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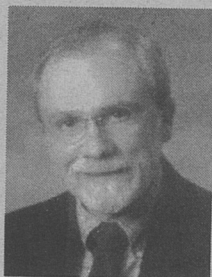
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Views: Big Brother Is Watching PWAs

The Vermont Health Department may soon be collecting unprecedented amounts of data from federally funded HIV prevention programs. Under pressure from the CDC, the department will be requiring all prevention programs in the state to use a web-based database called PEMS (Program Evaluation and Monitoring System) to collect data on their programs. This is a drastic change in both the amounts and the types information currently collected. Failure to provide this information will likely result in loss of federal funding, currently the only source for HIV prevention programs in the state.

The proposed draft version of PEMS contains 95 pages of questions and variables that providers will have to answer to document their services. Agencies are also required to answer detailed questions about their organization, their other funding sources and specific information on every staff member and volunteer.

Additionally, lengthy sets of questions for each client program activity must be reported. While not every question needs to be answered for each activity, there still will be a large amount of data to report that will be time consuming and especially burdensome on smaller community based organizations.

More troubling than the administrative headaches are significant concerns about confidentiality. PEMS has eight pages of identifying questions about each individual program participant, including their HIV status and risk behaviors. For the first time CDC is requiring that each person accessing prevention services be identified with a unique identifier. Unique identifiers are codes created using some parts of names, social security numbers, or other identifying data that sup-

**chuck
kletecka**

posedly conceal a person's identity. However, in small states like Vermont, it doesn't take very many bits of information to figure out who is who. For example, PEMS reports the month and year of birth as well as the county of residence. That information, along with several letters of a person's name, would be enough to break the code to identify an individual.

And it gets worse. The CDC is also requiring sexual partners be identified with their own unique identifier. The descriptive text in that field reads, "a system-generated unique key developed for part-

Also troubling is the fact that this will be a web-based database. All PEMS data will be stored at a central server with the CDC. How secure will this sensitive information be from computer hackers and unauthorized use? The CDC will also have direct access to all the information and will be able to pull-up data on any specific agency, program or individual it chooses, for whatever reason it chooses.

How many folks will steer clear of prevention programs because of these very real concerns is anyone's guess. But the communities most impacted by HIV and those who would benefit most from competent HIV prevention services have very real and historical concerns regarding the actions of "government." Once the word is out about PEMS, years of hard work building trust and respect for confidentiality will be undermined. In its place may well be an HIV underground where infections

The CDC is also requiring sexual partners be identified with their own unique identifier. Could this be a first step towards mandatory partner notification?

ners of index cases for PCRS." PCRS is Partner Counseling and Referral Services. Could this be a first step towards mandatory partner notification? If fully implemented, it would be theoretically possible to follow a network of individuals and all of their interacting HIV risk behaviors.

will flourish. Unfortunately, a very real possibility if the Big Brother-like PEMS becomes official policy. ▼

Chuck Kletecka is a Vermont PWA Coalition board member. For questions or comments, email him at chuckk@adelphia.net.