the justice system and in hospital emergency departments, we decided to focus our initial efforts on those two systems.

In 2011, Policy Clinic students and faculty worked with a health educator from the Duke Center for Health Policy and Inequalities Research to develop a two-hour legal ethics curriculum and manuscript on ***The Law and Ethics of Representing Clients with HIV in North Carolina***. The curriculum focuses on educating lawyers about HIV-related stigma and the consequences of confidentiality breaches. We cover the applicable state and federal law and the North Carolina Rules of Professional Responsibility. We presented the workshop twice in 2011—at the North Carolina Association of Women Attorneys' meeting in September, 2011 and for Legal Services attorneys in Charlotte in October, 2011. We plan on continuing to present this workshop to legal audiences in 2012.

With regard to HIV confidentiality breaches in hospital emergency rooms, students and faculty have worked with individual hospitals and physicians on post-breach remedies. In 2011, we worked with a large teaching hospital to create a new training module for hospital staff on best practices to use when discussing sensitive diagnoses. We realized, however, that in order to prevent what were usually inadvertent disclosures in hospital emergency departments, we needed to educate large numbers of North Carolina physicians and hospital risk managers so that breaches could be prevented altogether. In 2012, we approached the Medical Mutual Insurance Company ("Med Mutual") to discuss ways we could collaborate in providing education to emergency department physicians and hospital risk managers throughout North Carolina. Med Mutual has agreed to work with the Policy Clinic on this issue.

In March, 2012, Med Mutual published our article entitled, ***HIV, Stigma, and Confidentiality*** in its newsletter, MedNotes. The company then distributed the article re-print specifically to emergency room physicians throughout North

Carolina. The North Carolina College of Emergency Physicians also published a shortened version of the MedNotes article in its newsletter. In addition, the Policy Clinic students and faculty are working on a joint presentation with David Sousa, Senior Vice President and General Counsel for Med Mutual to be presented at a statewide meeting of the North Carolina Society of Healthcare Risk Managers.

Finally, students and faculty in the Policy Clinic worked with a health educator partner to develop a full training curriculum on HIV, Stigma and Confidentiality aimed at health care providers, particularly those who work in hospital emergency departments.

**B. Access to Medications:** The North Carolina AIDS Drug Assistance Program (“ADAP”) is a life-saver for the thousands of low income people living with HIV/AIDS in North Carolina. But funds are short in North Carolina, as they are across the country. It is important that North Carolina implement cost-saving measures to conserve the limited funds available for ADAP. A clinic student in the fall 2011 Policy Clinic worked with faculty to conduct an analysis of the feasibility and cost savings that would result if North Carolina’s ADAP program coordinated with North Carolina’s federal pre-existing condition insurance pool (“PCIP”) to use ADAP funds to buy insurance that would cover HIV medications at a lower cost. The analysis demonstrated that coordination of the two programs would not only result in significant savings to the ADAP program, but would provide comprehensive health care and prescription drug benefits to ADAP participants.

In December 2011, students and professors in the Policy Clinic met with John Dervin in Governor Perdue’s office, Jacquelyn Clymore, State AIDS Director, and officials with the state Medicaid program to present their analysis. As a direct result of the report prepared by the Policy Clinic, ***Feasibility & Cost Savings of ADAP Coordination with North Carolina Federal PCIP***, legislation has been introduced in the North Carolina General Assembly that would authorize the initiation of a pilot program enabling 10% of the total ADAP enrolled clients to obtain full medical coverage through North Carolina’s high risk insurance coverage.

**C. Health Care Reform Implementation in North Carolina:** Policy students are researching and working with partners to ensure that health care reform implementation takes into account the needs of people living with HIV/AIDS. We are preparing a white paper outlining key issues in planning for health care reform for people living with HIV in North Carolina. These issues include ensuring that the state Health Benefit Exchange and Medicaid expansion meet the needs of people with HIV/AIDS. A policy clinic student and faculty prepared and submitted comments to the U.S. Department of Health and Human Services in connection with the Department’s essential health benefit rule-making. Because DHHS has determined that the details of the essential health benefit are

to be determined by the states, we are working at the state level to make sure policy makers are aware of the needs of people living with HIV. A policy student is obtaining and reviewing benchmark plans that will be considered by the state of North Carolina.

Health Care Reform implementation will transform the environment in which the Ryan White program operates. Policy students are studying North Carolina's Ryan White program, as well as changes that occurred in the Massachusetts Ryan White program after health care reform was implemented there. We prepared a report on Ryan White challenges and opportunities that we circulated to key stakeholders in North Carolina. Clinic faculty members McAllaster and Rice have also been asked by the North Carolina State AIDS Director to serve on the Task Force HIV Health Care Transition 2014.

