ATTACHMENT B

REPORTS OF MEETINGS OF THE TASK FORCE ON AGING

TASK FORCE ON AGING AGENDA

10/30/81

- I. INTRODUCTION
- II. PURPOSE OF THE COMMISSION ON PERSONAL PRIVACY
- III. PRIORITY ISSUES IDENTIFIED FOR STUDY BY THE COMMITTEE ON AGING AND DISABILITY
- IV. DISCUSSION OF POSSIBLE ISSUES FOR STUDY REGARDING THE PERSONAL PRIVACY PROTECTIONS/ABUSES THE AGING POPULATION EXPERIENCES
- V. PUBLIC HEARINGS
- VI. SCHEDULE NEXT MEETING

Handouts:

- A. Executive Order
- B. Purpose of Commission
- C. Public Hearing Notices
- D. Agenda

COMMISSION ON PERSONAL PRIVACY

107 South Broadway, Room 1021 • Los Angeles, CA 90012

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THE PURPOSE OF THE COMMISSION ON PERSONAL PRIVACY IS:

TO EXPLORE problems of discrimination based upon sexual orientation and invasions of the right of personal privacy, particularly among such groups as the elderly, the disabled, ethnic minorities, adolescents, gays and lesbians, unmarried persons, and institutionalized persons;

TO DOCUMENT the extent of these problems;

TO NOTE the adequacy of existing law to protect the personal privacy of all individuals in this State;

TO REPORT its findings and to make any appropriate recommendations; and

SO THAT legislative and administrative action and public attitudes may be based upon accurate information in order that the public policies of this State to safeguard human potential as our most valuable resource, to judge individuals on their own qualities and merits, to protect against sexual orientation discrimination, and to protect the right of personal privacy against the threat of invasion, may be effectively implemented in both the public and the private sectors.

MINUTES OF TASK FORCE MEETING

10/30/81

Present: Lee Gilman, Marie Bolduc, Nora Baladerian

By telephone: Sharon Hensel

Few were present (more attempted to arrive but were preempted by the Dodger Street Parade held in front of the offices - traffic was impossible to break through)!

Main Topic: Critical issues for study were proposed, subsequent to a review of the purpose of the Commission, the Committee on Aging and Disability, and the position of the Task Force on Aging.

Issues Identified:

- 1. A review of regulations and laws protecting individuals who reside in institutions is needed.
- 2. A review of the current implementation procedures for confidentiality laws in residential facilities is advised.
- 3. Problem: Companion-aides who work for home health agencies or registries receive no training or supervision from the hiring agency.

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TASK FORCE ON AGING AGENDA

12/9/81

- I. INTRODUCTION
- II. PURPOSE OF COMMISSION
- III. PURPOSE OF TASK FORCE
- IV. IDENTIFICATION OF SPECIFIC ISSUES FOR STUDY
- V. PLAN FOR STUDY
- VI. TASK PLANNING
- VII. SCHEDULE FOR FUTURE MEETINGS

Handouts:

- A. Purpose of Commission
- B. Executive Order
- C. Public Hearing Notices
- D. Article
- E. Agenda

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TASK FORCE ON AGING

Minutes of Meeting, December 9, 1981

Present: Roy Azarnoff, Nora Baladerian (Commissioner), Marie Bolduc, Thomas Coleman (Commission Executive Director), Margit Craig, Cathy Gardner (Commission Staff), Lee Gilman, Sharon Raphael, Mina Robinson.

Present via Telephone: Evalyn Gendel, Bea Shifman.

I. Introduction: Each person introduced themself and offered some background information. Past director of Los Angeles' area aging Roy Azarnoff: committee. Nora Baladerian: Commissioner, Commission on Personal Privacy; Chairperson, Commission's Committee on Aging and Disability. Marie Bolduc: USC/UCLA - graduate intern, gerontology and social work; Task Force on Elder Abuse. Thomas Coleman: Executive Director, Commission on Personal Privacy; Attorney at Law. Margit Craig: Director, Project Caring; participant in advocacy group concerned with older institutionalized persons; member, National Council of Jewish Women. Cathy Gardner: Research Assistant, Commission on Personal Privacy; law student. Physician; training in sexuality, including Evalyn Gendel: aging and sexuality. Lee Gilman: Medical social worker; Director, Home Health Care of West Los Angeles. Sharon Raphael: Socialogist; Chairperson, Graduate School of Gerontology. Mina Robinson: Gerontologist; teacher; Master Thesis on "Older Lesbians"; Coordinator, 1981 conference at Dominguez Hills State College.

