Big Bro

March 1, 2000 By Shana Naomi Krochmal

The CDC blindsided many in the AIDS community with its December release of new recommendations requiring all states to report the names of people who test HIV positive—or risk losing federal funds. After 18 years, the agency says it needs hard numbers, not estimates, to track infections.

In fact, 35 states already use names-based reporting. Four others employ unique identifiers, a coding system widely backed by names critics because it counts each case of HIV while safeguarding anonymity. And even the CDC allows that if its regs are adopted nationwide, its surveillance data will remain sketchy—limited to the two-thirds of all HIVers who are diagnosed in a doctor’s office or other confidential testing sites. (The one-third diagnosed through anonymous testing centers or at home with kits will still go untracked.) To counter critics’ longstanding argument that fears of exposure and discrimination deter would-be testers, the CDC cited a 1999 study by the University of California that found no significant effect.

Activists also worry that the CDC’s regs will be legislated into this year’s reauthorization of the Ryan White CARE Act. With major AIDS organizations dependent on that money, getting them to give up funding rather than give out names may be the hardest sell of all.

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