

DYKE



PSYCHE

Conducting the National Lesbian Health Care Survey: First of Its Kind

BY ESTHER ROTHBLUM

Given the number and range of research projects about lesbians in recent years, it is easy to forget how challenging it was to survey lesbians even a decade ago.

But when Caitlin Ryan and Judy Bradford conducted what became the National Lesbian Health Care Survey in the 1980s, they were breaking new ground. This study eventually brought in 1,925 completed questionnaires from lesbians in all 50 US states. It figured prominently in the recent Institute of Medicine Report of the National Academy of Sciences. And even today, there are lesbians (including me!) who remember completing a questionnaire for this study 15 years ago.

Getting Started

In the late 1970s, Caitlin suggested forming a national organization that would be multi-disciplinary, focus on lesbian and gay health issues, and sponsor research and education. At the time, there was no available information on how lesbians conceptualize lesbian health or how stigma affected health, mental health, self-care, and access to care. She began to talk with other lesbians about the need for a survey.

With a grant from the fledgling National Lesbian and Gay Health Foundation, she hired a research consultant, sociologist and survey researcher Dot Parkel, to help design the study and develop questionnaire drafts. Caitlin says, "I remember talking with a researcher who was herself a closeted lesbian, who sat down with me and basically told me that I could not possibly do a study like this. She just felt that it was not feasible. And, of course, there was no such thing as a representative sample. I saw this woman recently and we laughed about her earlier skepticism. She said, 'I told you that you couldn't do and you went out and did it.'"

Judy got involved by attending the International Lesbian and Gay Health and AIDS Conference at New York University with a male friend from graduate school. They were both interested in AIDS research, which was just getting started then. Everywhere Judy looked — and she went to a lot of sessions — there were mostly men. Then she noticed a scheduled women's group, which turned out to be an organizing meeting for the National Lesbian Health Care Survey. Caitlin was facilitating the group; when Judy said she was a graduate student and described what she was doing, she suddenly became co-investigator, responsible for data analysis and preparing the survey report.

Getting It Out There

Caitlin had been very concerned about inclusion. Many early studies, and even those con-

ducted today, show highly educated samples of lesbians. She wanted to include women of color and women of different economic backgrounds without language being a barrier. So she talked with people about how to ask clinical questions in a non-clinical way. "I talked with women bus drivers, day laborers, women who had been recently diagnosed with cancer, about their experiences and how we should ask these questions," she says. "All of that helped frame how we would shape a questionnaire."

She elicited suggestions about language in focus groups in several different parts of the country. They pretested the questionnaire at several lesbian and gay conferences and with individuals around the country. They would ask the women in focus groups to fill out the questionnaire; then they would talk about it and hear what people thought of it to make it more accessible. After several cycles of that process, they final-

ized the questionnaire.

Since Caitlin had done the early lesbian and gay health organizing, she had a large address base of people around the country willing to help distribute questionnaires. Their distribution plan was kind of an unusual approach to snowball sampling. The methodology was intended to get the questionnaires out as broadly as possible to people all over the country, including Alaska. As part of the attempt to reach underrepresented, previously unsampled populations, they made a commitment to getting it to lesbians in the military, on Indian reservations, and in prison. They also tried reaching non-English speaking women and lesbians of color in a variety of ways, including having lesbians of color give it out to their networks around the country. Groups as varied as the National Coalition of Black Lesbians and Gays, the Wisconsin Governor's Task Force and the National Organization of Women

sent out information about the survey, and details appeared in a variety of lesbian and gay newsletters.

The survey went out in the fall of 1984; by early 1985, they had received surveys back from 1,925 lesbians from every state. Hearing from so many lesbians was not only a wonderful experience, but had the sense of a national movement. There was an electric energy — everyone had a great sense of how important the survey was.

Of course, the challenges did not end there. Another major issue was finding money and personnel for data entry and analysis. The early 1980s was not a time for funding lesbian projects. Once they managed to put together a shoestring budget, Judy sent the questionnaires out to the Virginia State Prison, where all the lab's data entry was done at that time. She says, "The questionnaires did not arrive back. When our project manager called about this, he was told they wouldn't code the sur-

veys. I got another company to do it, and the same thing happened. Finally, when it came to the third company I was told that the data entry staff were afraid to touch the questionnaires for fear of getting AIDS!"

Eventually, the final hurdles were overcome, and the landmark study was completed and released. Over the years, wherever Judy and Caitlin are, they continue to run into lesbians who participated in the survey, and who want to talk about the impact that it had on them. Many women wrote pages of material in addition to the answers they gave to the items on the questionnaire. ▼

Esther Rothblum is Professor of Psychology at the University of Vermont and Editor of the Journal of Lesbian Studies. She can be reached at John Dewey Hall, University of Vermont, Burlington, VT; email: esther.rothblum@uvm.edu.