II. Purpose of the Commission:

The purpose of the Commission was discussed as per the Executive Order and the "statement of purpose".

III. Purpose of the Task Force on Aging:

to develop recommendations which will go to the Governor and the Legislature:

Bea Shifman: Member, National Council on Aging; Social Worker;

- to provide some guidelines to the Courts in their use of the term, "Personal Privacy";

working with persons in minority communities.



III. (continues)

- to aid in producing a report by March, 1982;

- to consider the use and applicability of the U.S. Constitution's 14th Amendment re: due process (action and infringement by government);

- to consider the use and applicability of Article I, Section 1 of the California State Constitution (adopted by voters in 1972 and pertaining to privacy);

- to study personal decision making as related to intimate association. (Dr. Karst, Professor of Law at UCLA, has written an article on personal privacy, decision making and the right to intimate association. Distribution of this article to Task Force members was requested.)

IV. <u>Identification of Specific Issues for Study</u>: "Brainstorming" resulted in the following list of issues:

- 1. Eligibility to long term care for both members of a gay/non-married couple.
- Privacy rooms.
- 3. Training of aids, directors and administrators of care facilities.
- 4. Day Care Activity Center Populations: Issues re: bringing partners.
- 5. Home care situations that locate personal privacy issues (ie. training re: preserving privacy) LVN's, RN's, retirement homes.
- Attending physician's homophobia.
- 7. Gay/lesbian reluctance to use generic services for the elderly.
- 8. General lack of rights for elderly.
- 9. Family unit concept (discrimination written into tax 1: laws).
- 10. Discrimination against survivor where couple is not married. (For example, treatment at funeral home, ICU, CCU, ER, etc.)
- 11. Right to keep information re: income private. Exercise of this right means that eligibility to community services, including L.A. City Recreation programs, can be denied. (Means test).
- 12. Day Centers require financial screening where similar services do not require "means test".
- 13. Mechanisms so specific abuses re: sexual orientation can be dealt with in some way; (ie. not receiving adequate care in institutions).
- 14. Zoning laws discrimination against non-related persons living together. (It was pointed out that this was being investigated by another Commission committee.)



IV. (continued)

- 15. Become aware of patients' rights groups who are concerned with the rights of elderly patients/persons, and, these groups awareness/activity re: personal privacy, sexual orientation discrimination and elder abuse.
- 16. Educating the Elderly as perpetrators/victims of discrimination re: rights, stereotypes, myths, especially re: gay and lesbian persons.
- 17. Use of and access to medical dossiers.
- 18. Lack of programs for the gay and lesbian elderly community and non-integration into general programs; encourage special programs or integration.
- 19. Delegation of decision making, access to records, durable power of attorney.
- 20. Identification of older gays/lesbians in order to provide services in a "humane" and dignified format. (For example, census taking.)

V. Plan for Study:

A suggestion was offered by Roy that the Task Force use a "grid" for organizational purposes so as to aid in categorizing the issues. This suggestion was put into graphic form on the chalk board and is reproduced herein. (See attachment "A")

VI. Task Planning:

- 1. In General People agreed to let the staff and Nora know of other
 persons who may be interested in participating in the
 Task Force. The Task Force will develop a comprehensive
 list of personal privacy issues before any final decisions
 are made. A report will be made to the Task Force
 members, by same, on March 1, 1982. This report will
 (partially) contain an overview of the relationships
 between agencies (ie. federal, state, counties). The
 Task Force members will begin documentation.
- 2. In Particular
 Mina offered writing skills; Nora will chair; Roy will begin to develop a list of advocacy groups who are dealing with aging; Mina and Roy will work at identifying gay and lesbian services for the elderly; Mina and Sharon indicated interest in reporting elder abuse; Marie, Mina, Sharon and Lee will investigate the training given to service providers as re: to issues 1,2,3, and 5 under section IV. of these minutes.

VII. Schedule for Future Meetings:

Wednesday, January 6, 1982 at 2:00pm. was agreed upon for the next meeting of the Task Force. The meeting will again be held at the Commission's Office in the State Office Building, 107 South Broadway, Room 1021, Los Angeles, CA 90012.



