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November 21, 2011

Susan Meister
Administrative Rules Coordinator
Illinois Department of Public Health
535 W. Jefferson, 5th Floor
Springfield, Illinois 62706-4700

Re: Emergency Rulemaking; Title 77 Ill. Adm. Code 692

Dear Ms. Meister:

Recently the Illinois Department of Public Health (IDPH) proposed adoption of rules for the AIDS Drug Assistance Program (ADAP). We appreciate IDPH's dedication to operating an efficient, cost-effective ADAP and laud their commitment to meeting the needs of low-income people with HIV.

Across the state, businesses, families and individuals are in economic crisis. Lost jobs have restricted access to health insurance. Individuals living with HIV/AIDS also carry a unique burden as they seek affordable treatment options during this severe economic downturn. Not surprisingly, the burden on ADAP, which provides lifesaving medications to underinsured and uninsured Illinoisans, has also significantly increased, and state funding has not kept pace.

In the context of the state's fiscal crisis, we agree that changes to ADAP are reasonable to protect treatment access for the thousands of individuals who depend on Illinois ADAP for their lifesaving medications. However, we are extremely concerned that some of the proposed changes constitute needless barriers to enrollment that will raise the state's short-term and long-term health care costs by worsening the health of people with HIV and causing additional people to be infected with HIV.

After extensive consultation with medical providers, agencies that provide case management to people with HIV, other service providers, and people living with HIV, AFC submits the following comments on the proposed rules.

Section 692.5: Proposed rule language "Definitions"

Recommended change: "means a federal program that assists very low income (less than \$1,000/month) Medicare Part D eligible individuals with their prescription drug coverage. The program pays Medicare Part D premiums and all copayments except \$2 and \$3 on generic and brand, respectively. The program was established by Patient Protection and Affordable Care Act (P.L. 111-148).

Recommend change: "means a State pharmacy assistance program that provides prescription drug assistance to low-income senior citizens and disabled persons, established by 320

ILCS25/and administered by the Illinois Department on Aging. obtainable through the Department of Healthcare and Family Services (HFS).

Recommended change: Proposed rule language “medical care expenses for certain low-income....”

Recommended change: Proposed rule language “people aged 65 or older and certain individuals with disabilities. Enrolled individuals must pay deductibles and co-payments.”

Recommended change: Proposed rule language (new) “Prescription insurance means insurance paid for or provided by an employer, family member, or the applicant that covers prescription medications.”

Rationale: The proposed changes add clarity to the definitions.

Section 692.10(a): Proposed rule language “Medical requirements.....”

Recommended change: ~~Medical requirements~~-Eligibility requirements...”

Rationale: Eligibility requirements more accurately denote the sections responsibilities.

Section 692.10(b)(1): Proposed rule language “Applicants with no active prescription insurance coverage...”

Recommended change: “Applicants with no ~~active~~ prescription coverage”

Rationale: “Active” is confusing and not defined, and it is unclear when coverage is “active” or not.

Section 692.10(b)(2): Proposed rule language “Applicants with active prescription coverage...”

Recommended change: “Applicants with ~~active~~ prescription coverage”

Rationale: See above.

Section 692.10 (b)(4): Proposed rule language “Applicants shall not be eligible for payment for prescription drugs from any other government entity.”

Recommended change: “Applicants shall not be eligible for payment for prescription drugs from any other government entity, except Medicare, Medicaid (if spend-down is met) or Illinois Cares Rx.”

Rationale: Medicare and Illinois Cares Rx are governmental entities, and should be exempted here since they are clearly permitted elsewhere in the proposed rule.

Section 692.10(b)(5): Proposed rule language “If eligible for Medicare Part D, the applicant shall provide...”

Recommended change: “If eligible for Medicare Part D, the applicant shall enroll in Medicare Part D and provide...”

Rationale: Since 2006 when Medicare Part D began, it has been Illinois ADAP policy to require individuals to enroll in Medicare Part D, if they are eligible. This should be reflected in the rules since it saves significant state and federal ADAP funds.