More Letters

continued from page five

Not Only on the Board, But a Reader, Too

Editor:

It is often the case that we take time to write papers to complain, vent, accuse or criticize. I am happy to report that this letter is none of the above. I have wanted to write for some time to express my thanks to Charles Emond for his monthly installment of "Stonehenge To Stonewall or Gay History In A Nutshell".

This is one of my favorite pieces in *Out In The Mountains*. Not only do I learn something each time I read it but it also makes me smile. I find Mr. Emond's humorous approach to presenting our history to be fun and informative. History is important to all people and communities, including our own and I am glad that Mr. Emond is one of my teachers. I haven't had this much fun with history since reading "The Cartoon History of the Universe".

Please pass along my thanks to Charles for his wonderful history lessons each month, and I look forward to his future installments.

Roland Palmer
Hinesburg, VT

Editor's Note and shameless columnist plug: Charles Emond will be teaching Hidden History: Homosexuality in Western Civilization, the course upon which Stonehenge to Stonewall is based, at Community College of Vermont in White River Junction this fall.

More Pride Fireworks

Editor:

Rarely do I lower myself to say "I told you so," but after reading Bob Bolyard's weepy letter to the editor in last month's issue of *OITM*, I felt it was my duty to make everyone aware of the truth about Pride.

Bob stated that for the second year in a row Pride "failed to collect enough money...to pay for the expenses of the day." Surprise! Also, he stated that the majority of the attendees "didn't do a darn thing to support it."

Other interesting quotes: Samadhi Singers did a benefit for Outright Vermont, not for Pride (did Pride even bother to ask them to do a benefit?); Kick-Off Pride Week event with Yolanda and Noel didn't get a "kickback" (he forgot to mention that each performer only received \$20 for the night — were they supposed to give it right back, after having to fight for it? Also, the band members and Noel's accompanist had to be paid regardless); Interfaith Pride Worship Service and Pride Ball at City Hall gave no money to Pride from their events. Did any of these events even state they would give money to Pride?

Also, Bob stated that the Pride guide ad revenue went to print the guide. Why didn't he bitch about RBA giving money to Pride?

What Bob purposely forgot to mention is

1. About a year ago I searched through thousands of pages of grants to pick about a dozen grants that would fund Pride. Not one grant foundation was

approached. Their reasoning: "We don't know how to write a grant." Solution given: Contact Volunteer Connections through United Way to help. To the best of my knowledge the phone call was never made;

2. United Airlines donated two airline tickets to raffle off to help raise money to get the nationally known a capella group Men Out Loud here for pride. The committee never pursued it.

3. Various vendors wanted tables at Pride, including a couple of video retailers and a t-shirt company as well as the Human Rights Commission from Washington and the Gay Financial Network (GFN) from Florida. To this day I don't believe any of them were even contacted.

4. The committee turned down trying to get Greg Louganis, Chasity Bono, and the cast from the NBC hit show "Will and Grace" to appear. Note: No money would have had to changed hands for this to happen. Instead, they decided against it.

5. The committee also slammed Yolanda and Cherie Tart at the first meeting last summer then in the same breath said they wanted to have them perform. Then they expected because they were gay and Vermonters that they should perform for free and were upset when Yolanda turned them down to go to Portland and get paid and promote her new CD. Would anyone of you turn down a paying job?

Also, I'm curious (and I mean no disrespect to him) to find out how much they paid Craig to DJ. Pride cries about being poor yet they turned down free money.

I think most of the current members should pay the debts (since they are not a non-profit organization, the committee members are solely responsible to pay for any debts incur) and let another group who will run the organization as a business (not as a party, like Bob likes to loudly state) take over.

And isn't it surprising (maybe not) that after telling them to have a theme this year (the 30th. year of Stonewall), they refused that, too.

Dean Pratt
Burlington

Another Voice on the Same Subject

Editor:

I read the July letter to editor regarding Pride by Bob Bolyard.

The Pride Vermont organization should reevaluate how they do business, and operate the group as a business. Bob appeared critical of the fact the Rainbow Business Association did not donate any proceeds from advertising in the Pride Guide to the Pride committee. But, he should consider how many more people may have attended Pride Day because of the Pride Guide being distributed prior to the event. So it was an indirect contribution from the RBA.

Maybe the Pride Vermont organization should try cutting some of the unnecessary expenses from their budget, and try getting more bang for their bucks, as pointed out in the July letter from Dean Pratt.

Scott Brimblecombe