VIII. Miscellaneous:

Items handed out at 12/9/81 meeting:

- 1. Statement of Purpose
- 2. Executive Order
- 3. Public Hearing notice
- 4. article on Sexuality and Aging
- 5. Agenda

Minutes prepared by Cathy Gardner 12/30/81



A	Institutions	Community based programs	Residential
State & Federal Regulations			
Relationships			
Education/ Training			
Economics			
Reporting			
Advocacy Groups			

Attachment "A"

COMMISSION ON PERSONAL PRIVACY

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TASK FORCE ON AGING

PROPOSED AND PARTIAL AGENDA

1/6/82

- I. SCHEDULE FOR FUTURE MEETINGS
- II. VOLUNTEERS TO STAFF TASK FORCE
- III. PREPARATION OF REPORT TO BE SUBMITTED VERBALLY TO COMMISSION MEMBERS AT JANUARY 30TH MEETING
- IV. FURTHER EXPLORATION OF ISSUES TO BE STUDIED
- V. ASSIGNMENT OF SPECIFIC TASKS

*Additions and/or modifications to the agenda welcomed.

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December 30, 1981

	Institutions	Community Based Programs	Residential
State & Federal Regulations			·
Relationships			
Education/ Training			
Economics			
Reporting			
Advocacy Groups	_		

Please fill in this form based on Roy's "grid" and indicate:

- 1. Areas of interest
- 2. Amount of time you can contribute to work in this area

Also, please add your special skills such as writing, resources, library access, etc. and return this to the Commission's office.

TASK FORCE ON AGING

Minutes of Meeting, 1/6/82

Present: Roy Azarnoff, Nora Baladerian (Commissioner, Task Force Chair), Zoran K. Basich, Marie Bolduc, Thomas Coleman (Commission Executive Director), Cathy Gardner (Commission Staff), Evalyn Gendel, Lee M. Gilman, Jonathan Glassman, Betty V. Graliker, Sharon Raphael, Mina Robinson, Beatrice Schiffman, Colleen Treiner.

I. INTRODUCTION

Each person present and on the telephone introduced themself to the group. New to the Task Force:

Zoran K. Basich: Attorney in private practice, Los Angeles, CA. Has extensive experience in financial matters, inheritance law, etc.

Jonathan Glassman: Director, Los Angeles County Department of Senior Citizens Affairs.

Betty Graliker: Chief Counselor, Frank D. Lanterman, Regional Center for Citizens with Developmental Disabilities, and Community Liaison.

<u>Colleen Treiner</u>: Staff at Home Support Services in West Los Angeles, Graduate Student from USC in Gerontology.

II. DISTRIBUTION AND REVIEW OF MATERIALS

Tom Coleman, Executive Director of the Commission led the meeting. The following materials were distributed: Task Force Roster, List of Committees and Task Forces of the Commission, minutes of the meeting of 12/9/81, Agenda for the Commission meeting in Sacramento, 1/30/82, Staffing Chart, Organizational Chart of the Committees, and the Agenda for this meeting. The meeting proceeded through the steps outlined on "COMMITTEES AND TASK FORCES January Meeting Checklist" (see Attachment Item "A").

- A. All persons present indicated their desire to be considered members of the <u>Task Force</u> with the exception of: Betty Graliker and Colleen Treiner who deferred commitment until the next meeting.
- B. The name of the group was confirmed as is, "Task Force on Aging".

C. Schedule for all future meetings was established. All will be on Wednesday afternoons, 2 p.m. - 4 p.m. except 1/20 which is 2 p.m. - 5 p.m. and 5/14 from 10 a.m. - 12 p.m. Dates are:

1/20 3/10 4/28 2/10 3/31 5/14

- Staffing availability and Recruitment of Volunteers was D. presented. Cathy Gardner, staff to this Task Force is available Monday afternoons and all day Wednesday. This is not sufficient for the quantity of work required. Jay Glassman offered to have minutes and other mailings of this Task Force typed and mailed out from his office. Also any reasonable xerox requests could be met by him. His word processing resources are also available to the Task Force. He suggested contacting the Andrus Gerontology Center for volunteers...Lee Gilman has already done this. Roy will encourage Jay's coalition committees to participate with the Task Force, Sharon and Mina may be able to get some new student interns as the semester begins at Cal State Dominguez. Lee has also contacted UCLA for volunteers/students. Jay suggested that the National Council on Aging be contacted if we can provide training that will lead to actual employment at the end of the Task Force.
- E. Review of Commission Report; Committee and Task Force Operating Procedures (see Attachment Item "B"). Discussion included research materials available. Marie will report back to Task Force on procedures and cost of bibliographical searches by the Andrus Center Library. Collen, familiar with Andrus Center Volunteer program will assist and report back also. Sharon offered the network capabilities of the National Association of Gay and Lesbian Gerontology Center. Jay suggested also the resources of SCAN for searches. Questions regarding the comprehensiveness of our report and the exact topics to be covered will result from our next meeting and the resources we develop.
- III. Task Force Report for full Commission consideration must be prepared by Nora by 1/24 for presentation 1/30. This report must include the Task Force proposals for study including topics, individual participation in the preparation of the report, and resources available to work with us. Tom reviewed with the Task Force the "Suggested Criteria and Considerations for Use in Selecting One or Two Problems for In-Depth Study". These will be used by Task Force members in deciding problem areas to select and propose at the next meeting. A copy of the summary of contractually required issues for study will be mailed to all members (see Attachment, Item "C").