Section 692.10(b)(7): Proposed rule language “If eligible for federal Extra Help or Illinois Cares Rx Plan (ICRx), the applicant shall apply to both programs. Approval or denial documentation shall be provided to the ADAP as well as a clear copy of both the front and back of the ICRx card”

Recommended change: “Approval ~~or denial~~ documentation shall be provided to the ADAP as well as clear copy of both the front and back of the ICRx card.”

Rationale: Mandating that applicants must provide ADAP with “denial documentation” from the Extra Help program places a repetitive and unnecessary burden on applicants; ADAP already has documentation of an applicant’s income requirements. To be more efficient and to accelerate the application process ADAP should reference the income verification documents previously submitted by the applicant.

Section 692.10(b)(8) (new)

Recommended change: “Clients enrolled in ADAP on July 1, 2011 in the 301-500% income bracket of the federal poverty level shall be grandfathered into ADAP on a go-forward basis, as long as renewals are complete and submitted on time.”

Rationale: The ADAP rules should reflect that any individual who is actively receiving ADAP on July 1, 2011 may continue to receive assistance as long as their income remains below 500% of federal poverty.

Section 692.10 (d): Proposed rule language “Persons enrolled in the ADAP shall reapply every six months.....”

Recommended change: “Persons enrolled in ADAP shall recertify ~~reapply every six months~~ annually in order to continue receiving drugs through the ADAP.

Rationale: We are extremely concerned about the impact of the federally-mandated six month reapplication requirement, which IDPH has already implemented. *We urge IDPH and the Quinn administration to seek federal permission to develop an alternative to the six-month requirement and restore annual renewals.*

The federally-mandated six-month reapplication requirement is already resulting in unacceptable interruptions to treatment. According to IDPH data released October 21, 2011, from January to July of this year 35% (one in three) of ADAP clients experienced delays in receiving medications as a result of the six month renewal policy. This policy will increase long-term health costs for the state and worsen the AIDS epidemic:

1. Treatment interruptions cause harm to individuals living with HIV by allowing HIV to mutate, requiring more complex and costly treatment, weakening the immune system, and leading to costly hospitalizations and premature death and disability;

2. If people with HIV don't have access to medications, the amount of HIV in their blood rises, increasing the likelihood of transmission to another individual. New evidence demonstrates that consistent access to HIV medications reduces by 96 % the chance that HIV will be passed along to someone else. The six-month reapplication policy, by establishing an administrative barrier to treatment, will result in new HIV cases and in turn raise future treatment costs for the state;

3. In Illinois an estimated 18,000 people with HIV – 50% of Illinoisans who know they have the virus – are not receiving HIV treatment. Extensive efforts are underway to identify and engage these individuals in care, but the six-month reapplication requirement is undermining those efforts by creating administrative barriers to receiving medication.

We acknowledge the emergency due to the threat of loss of federal funding for ADAP. However, we urge IDPH to advocate for the federal government to grant Illinois flexibility to revise this policy without jeopardizing federal funding. States have long been incubators for experimental policy ideas with regard to health care. Incentivizing states to find creative and cost-effective ways to control health care cost may yield the most unique and effective solutions that could be adopted widely.

Section 692.10(d)(3) (new):

Recommended change: “When appropriate and approved by the client, ADAP will use identified client advocates (case managers, medical providers, social workers) to expedite and assist with the application.”

Rationale: Making client advocates eligible for application information, with permission from clients, will help to expedite the ADAP notification and processing procedure.

Section 692.10(d)(4) (new):

Recommended change: “To ensure a client’s successful receipt of life-saving medications, clients and/or client advocates will be notified within one business day of any change in application status, such as complete, incomplete, denied, approved, or destroyed. Clients or advocates should be able to choose to be notified by either email or postal mail when the status changes.”

Rationale: Ensuring ADAP clients and/or client advocates have immediate status notification of an application will help to expedite the processing procedure. IDPH’s online application system allows individuals learn the status of their application status only with a confirmation number that clients too often lose. Calls to the ADAP office are often unreturned because of the high workload. IDPH should email or mail clients about application status changes. We hear again and again from clients that IDPH said their application was missing a document, but they were never informed and given the opportunity to resubmit, or that an attachment was not received that the client sent. ADAP is making determinations about client eligibility that will determine if they are able to maintain their health, and clients must be adequately informed throughout the process. We understand that there are privacy and confidentiality concerns about sending ADAP information by email, but believe these can be successfully resolved, and are eager to help IDPH consider the issues and develop a solution.

