



December 4, 2006

Samuel Dooley, M.D.
Associate Director for Science and Program Integration
Office of the Director
Division of HIV/AIDS Prevention
Centers for Disease Control and Prevention
pcrs@cdc.gov

Re: HIV Partner Services Draft Guidelines

Dear Dr. Dooley:

The undersigned organizations are submitting these comments on the HIV Partner Services Draft Guidelines ("Draft Guidelines") for CDC to consider as it revises them. Representatives of many of the undersigned participated in the HIV Partner Services Consultation held in Atlanta November 16 and 17, 2006, and wish to thank CDC for inviting us to do so. We felt that the consultation provided an important opportunity for feedback by some stakeholders on the Draft Guidelines. We also appreciate this opportunity to submit written comments for CDC's consideration, both to amplify comments that some of us made at the Consultation and to present additional substantive comments. It is clear that a lot of work has gone into developing the Draft Guidelines and we appreciate CDC's stated willingness to revise them in response to input from stakeholders.

We agree with the CDC that HIV Partner Services can be beneficial for persons with HIV infection, their partners, and affected communities, but only if the services are provided in the proper manner. Partner Services ("PS") are most likely to be successful in identifying HIV-positive individuals and getting them into care if PS is conducted in a client-centered manner that is respectful of the persons with HIV infection and their partners and takes into account the ways in which HIV differs from other STIs.

The Partner Services principles (at p. 1 to 3 of the Draft Guidelines) set forth many important points with which we agree. In order to ensure that PS is conducted in accordance with those principles and is successful at identifying HIV infected

individuals and getting them into care, we believe that the Guidelines should regularly refer to these principles to reinforce them as the basis for developing and evaluating PS programs. More specifically, we believe that the Guidelines should be revised as set forth below.

I. Standards based on the principles should be added:

The principles set forth at lines 23 to 89 are so necessary for the ethical and successful conduct of PS that standards based on them should be included in the Guidelines, to make it clear that PS must be conducted in accordance with those principles.¹ In particular, the following standards should be specified in the Guidelines (in a "Standards" section following the Introduction and Overview section):

- Participation with and acceptance of Partner Services must be voluntary for both the index patient and his or her partners. Each person offered PS must be informed that acceptance of PS is not required and that his or her eligibility for other services will not be affected by whether or not he or she accepts PS.
- Coercive tactics must not be used to elicit information about partners or to elicit agreement to participate in PS.
- Prior to eliciting information about partners, the index patient must be informed about the possible negative and positive consequences of revealing his or her own or others' serostatus to anyone else and about the possible ramifications under state law of providing information about sex or drug-injection partners.
- Information obtained through PS shall be used solely for legitimate public health purposes. Prior to eliciting information from index patients or partners, the person must be informed of the purposes of collecting the information. Information collected through PS can only be used for those stated purposes.
- PS must be conducted in an entirely confidential manner and, to the fullest extent possible under applicable laws, any information obtained in PS must not be shared with and must be withheld from other government or private entities, including law enforcement and courts.
- PS programs must provide penalties for any breaches of confidentiality.
- PS must be delivered in a nonjudgmental, culturally appropriate, competent and sensitive manner.

¹ The Glossary contemplates that CDC will set forth some "[e]lements or procedures that must be followed by CDC grantees in virtually all cases where CDC funds are used to support services." (Glossary of Terms Associated with Partner Services, emphasis in original) However, the Draft Guidelines set forth specific standards only as to "record keeping and data collection, management, and security." (Appendix 2)

- Counseling and support must be provided to index patients who choose to notify their own partners.
- Client-centered counseling must be offered and, if requested, provided to each index patient and each contacted partner.
- Counseling must be designed to assist index patients and HIV-positive partners in understanding that disclosure will be an ongoing issue in their lives and that partner services will continue to be available.
- PS must be offered and, if requested, provided to persons who test for HIV anonymously.
- Before undertaking PS, the entity doing so must demonstrate that it has the capacity to ensure that it can comply with the required confidentiality and security standards.

Similarly, the importance of various points in the text should be indicated by using stronger wording, such as “it is essential that the PS providers assure” (line 1118), rather than wording such as “partners should be informed” (line 1106).

II. The reasons that HIV PS is not identical to PS for other STIs should be explained more fully:

The Draft Guidelines make the important point that “HIV entails unique considerations and approaches [for PS] . . .” (lines 25-26). In order to successfully integrate HIV PS with the provision of partner services for other STIs, the Introduction and Overview section should include a subsection highlighting the different approaches for HIV PS and explaining why HIV is different from other STIs and why PS for HIV should not be handled identically to PS for other STIs. Although the Guidelines refer in various parts of the text to the fact that differences exist (e.g., lines 25-26, 153-54, 1216-1231), comments from some health department representatives at the Consultation indicated that the need to conduct HIV PS somewhat differently was not clear from the current draft.