Task Force Minutes 1/6/82 Page 3

IV. Agenda for the next meeting will include identification of issues selected for study, and agreement on one or two to propose to the full Commission. Also, members should consider the time and resources they are prepared to expend in this effort, and make this known at the next meeting for proper planning for completion of the report.

NEXT MEETING: 1/20/81 2:00 p.m. - 5:00 p.m., State Office Building

(*Indicates promise of work to be completed.)

TASK FORCE ON AGING

Minutes of Meeting, 1/20/82

<u>Present:</u> Nora Baladerian (Commissioner, Task Force Chair), Marie Bolduc, John Cohan, Cathy Gardner (Commission Staff), Lee Gilman, Jonathan Glassman, Sharon Hensel, Sylvia Morrisson, Sharon Rafael, Mina Robinson, Bea Schiffman.

I. INTRODUCTIONS

Each person present and on the telephone introduced themself to the group. New to the Task Force:

John Cohan: Attorney in private practice, host of television talk show, "Visions of Today" on cable television.

<u>Sharon Hensel</u>: Speech pathologist in private practice, including work with elderly patients, stroke patients, others in institutional settings.

Sylvia Morrison: Staff at Los Angeles Regional Family Planning Council, previous work involved a Study on Aging for the United Way. Staff work at LARFPC includes much demographic, cultural, and budgetary expertise.

- II. Identification of Issues Selected for Study by the Task Force, and resources available for the completion of a product acceptable for including in the report of the Commission's references and as a whole in the Supplement.
 - A. Issues for study: Proposals
 - 1. Invisibility of older lesbians and gay men which result in problems such as those listed in items #7, 18 and 20 by the Task Force (see minutes of Meeting 12/9/81). A written proposal prepared by Mina Robinson and Sharon Rafael was distributed (see Attachment), including a plan for study. Their proposal was immediately approved by the Task Force as one report that would result from the Task Force. Sharon and Mina are prepared to conduct the study and complete a report, however, any contributions and assistance are welcomed. Commitments will be made following a final decision on the complete work of the Task Force.
 - Right to keep personal information, such as income, private (#11), such as means test data. Jay Glassman would be interested in studying this issue, including questions of the appropriateness of means test, maintenance of confidentiality, aggregation of information on MIS programs.

- 3. Issues of elder abuse (#13). Jay Glassman would be interested in studying current proposed legislation such as the bill proposed by Gerald Felando, AB 1805. Issues: Real protections of the person and personal privacy of the victim of abuse, assurances of such protections, value of a mandatory reporting requirement, in prevention.
- 4. Economic discrimination against elderly persons, invasion of the State in personal decisions of living status (marriage/living "in sin"). Jay Glassman would be interested in studying State vs. Federal regulations in this area, and inheritance tax issues.
- 5. Employment discrimination based on age. (Jay Glassman)
- 6. Team medical examinations and discussions without (respectful) participation/inclusion/consent of the elderly patient, Lee Gilman would be interested in studying regulations, practice and effect of this.
- 7. Death pronouncements by telephone without physical presence of a physician are, according to Lee, a common practice. Study would include legalities, invasion of personal privacy including following through on deceased's instructions re: personal effects, funeral arrangements, etc.
- 8. Additional personal privacy invasion issues related to medicine: informed consent of patient for treatment and discharge planning. (Lee)
- 9. Right to vote is removed as a part of a conservatorship decree. Is this an appropriate abrogation of personal rights? (John Cohan)
- 10. Extent of implementation of existing protections for personal privacy. Is there a problem?? (Marie) This includes medical right to refuse treatment. What is level of awareness of providers of personal privacy protections, including consequences for failure to implement these.

