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January 8, 1999

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RE: Comments on the Draft CDC Guidelines for National HIV Case Surveillance

To Whom It May Concern:

The San Francisco AIDS Foundation appreciates the opportunity to comment on the recently released "Draft Guidelines for HIV Case Surveillance." We are pleased that the draft guidelines state that flexibility will be given to states to design and implement HIV reporting systems that best meet the needs of their jurisdictions. However, we believe that the draft guidelines should be revised to better reflect the scientific research findings on the impact of names-based reporting on HIV testing and to address the needs of individuals living in communities that are profoundly affected by HIV.

The Foundation's concerns are as follows:

1. The CDC inappropriately advises states to use names reporting.

Although states are given a choice of using either names or unique identifier (UI) systems, both the language and the presentation of scientific evidence in the guidelines clearly reflect the CDC's bias towards names reporting. The guidelines state: "CDC advises that State and local surveillance programs use the same name-based approach for HIV surveillance as is currently used for AIDS surveillance nationwide" (p. 8). Such advice is scientifically unfounded (see below). The guidelines should be revised so as not to favor one system over another in order to provide state health officials true flexibility in designing the system that best meets their community's needs. To this end, the sentence "advising" names reporting should be eliminated.

Although the draft guidelines appropriately pledge technical assistance regardless of the type of HIV surveillance implemented, the CDC's preference for names reporting, while not being overtly stated, appears to be linked to the provision of funds. This bias is apparent in statements such as: "based on published evaluations, the CDC has concluded that name-based HIV/AIDS surveillance systems are the most likely to meet the necessary performance standards as well as to serve the purposes for which surveillance data are required" (p. 8). The CDC actually stated in a letter to Washington State that supplemental funding for HIV/AIDS surveillance was contingent upon the implementation of names-based reporting. While the statement was later re-

tracted, there is an underlying and pervasive impression among states that federal funding is contingent upon names-based reporting. The CDC should work to reverse this impression by presenting unbiased information and support to states implementing non-names based systems.

2. Regarding the performance standards, the guidelines do not contain discussion of sufficient time for implementation.

The guidelines should contain a reasonable transition period for implementation of reporting systems before any evaluation for funding purposes is completed. Based on the experience of several states implementing HIV surveillance systems, *five years* appears to be an adequate amount of time to establish a system and ensure that it is functioning at the levels set out in the guidelines.

In addition, at least one of the performance standards must be modified—the requirement that risk information be gathered on 85% of cases. Most states with names reporting have not met this criterion and there is little evidence that they will be able to do so, even with years of experience. Risk information – which is often very difficult for providers to secure—would be better obtained through representative sample surveys and sentinel studies. This should be discussed in detail in the guidelines and the 85% requirement should be eliminated.

3. The presentation of research on testing behavior is biased.

The scientific evidence presented to discount the impact of names-based reporting on individuals' willingness to seek HIV testing is both biased and flawed. Key studies that demonstrate that HIV names reporting deters individuals from seeking testing are not mentioned anywhere in the guidelines (Myers et al 1993; Reed 1996; Kegeles et al 1990; Kegeles et al 1989; Fordyce 1989; Johnson et al 1988; Judson and Vernon 1988).

Not only are these studies not discussed, but those studies that are cited draw questionable conclusions that are not justified by the data and methods used (Nakashima et al 1998; Hecht et al 1997). For example, while the Nakashima study examines testing patterns in states that implemented names reporting, the study did not include comparisons to states that did not implement such a policy. It is thus impossible for the authors to prove that testing rates might not have increased *more dramatically* had names reporting not been instituted in those states. In addition, the study's authors do not examine carefully the experience of *key subpopulations* that are most at risk for HIV infection. While Nakashima and colleagues do show that testing increased or remained stable overall in some states, changes in testing frequency across *high-risk groups* did not correspond to the *overall* change. Contrary to the conclusions drawn by the CDC, Nakashima's results suggest that the highest risk groups may be reluctant to test with names reporting. These results have very important public health ramifications and raise serious concerns about the deterrent effect of names reporting for African Americans and, in some cases, injection drug users. If this study is going to be used in the guidelines, it should be presented fairly, and the population-specific trends should be presented in greater detail.