Policy students are also providing education about Health Care Reform for people living with HIV/AIDS and the broader HIV community. They have created educational brochures about health care reform and have made several presentations this semester on health care reform for persons living with HIV and their providers.

**D. Medicaid Prior Authorization for HIV Medications:** Because of a funding crisis in the North Carolina Medicaid program resulting from the 2011-2012 state budget, the North Carolina Department of Health and Human Services is considering a wide range of cost saving measures, including prior authorization for antiretroviral medications. Research and provider interviews conducted by a Duke Policy Clinic student indicate that requiring prior authorization for HIV medications for Medicaid recipients will not save money and may result in treatment interruptions for people who rely on Medicaid for their prescription drugs. Policy clinic students and faculty discussed this issue with State Medicaid officials in the meeting referred to above with John Dervin in Governor Perdue's office. We worked with the North Carolina Division of Medical Assistance (DMA) to gather data. After advocating in several meetings against an imposition of a prior authorization requirement for HIV medications in the Medicaid program, DMA and the North Carolina Department of Health and Human Services have decided not to seek a prior authorization requirement for HIV medications. This is an outstanding victory for persons living with HIV/AIDS and would not have been accomplished without the advocacy of the Duke Policy Clinic student.

**E. Occupational Licensing:** In mid-2010, the US Department of Justice wrote to all of the state Attorneys General urging them to examine state occupational licensing laws that might discriminate against people living with HIV/AIDS in violation of the Americans with Disabilities Act. Laws in many states, including North Carolina, contain language excluding those with "contagious," "communicable," or "infectious" diseases from obtaining licenses to be barbers, cosmetologists, etc. This kind of language can be used to exclude people living with HIV/AIDS, even when there is no risk of transmission in the occupation.

Policy Clinic students have examined North Carolina occupational licensing rules and laws and conducted research on transmission risk in the identified occupations concluding that the risk of transmission is negligible, especially if standard precautions are followed.

We decided to focus initially on the North Carolina barbering regulations which provide that people with “infectious” or “communicable” diseases may not work in the state as barbers. The Duke Legal Project has had one client who had this regulation construed against him. The policy student who worked on this issue sent a letter to the North Carolina Board of Barber Examiners requesting their support in seeking a formal rule change. We met with officials of the North Carolina Board of Barber Examiners to discuss our concerns. As a direct result of the Duke Policy Clinic’s advocacy, the Board of Barber Examiners has agreed to amend its rules to remove the problematic language. Clinic faculty and students will continue to offer assistance to the Barbering Board as it completes this rule-making process.

F. **Medicaid Transportation:** Lack of transportation has been identified as a major barrier to accessing health care for people living with HIV/AIDS in North Carolina, particularly in the rural parts of our state. Students in the Duke AIDS Policy Clinic evaluated the Medicaid funded transportation policies in a ten-county region in Eastern North Carolina. In many counties there is a lack of transparency about how to access Medicaid funded transportation: the policies are not in writing; there are no client brochures; nor is the information available on county websites. County policies regarding how to access transportation also vary widely. In January, 2012, North Carolina revised its State Medicaid Transportation Policy in an effort to standardize many of the procedures and policies across counties. The policy student who worked on this issue in 2012 evaluated the compliance of each county in the targeted region with the newly adopted State Policy and identified best practices on a county level. We have prepared a memo that will be submitted shortly to the North Carolina Department of Transportation outlining our findings and making recommendations for policy improvements. The policy student also developed county-level client brochures for each of the targeted counties that will provide a quick reference on how persons living with HIV can access Medicaid funded transportation in their county.

III. **Technical Assistance for Legal Providers in Alabama and Mississippi:** In addition to our policy work in North Carolina and the Southeast, the Duke AIDS Legal Project was asked by AIDS United to provide technical assistance to new HIV legal providers in Alabama and Mississippi: Legal Services Alabama, Birmingham AIDS Outreach, and the Mississippi Center for Justice. Students and faculty in the Duke AIDS Policy Clinic researched and prepared manuscripts with extensive appendices on the federal and state statutes and case law affecting persons living with HIV/AIDS in each state in the areas of public health,

confidentiality, discrimination, disability, and ethics. Students and clinic faculty have co-presented the material at three day-long continuing legal education programs—one in Birmingham, Alabama, one in Montgomery, Alabama, and one in Jackson, Mississippi. As a result of this work, we have made valuable connections with our colleagues in the Deep South, and we continue to act as a resource for these new programs.