Of the above suggestions, the following were selected for proposal to the full Commission:

1. Invisibility of older lesbians and gay men.

Task Force Minutes 1/20/82 Page 3

2. Age discrimination as it effects personal privacy in the areas of:

Information collection, protection and dissemination Medicine Physical abuse Employment Control over one's own affairs

The following are the commitments of time and effort:

- Sharon Rafael and Mina Robinson will assume full responsibility to write, conduct research (interviews, literature), bibliography development, type, edit and source their report. They welcome assistance for their study.
- Jonathan Glassman will participate as a team member in the preparation of a report, to be selected at the next meeting.
- 3. Lee Gilman, Marie Bolduc, and J. Glassman will recruit volunteers to assist the Task Force members.
- 4. All other members* expressed a commitment to serve as a member of a research team.

Nora will prepare a written report of these proposals for submission to the Commission. Following the approval of the Commission of these issues, specific commitments and working plans will be developed at the meeting of 2/10/82.

NEXT MEETING: 2/10/82 2 p.m., State Office Building

*See attached for current listing of committed members of the Task Force.

NOTE: Bea Schiffman inquired about the availability to Task Force members of the transcripts of the Public Hearings. These will be completed by 2/19 and available after that, upon request. They will be cataloged by topic, and can be requested by topic selection.

PROPOSAL TO THE TASK FORCE ON AGING OF THE COMMITTEE ON AGING AND DISABILITY OF THE STATE COMMISSION ON PERSONAL PRIVACY

by Sharon M. Raphael and Mina K. Robinson

One major focus that we feel needs to be included in the Task Force Report pertaining to personal privacy and sexual orientation are the problems and issues that result from the <u>invisibility</u> of older lesbians and gay men.

We are willing to take responsibility for researching and analyzing the data (including recommendations) for the Commission. We propose to address these issues in the following way. We will review the literature, collect information from persons knowledgeable on this subject and list areas in which problems are found to exist and/or important issues arise.

We then propose to develop ways of preventing intrusions into personal privacy and discrimination based on sexual orientation of older lesbians and gay men, consulting with appropriate persons as necessary.

We have included two diagrams which provide a framework for organizing the data, a catagorization of settings and situations in which discrimination and problems occur.

We welcome the participation of other Task Force members in this endeavor.

FRAMEWORK FOR ORGANIZING DATA

RESIDENTIAL

Programs & Facilities Used by all older persons	Regulation Problems	Discriminatory Non-Utilization Problems
Hospitals	Example: Access Denial in Intensive Care	
Long-Term Care Facilities		
Intermediate Care Facilities		
Short-Term Care Facilities		
Board and Care Homes		
Retirement Hotels		
Retirement Communities		
Subsidized Housing		Example: Ineligibility based on Family Status
		

Programs Needed to Meet the Special Needs of Older Lesbians and Gay Men

Example: Nursing homes targeting lesbian and gay men population

FRAMEWORK FOR ORGANIZING DATA

NON-RESIDENTIAL

Programs & Facilities Used by all older persons	Utilization Problems	Non-Utilization Problems
Health Related Facilities		Example: Fear of Discrimination
Senior Citizens Centers		
Information & Referral	Example: No lesbian/ gay info given	

Programs Needed to Meet the Special Needs of Older Lesbians and Gay Men

Example: Information, Referral Service targeting lesbian/gay population

TO: MEMBERS OF THE COMMISSION

FROM: NORA BALADERIAN, CHAIR, TASK FORCE ON AGING

RE: WORK PLANS OF THE TASK FORCE--PROPOSED

DATE: 1/25/82

THE TASK FORCE ON AGING, HAVING MET FOUR TIMES SINCE CCTOBER 1981 IS COMPRISED OF 14 ACTIVE MEMBERS BOTH IN NORTHERN AND SCUTHERN CALIFORNIA. THEY ARE PROPOSING THE FOLLOWING TOPICS/ISSUES FOR STUDY, AND ARE WILLING TO COMMITT THEMSELVES TO THE PREPARATION OF REPORTS AS APPROVED BY THE COMMISSION, IN A COCPERATIVE EFFORT AS DESCRIBED BELOW.

THESE ARE THE TOPIC AREAS PROPOSED FOR STUDY:

- 1. Invisibility of older lesbians and gay men which results in problems of inaccessibility to generic services, lack of services designed for their participation, economic discrimination, housing discrimination, and community service inaccessibility. As a matter of personal privacy, sexual orientation should hot be used proactively or inadvertently to deny resources to this group. From this study it is hoped will emerge workable recommendations to eliminate barriers to resources while maintaining the right of the individual to reveal or disclose orientation.
- 2. Age discrimination as it effects Personal Privacy in these areas:
 Information collection, protection and dissemination, especially in regards to its place in means tests for generic services.