A separate discussion on this topic should include reference to the stigma and discrimination that is still associated with a diagnosis of HIV infection; the significance of the fact that HIV -- in contrast to other STIs -- is not curable; the need for lifelong attention to disclosure; the need to consider whether PS is more likely to be accepted if offered at a time later than the moment of diagnosis and/or by someone other than a health department representative, such as by staff of a CBO; and the other relevant ways in which the epidemiological, biological, and clinical characteristics of HIV, and the social and legal concerns associated with an HIV diagnosis, differ from those of other STIs, such as syphilis. A clear discussion of both the differences and the reasons for those differences is especially important because the same PS worker may be working with clients diagnosed with HIV and with clients diagnosed with other STIs

(and even with clients who are diagnosed with both HIV and another STI, as noted in line 1258). The differences should also be highlighted in the section on "Program Structure and Design" (lines 1787-1819) and this topic should be identified as one that should be discussed as part of the training of persons conducting HIV PS. In addition, the Guidelines should note that coordinating HIV and STI partner services may benefit the patient by avoiding the burden of multiple interviews, but that such coordination must be handled in a way that maintains boundaries between STI and HIV services and surveillance.

III. The drawbacks to linking Partner Services with disease surveillance activities should be discussed and CDC should not recommend linkage:

As the Consultation made clear, there is no consensus among stakeholders on whether HIV PS should be linked with disease reporting. Some participants felt that the CDC was recommending such linkage; in revising the Draft Guidelines, CDC should make it clear that it is not making such a recommendation. Moreover, the section on "Linkage with Disease Reporting" (lines 341-385) needs to discuss the possible drawbacks to sharing data between PS and surveillance. Those drawbacks include the risk of making PS less effective. In order to ethically conduct PS, prior to eliciting information there must be full disclosure to index patients and their identified partners of who will have access to that information, all the ways in which the information will be used, and the possible ramifications for them of such use. Linking PS with disease surveillance, and thus allowing greater access to the information and increasing the uses to which the information is put, is likely to make some individuals less willing to accept PS, thus thwarting the public health goal of getting more persons who are infected with HIV aware of their status and into care.

The section on "Linkage with Disease Reporting" makes important points about the need, if there is linkage, to include explicit protocols "for contacting providers and patients" and "ensur[ing] that security and confidentiality protections are in place;" to protect the "quality, confidentiality, and voluntary nature of prevention services;" and to avoid use of individual-level data for any non-public health purpose. The Guidelines need to be revised and strengthened by turning those points into "standards," to make it clear that, if there is linkage, certain protections must be in place, including: fully informing all clients and their partners, prior to eliciting information, of who will have access to the information and all of the purposes to which the information might be put; prohibiting the use of individual-level data for any non-public health purposes; prohibiting the release of individual-level data to parties involved in court (civil or criminal) or administrative proceedings and to non-health agencies of federal, state, and local government, including law enforcement; limiting the data that will be shared; and specifying penalties for any breaches of confidentiality of the data.

IV. The public health benefits of ensuring that PS is confidential and voluntary should be more directly addressed:

The Introduction and Overview section should include an explicit discussion of the link between a client-centered, voluntary, and confidential approach to PS and positive outcomes from the standpoint of public health. Ensuring that PS is conducted in a manner that is respectful of the index patients and elicits truly voluntary participation is likely to lead to greater cooperation and, therefore, greater effectiveness in eliciting accurate partner information. In addition, providing assurances of confidentiality is vital for gaining cooperation, especially given the continuing stigma and discrimination associated with an HIV diagnosis and the criminal laws associated with some risk behaviors.² Moreover, conducting PS in a manner that is conducive to trust will make it more likely that newly identified HIV-infected individuals will access care.³ The Guidelines should explicitly state that strong confidentiality protections and safeguards to prevent sharing of information obtained through PS with law enforcement and the courts are necessary components of any PS program and that PS providers must be prepared to resist efforts by law enforcement officials to obtain information. Without such safeguards, PS is unlikely to be effective and to further its public health goals.

V. The requirement of voluntariness must be more fully discussed in the Guidelines:

As noted in Point I, above, voluntariness is so important a principle that it should be included among mandatory standards for CDC-supported PS. We agree that PS should be offered to each person who tests positive for HIV, but each person must be informed that acceptance of PS is not required and that his or her eligibility for other services will not be affected by whether or not he or she accepts PS. Acceptance of the services must be voluntary for both the index patients and the partners. The index patient must be informed that he or she can refuse to identify partners and can refuse to receive assistance in contacting partners. The partners must be informed that they can refuse to find out why they have been contacted and can refuse to be tested.⁴ Both index patients and partners must be informed of who will have access to

² See, e.g., Passin, W.F., et al., *A systematic review of HIV partner counseling and referral services: client and provider attitudes, preferences, practices, and experiences*, 33 SEX. TRANS. DIS. 320-328 (2006) (fear of lack of confidentiality identified as barrier to participation in partner notification).