The draft guidelines also reference the Hecht study, in which 19% of respondents reported that "fear of reporting to the government" was a concern that contributed to their decision to delay testing. Again, the language used to describe the findings reflects bias. This finding is pre-

sented as "less than 20%" (versus, for example, "nearly 1 in 5") which intentionally minimizes the importance of these data. This is especially important because the Hecht study targeted high-risk populations, which make up a greater percentage of the populations in the states that have not yet instituted HIV surveillance. In fact, only 6 of the 32 states currently collecting HIV data with names-based reporting systems have higher-than-average AIDS case rates in their populations.

Encouragement of names reporting may be particularly dangerous for the remaining states that have yet to introduce an HIV reporting system. In many of these states, reported AIDS cases are disproportionately among high-risk groups (as evidenced by figures from 1997). For example, the proportions of AIDS cases in California and Washington among men who have sex with men (64% and 55%) are much higher than the national average (35%). Similarly, in Illinois (30%), Massachusetts (34%) and Pennsylvania (43%), the proportions of cases associated with injection drug use are greater than the national average of 24%. The proportion of cases among African Americans in Georgia (72%), Illinois (56%) and Pennsylvania (60%) are greater than the 45% national average. These discrepancies indicate that encouraging names reporting among these states may be irresponsible, since their populations may be more likely to be deterred by these policies.

Finally, while the CDC's attention to the importance of anonymous testing in the guidelines is to be applauded, it is inherently contradictory to recognize the importance of anonymous testing while at the same time call for names-based systems over unique identifier systems. The CDC acknowledges that anonymous testing has been clearly associated with earlier testing and treatment (Bindman et al 1998). These results prove that some segments of the population are extremely concerned about the confidentiality of their HIV status. This suggests that these same individuals would be reluctant to seek testing and or treatment if HIV names reporting was implemented and, in fact, the draft guidelines should make the provision of anonymous testing a condition of funding.

4. Discussion of ineffectiveness of UI and purported superiority of names-based systems is biased.

The presentation of the evaluation findings on the efficacy of unique identifier systems for HIV reporting is misleading and outdated. The CDC's criticisms of Maryland's system are based on evaluation data from 1994-1996. These data do not reflect the progress and evolution of Maryland's UI system, or the fact that Maryland was not funded by the CDC to implement their UI system. In reality, recent evidence indicates that Maryland's system provides complete data at a reasonable cost, comparable to rates found in states that use names-based reporting. Criticisms of the Texas system must be considered in light of the fact that health officials in the state were never particularly committed to the implementation of a unique identifier system and therefore had little incentive to work for the program's success. Reference to "published evaluations of non-name based HIV surveillance" (p. 8) thus presents an incomplete picture of the available data on UI systems. Maryland has much more updated information available about their system that reflects their ability to meet the CDC's criteria and this data should be incorporated into the guidelines.

The CDC's biased use of conclusions on the efficacy of names reporting is also evident in the guidelines. The CDC is "advising" names reporting based on what appears to be anecdotal evidence from the 32 states that currently use names based systems. The CDC does not report

performance data on names-based systems that may in fact reflect "operational difficulties" in those states. The CDC seems to be reasoning that because names based systems are ubiquitous and because they require fewer contingencies to implement, that they are better. The notion that ease of implementation is equivalent to superiority is highly problematic because the concerns about names reporting far outweigh ease of use.

5. The language regarding the linkage of HIV reporting systems and partner notification is weak.

The draft guidelines do not send a clear and compelling enough message to states that they *should not link partner notification and HIV surveillance systems*. The draft guidelines state that the CDC "does not direct" states to link partner notification and HIV surveillance systems and that doing so "does not necessarily improve the provision of HIV prevention and care services" (p. 12). This language should be strengthened considerably to encourage states not to link these distinct systems. The CDC should also discuss research findings that suggest that HIV names reporting does not improve partner notification or access to care (findings presented by D. Osmond to the CDC Consultation on HIV Reporting, May 1997, Atlanta, GA).

6. The guidelines refer narrowly to community representatives concerns' with HIV reporting.

The draft guidelines inaccurately suggest that concerns regarding confidentiality and fear of illegal disclosure of HIV information is only of concern to community groups. In fact, a number of state and local public health officials share this concern. Positioning these considerations as merely "community concerns" suggests that there are not legitimate public health consequences to names-based reporting. The language should be revised to reference the concerns of both the community and public health officials regarding the deterrent effect of names-based systems.

Thank you for the opportunity to comment on the guidelines. I hope that our comments will assist the CDC in working to ensure that the important goal of securing improved HIV data is implemented thoughtfully and responsibly. If you have any questions, please do not hesitate to contact me.

Sincerely,

Regina Aragón

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Public Policy Director

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