Medicine: Practice, planning & participation of the patient

Physical abuse- as this effects rights to proper treatment of one's own
body, and protections from the State against abuses

Employment - discrimination based solely on age

Control over one's own affairs - including implementation of declarations made for arrangements at death, personal effects, residential and medical treatment, financial control.

Of these proposed topics, the first, invisibility of the older lesbian and gay man, has been proposed by Mina Robinson and Sharon Raphael, who have made a committment to follow through this study in its entirety from research plan to typing, editing, and submission as following the criteria and report format. The remaining topics, when approved by the Commission, will be studied in a cooperative format. Committments of time and effort will be made at the meeting following our suggestions. I believe that only one or at the most two of these issues will be manageable by the Task Force, in view of the tremendous effort required for a report as defined in the proposals from staff office. Cne of the Task Force members can provide typing, word processing and xeroxing services, once the report is prepared to this point. Volunteers are currently being recruited by three members of the Task Force,

TASK FORCE ON AGING

Minutes of Meeting 2/11/82

Present: Nora Baladerian (Commissioner, Task Force Chair), Roy Azarnoff, Marie Bolduc, John Cohan, Margit Craig, Elizabeth Hammel, Lee Gilman, Sister Mary Helen, Sharon Rafael, Mina Robinson, and Bea Schiffman.

I. INTRODUCTIONS

Marie Bolduc introduced two volunteers from the Andrus Center who were visiting: Elizabeth Hammel and Sister Mary Helen.

II. REPORT FROM THE COMMISSION

Nora Baladerian reported that the Commission heard the proposals from the Task Force, and were enthusiastic in their support of our plan of action. The report proposed by Mina Robinson and Sharon Rafael on the Invisibility of Older Gay Men and Lesbians was approved.

In regard to the other topics of concern to the Task Force, the one area of suggested study that most closely answers the fulfillment of the Inter-Agency agreements made for the funding of the Commission, is the topic of "Control over One's Own Affairs". It was the recommendation of the Commission that this Task Force study this topic as thoroughly as possible, within the strict time frame remaining.

In regard to the issue of information collection, maintenance and dissemination, the Commissioner who Chairs the Committee on Data Collection and Dissemination stated that he would not be able to include information or research on situational data collection/dissemination, or be able to specifically comment on the types of data abuses that the Task Force is concerned with. In this sense, then, any work we do on the issue of data would not duplicate other Commission efforts. However, in view of the limited time and resources of the Task Force, it is recommended that we select one topic for intensive study and complete a report. Should there be time afterwards, or should one individual wish to do so, Gary Cooper, Chair of the Data Committee would be pleased to receive information we might have on this topic, for inclusion, if possible, in his report.

The Inter-Agency agreement that we will be working on reads as follows:

"Develop recommendations for the education of state hospital employees and other caretakers about attitudes, policies, programs, and other practices concerning infringement of the personal privacy rights of the disabled, sexual minorities, and elderly disabled."

Our work can focus on the education and training of caretakers of the elderly who live in institutions, or who receive services in the community by approved practitioners.

III. PLAN FOR STUDY

The following represent our decisions regarding how to proceed:

TASK FORCE Minutes 2/11/82 Page Two

The Task Force will concentrate on the issue of personal privacy principally in institutional living situations.

We will examine current legislative and regulatory bases for the protections of personal privacy that currently exist.

We will examine the bill now in the State Legislature for Long Term Health Care Planning.

We will gather the existing literature on the subject of personal privacy protections and training of care providers.

We will examine the implementation procedures that have been outlined in the regulatory and legislative mandates.

We will seek to demonstrate that at this time the implementations (if they exist) are not adequate, and that abuses of personal privacy are occurring within our State.

We will make recommendations based upon the above to assure that existing protections have meaning in practice.

The following represent the current work committments:

RESEARCH: Marie - literature search at Andrus

Roy

Lee

Working as a team they will identify the current regulations and literature on the subject, and make an analysis of this.

- Lee will write a portion of the report dealing with demonstration of the problem. Margit will assist.
- John will obtain a copy of the Long Term Care Planning bill, and write an analysis of this in terms of privacy protections.
- Sharon and Mina will contribute resources they already have on this topic, and make them available to the research team.
- Roy and Jay Glassman will be willing to edit the initial drafts of the report.
- Bea will look for written documentation of abuses of personal privacy and for training of facility care providers. (A recommended question would be have any facilities actually been fined \$1000 for personal privacy abuses as mandated in Title XXII.)