Section 692.10(e): Proposed rule language “The department shall suspend a client’s enrollment in the ADAP....”

Recommended change: “The Department shall place on hold (suspend) pending notification to a client and/or client advocate a client’s enrollment in the ADAP....ADAP staff must help applicants missing verifications in any way possible.”

Rationale: The emergency rule does not define the term “suspend”, does not establish a procedure for notifying a client or client advocate that they have been suspended, and does not notify the client of an appeal process or how to enroll again. The proposed rule denies the client due process. The proposed rules make it unclear whether the application will be closed completely, placed on hold, or other action(s) taken. Without specifics the emergency rule is vulnerable to arbitrary application and fails to provide adequate notice and guidance to clients and entities that would be affected by it. The proposed requirement that ADAP staff assist applicants that are missing information is consistent with Department of Human Services manual, WAG 02-07-03.

Section 692.10(e)(3): Proposed rule language “The Department shall suspend a client’s enrollment in the ADAP under the following circumstances: ...Failure to use a minimum of one drug from any category of the ADAP within 90 days...”

Recommended change: “...Failure to use a minimum of one drug from any category of the ADAP formulary within 90 days after enrollment to the ADAP. If a medical provider determines that a client must stop taking a drug for a period of time for a medical reason, the client will not be penalized. ADAP shall provide written notification to a client and/or client advocate 30 business days prior to suspension for non-utilization that their eligibility will be suspended if they do not fill a prescription listed on the ADAP formulary.”

Rationale: *Sub-section (e)(3)* indicates that if a client does not use a least one ADAP drug within 90 days of enrollment, their participation in ADAP is suspended. This rule could directly interfere with the physician-client relationship. In many instances, physicians may deliberately take a patient off of HIV medications for a period of time for a medical reason. This rule would seek to punish a patient for adhering to their physician’s medical advice. In addition, there is no notification to the provider or client that they will be suspended from the program for not using medications.

Section 692.10(g): Proposed rule language “Department will request the advice of the medical issues subcommittee of the Ryan White ADAP Medical Issues Advisory Board...”

Recommended change: “Department ~~will~~ shall request the advice of the medical issues subcommittee of the Ryan White ADAP Medical Issues Advisory Board ~~when necessary~~ to assist with determining”

Rationale: We respectfully submit that the word “shall” be inserted. We also suggest that the words “when necessary” be stricken. The proposed emergency rules regulate the ADAP Medical Advisory Board to an entity lacking substantive input into the process for formulating which HIV

medications will be covered under ADAP. Members of the Advisory Board were selected because of their experience in the areas of research, advocacy, and medical knowledge and their willingness to impart their expertise on these issues. The Board's recommendations should be given weight and be incorporated as an essential part of the decision making process regarding HIV medications.

Section 692.15(c): Proposed rule language "Demographic and income information..."

Recommended change: "Demographic (name, date of birth, relationship)..."

Rationale: Demographic information is not a defined term and needs more clarity.

Section 692.15(d): Proposed rule language "or other document provided by the applicant..."

Recommended change: "except to the extent that the Department can obtain that information from SOLO or official on-line sources, or has previously requested and received that information and the application has indicated there has been no change."

Rationale: Mandating that applicants must provide ADAP with information that is already assessable is a repetitive and unnecessary burden on applicants.

AIDS Foundation of Chicago (AFC) is a local and national leader in the fight against HIV/AIDS. We collaborate with community organizations to develop and improve HIV/AIDS services; fund and coordinate prevention, care and advocacy projects; and champion effective, compassionate HIV/AIDS policy.

Thank you for reviewing these recommendations. If you have any questions, please feel free to contact me at 312-334-0928 or at rgardenhire@aidschicago.org.

Sincerely,



Ramon Gardenhire
Director of Government Relations