³ See, e.g., Wood, E., et al., *Expanding access to HIV antiretroviral therapy among marginalized populations in the developed world*, 17 AIDS 2419-2427 (2003).

⁴ Similarly, partners have the right to decline other services; for this reason, the text at lines 1118-1120 should be altered to read: "For partners who test positive and do not decline such services, it is essential that the PS providers assure that the newly diagnosed HIV partners are connected to early intervention, medical care, and prevention counseling and that partner services are again initiated."

information and all the uses to which the information might be put, before information is elicited.

In order for participation in PS to be truly "voluntary" and to be conducted in an ethical manner, each person offered PS also must be fully informed -- before information is elicited -- of the possible ramifications for him or her of providing information about partners and accepting PS. In particular, before information about partners is elicited, each index patient must be informed as to what information could expose the person to civil or criminal penalties, so that the index patient does not unwittingly divulge incriminating information.

The Guidelines should explicitly state that coercive methods of obtaining cooperation or information must not be used. The Draft Guidelines only acknowledge the risk of coercion at line 551, with reference to "interview settings." The need to avoid coercive tactics should also be mentioned in the context of training, refusal of partner services, interviewing and counseling index patients, and notifying partners of their exposure, as well as in standards, as suggested in Point I.

As noted at the Consultation, the conditions of incarceration are fundamentally different from the conditions outside correctional settings. Those differences are especially, but not exclusively, relevant to the issue of voluntariness. As recommended by one of the work groups at the Consultation, separate guidelines need to be developed for HIV PS for persons held in jails, prisons, juvenile detention facilities, and secure mental health facilities.

VI. The need for confidentiality must be addressed more fully in the Guidelines:

We commend the CDC for the frequent references in the Draft Guidelines to the need for confidentiality, as the importance of ensuring confidentiality cannot be stressed enough. However, statements regarding the importance of confidentiality lack teeth in the absence of an effective civil and criminal enforcement mechanism. The effectiveness of PS depends upon all aspects of the services being conducted in a confidential manner and the confidentiality of all information being strenuously protected. In addition to including confidentiality among the required "standards" for PS, see Point I, the Guidelines should address the necessity of meaningful sanctions for any breaches of confidentiality, such as providing that client consent forms state that clients may file breach of contract suits for any confidentiality violations. Moreover, the Guidelines should specify standards for a PS privacy policy, including protections such as ensuring that there is no risk of disclosure of information to law enforcement, that the information collected may be used only for the stated purpose of its collection, that the information may not be shared with persons other than as

specifically disclosed to the client, and that client-identifying data linking index patients to partners will not be maintained after partner contact has been achieved.

Also, the need for confidentiality should be addressed in additional sections of the Guidelines. The section on "Contacting Index Patients" (lines 628-643) should specify that, where in-person contact is not possible and therefore another contact method is used, the contact must be made in a way that does not indicate it is from a PS provider. Similarly, the Guidelines should specify that protocols for conducting field tours with clients (lines 872-875) must include protocols ensuring that the PS provider will not be identifiable as such while on the field tour. The risk of loss of confidentiality due to provider contact of partners should be added to the disadvantages of provider notification (lines 994-997).⁵ The Guidelines should not list "unannounced home visits" as a possible strategy for resolving inconsistencies in case management information (lines 1321-1322), but instead should state that "unannounced home visits" should not be made, because they pose a very high risk of loss of confidentiality. The discussion of confidentiality in the section on "CBOs Conducting Partner Services" (lines 2143-2154) should be strengthened by stating that CBOs should not conduct PS unless they have protocols ensuring that the services will be conducted in a confidential manner, that all information will be maintained in a confidential and secure manner, and that penalties will be imposed for any breaches of confidentiality.

VII. The importance of training of those conducting HIV PS should be stressed:

The Guidelines need to more fully address the issue of staff training and supervision. PS must be delivered in a competent and sensitive manner to be successful, as indicated by the Guidelines at lines 35-36. For example, index patients who are informed in a competent and sensitive manner about the positive and negative ramifications of providing information are more likely to provide information. And how partners are approached will influence the extent to which the index patient and/or the partner may be stigmatized.

The discussion of training at lines 528-533 should be expanded. For example, that section should mention the need to train interviewers in non-coercive methods of eliciting information and in the proper amount of detail and information to include in PS documents. Also, the Guidelines should state the necessity of requiring training of any providers outside of the health department's PS program (including CBO staff). The Guidelines should also acknowledge the need for frequent trainings, given staff turnover, as well as continuing training for counselors.