Margit - Sample survey, of SNF's regarding training of staff. These tasks will be begun immediately. We will meet again as previously scheduled on:

March 10, 1982 2 P.M. State Office Building

Sister Mary Helen will be contacting Task Force members to confirm their attendance and need for parking validations!!! Also to assure participation by telephone for those who cannot physically attend.

THANKS TO YOU ALL!!!!! SEF YOU SOON.

TASK FORCE ON AGING

Minutes of Meeting 3/10/82

PRESENT: Roy Azarnoff, Maire Bolduc, Margit Craig, Lee Gilman, Bea Schiffman (via telephone), and Nora Baladerian.

- I. Handouts were provided to all present including the following:
 - Report received from John Cohan on the Long Term Planning Bill,
 "The Torres-Felando Act"
 - Copy of the survey instrument developed by Margit Craig in her survey of 6 LTC/SNF facilities.
 - 3. Summary of Licensing Violations coelected by Ellen McCord, from the Dept. of Social Services.
 - 4. Article, "Close Friendship Patterns of Older Lesbians"
 - 5. Announcement flyers for a sexuality rap group program for elder women
 - 6. "Patient's Bill of Rights" for patients receiving Home Health Services
- II. Margit Craig reported on the survey she conducted. All participants are persons personally known to her, which assisted greatly in their willingness to provide information and take the time to respond. It is her feeling that at this time, gay and lesbian patients probably do not make their orientation known, as this would probably upset their long-held self protective defenses. Thus, administrators and staff of their residential programs are not aware of any special interests or needs on their part. Some of the administrators suggested that Margit "check back" in two years, for progress.
 - Marie Bolduc announced that Sister Mary Helen Pettid would be interested in conducting additional surveys, if she were provided with the information and supplies for doing so. Nora will contact her and assist with selection of facilities that are geographically respresentative of the County, and include private and public facilities. At this time, Margit would not be able to actively continue survey work, but will do so as the opportunity

TASK FORCE ON AGING Meeting 3/10/82 Page Two

arises during the normal course of her work.

III. The team that has formed to study Privacy Rights in Institutions, has gathered information on the laws and regulations governing institutions. and penalties for non-compliance. Exactly how this occurs appears to be quite personalized. Training of the surveyors will be a matter of further investigation by this Team. Protections for personal privacy are apparently adequately outlined and described in the governing regulations. It is the implementation of these that requires remedy. Perhaps the regulations could be amended to prescribe specific training content and hours required for administrators, charge nurses, attendants and aides, that include personal privacy protections and sexual orientation discrimination protections. At this time, the implementation regulations are virtually meaningless, due to personalization on the part of the surveyor, amount of time allowed for remediation with no specific checkback on the part of the surveyor, litigation delays, negotiations and cost to the County for such litigation. Additional recommendations to improve implementation would be reduction of the patient-staff ratio: develop a system of training for above indicated staff, that would handle the rapid staff turn-over problem; develop training for the surveyors to observe personal privacy protections/abuses. One of the team members will investigate training requirements and content for surveyors. Bea described a grogram she developed in Northen California where intern physicians and social workers spent 6 months (weeks??) in rotation at a facility for the elderly, together with training for this type of service. This has produced an excellent cadre of professionals sensitive to the needs of this population. Perhaps this could be duplicated here, i.e. State-wide. Reimbursement for this was provided through the City Adult Education Department. Sea will furnish a write-up on this program.

TASK FORCE ON AGING Meeting 3/10/82 Page Three

IV. THE NEXT MEETING: The meeting of 3/31 is difficult for some of the Task Force members, and impossible for others. The next meeting has been scheduled for April 7, 1982, 2 P.M., State Office Building. We will ask Sister Mary Helen to again call the Task Force members to be able to arrange 'for parking validations.

MANY THANKS TO ALL PARTICIPANTS

TASK FORCE ON AGING

Closing Summary:

Following the meeting held on 3/10/82, no further formal meetings were held. The Sub-Task Force that worked together opted to continue their work on an ad hoc basis.

Their completed report was submitted to the Commission offices by Marie Bolduc on 4/14/82. The members who completed that report, Lee Gilman, Marie Bolduc, and Roy Azarnoff are to be commended for their diligence and perseverance, as their work was done totally on their own without clerical or research assistance from the office.

Recognition is also deserved for all the other members of the Task Force whose contributions of time, and consultative assistance created the existence of the Task Force and made the submission of the report a reality.