⁵ Additional disadvantages to provider notification that should be listed are that the partners may be more reluctant to cooperate and may be more reluctant to accept services if notified by a stranger.

VIII. Miscellaneous comments:

The language throughout the Guidelines and in training and program materials should not imply directionality of infection. That is, there should not be any stated or implied assumption that the index patient infected any HIV positive persons located by PS, nor that the source of the index patient's infection has been discovered.

The sections on "Partners" and "Social Contacts and Associates" should be revised to better develop the discussion on case management. Those sections should specifically address issues particular to victims of rape and other violent crime and to immigrants. In addition, those sections need to be revised to eliminate inconsistencies and reduce repetitiousness. The separate section devoted to minors should include discussion of the special issues related to the partners, social contacts, and associates of minors.

IX. Concluding comments:

We look forward to reviewing the revised Guidelines, including the sections that were identified at the Consultation as incomplete in the Draft Guidelines. In particular, the complete section on Legal Authorities and Issues should discuss the impact of criminal laws relating to HIV transmission, injection drug use, and prostitution on some individuals' willingness to reveal partner information or even be tested, including the different considerations faced by a patient who has previously tested positive compared to a patient who has just tested positive for the first time.⁶ The section on special considerations related to minors will need to address the reasons why and ways in which PS should be conducted differently with minors, including the impact of minor-specific laws on PS (in particular, those relating to confidentiality of medical care for minors and reporting of sexual activity of minors).

An overarching concern of ours is that a lack of financial resources may reduce the effectiveness of PS and/or result in it being conducted improperly. To be effective, Partner Services must be done well, which will require significant staff time. And for PS to be meaningful, it must be possible to link each person who tests positive with health care, which will also require increased funding. Increasing the number of persons identified as infected with HIV without making available to them all needed services will not serve those individuals or the public.

⁶ See, e.g., Passin, *supra*, at 327 ("Some drug users may be unwilling to provide partners' names because they are engaging in an illegal activity and fear their partners would face legal ramifications"); Webber, D.W., *Self-incrimination, partner notification, and the criminal law negatives for the CDC's "Prevention for Positives" initiative*, 19 AIDS & Pub. Pol. J. 54-66 (2004) (including discussion of the use of "confidential" healthcare or public health HIV status information for criminal prosecutions).

As a new draft of the Guidelines is developed, it will be important to provide an opportunity for review and comment by more stakeholders. Those of us who were included in the Consultation appreciate the opportunity afforded us, but we recognize that, inevitably, many other organizations with significant relevant expertise and involvement with those who will be affected by PS were not part of that process. In addition, with more time to review the Draft Guidelines both before and after the Consultation, the undersigned would have been able to provide additional suggestions for improving the guidelines, including suggestions for further research needed. We specifically urge that, before finalizing the Guidelines, you publish them in the Federal Register, with at least a sixty day period for comments, both to allow us to comment on the revised language and so that other community input can be obtained.

We are interested in continuing this dialogue, so that Partner Services are provided in a way that benefits individuals living with HIV and their partners while serving important public health goals.

Sincerely,

AIDS Foundation of Chicago

David Ernesto Munar, Associate Director
411 S. Well St., Suite 300
Chicago, IL 60607

American Civil Liberties Union

Washington Legislative Office
Christopher E. Anders, Legislative Counsel
915 15th Street NW
Washington DC 20005

The Center for HIV Law and Policy

Catherine Hanssens, Executive Director
65 Broadway, Suite 832
New York, NY 10006

Community HIV/AIDS Mobilization Project (CHAMP)

J. Walton Senterfitt, Board Chair
293 Oxford St.
Providence, R.I. 02905

Health GAP (Health Global Access Project, Inc.)

Jeanne Bergmann, Organizational Development Coordinator
20 E. 9th St., # 18A
New York, NY 10003

HIV Law Project

Samuel Dooley, M.D.
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Tracy L. Welsh, Executive Director
15 Maiden Lane, 18th Floor
New York, NY 10038

Lambda Legal

Bebe J. Anderson, HIV Project Director
120 Wall St., Suite 1500
New York, NY 10005

HIV/AIDS Bureau, Massachusetts Department of Public Health

Kevin Cranston, Director
250 Washington St., 3rd Floor
Boston, MA 02108

National Association of People with AIDS

Frank Oldham, Jr., Executive Director
8401 Colesville Rd., Suite 750
Silver Spring, MD 20910

National Minority AIDS Council

James Albino, Government Relations and Public Policy
1624 U St., NW Suite 200
Washington, DC 20009