ATTACHMENT C

SUMMARY OF RESPONSES TO PERSONAL PRIVACY AND SEXUAL ORIENTATION DISCRIMINATION TRAINING PRACTICES SURVEY (CONDUCTED BY MARGIT CRAIG, DIRECTOR, PROJECT CARING)

SUMMARY OF RESPONSES TO PERSONAL PRIVACY AND SEXUAL ORIENTATION DISCRIMINATION TRAINING PRACTICES SURVEY, CONDUCTED BY MARGIT CRAIG, FEBRUARY 1982

Number of Respondents: 4

Description of Respondents: Administrators of Skilled Nursing Facilities

- 1. Do you give in-service training to your staff with regard to:
 - a. Patients' Bill of Rights: ALL STATED THEY DO, ONE PROVIDES COPIES.
 - b. Personal (i.e., sexual) Privacy: ALL STATED YES DURING INITIAL ORIENTATION, "VERY BRIEFLY", "ONLY ABOUT PRIVACY".
 - c. Is the facility implementing these policies and are there consequences for not making information available? COPIES OF BILL OF RIGHTS IS POSTED AND MADE AVAILABLE TO PATIENTS AND THEIR FAMILIES: WHEN INDICATED.
- 2. Are you aware of gay men and lesbians amongst your patients? THREE RESPONDENTS SAID, "NO", FOURTH DID NOT RESPOND.
 - a. If so, do you give special instructions to your staff to assure the patients' privacy and dignity? TWO RESPONDENTS SAID, "NO", ONE DID NOT RESPOND, ONE SAID, "IF THERE WERE RUMORS, WE SHOULD DEAL WITH THEM IMMEDIATELY AND OPENLY".
 - b. If not, why not? #1 STATED, "AREA DOES NOT HAVE ANY"; #2 STATED, "NOT APPLICABLE"; #3 STATED, "NO DISCRIMINATION, NO JUDGEMENTAL ATTITUDES ENCOURAGED, IF THERE WERE REQUEST SAME ROOM WOULD BE MADE AVAILABLE FOR ANY COUPLE"; #4 STATED, "NO THOUGHT HAS BEEN GIVEN TO SUBJECT OF SEXUAL DISCRIMINATION".
 - c. Do you provide training in sexuality, both homosexual and heterosexual? TWO STATED THEY DID NOT, ONE DOES "DURING IN-SERVICE", ONE, "VERY LITTLE".
- 3. Are you aware of discrimination or privacy infringements experienced by your patients? If so;
 - a. By staff? COMMENTS: "YES AS REGARDS TO BATHING PRACTICES AND OMISSION OF USE OF PRIVACY CURTAINS"; "STAFF NEEDS TO BE REMINDED OF PATIENTS' DIGNITY AND NEED FOR PRIVACY"; "SOME INFRINGEMENTS OF PRIVACY".
 - b. By patients and families? COMMENTS: "PATIENTS BECOME OBJECTS AND THEIR DIGNITY AND PRIVACY IS OFTEN IGNORED BY FAMILIES AND FRIENDS" (THIS COMMENT FROM 2 RESPONDENTS) ONE SAID NO, ONE DID NOT RESPOND.

- 4. How do you and your staff react to incidents of sexuality of any kind amongst the patients? COMMENTS: "DEPENDS ON EDUCATIONAL LEVEL AND LIFE EXPERIENCE"; "IN NORMAL FASHION"; "TRY AND VIEW IT AS NORMAL PHYSIOLOGICAL RESPONSE"; "NON-PROFESSIONAL STAFF BRING THEIR OWN VALUES AND LACK OF UNDERSTANDING OF SEXUALITY IN ANY ONE".
- 5. Are you aware of patient abuse because of sexual activities of any kind? THREE SAID, "NO", ONE STATED, "ONLY RUMORS, NEVER ABLE TO VERIFY INCIDENCES".
- 6. Do you have written policies for your professional and non-professional staff? RESPONSES: #1 "NO, NO NEED"; #2 "NO...PERSONNEL PRACTICES, PATIENT CARE MANUAL"; #3 "YES, CONTAINED IN PATIENT CARE POLICIES, JOB DESCRIPTIONS AND PERSONNEL POLICIES"; #4 "NO".
- Do you have any recommendations to forward to the Commission on 7. Personal Privacy? #1: "NEED TO PREPARE PROFESSIONAL AND HANDS-ON STAFF FOR COMING CHANGES IN NURSING HOME POPULATION"; #2 "YES, TO ENCOURAGE GREATER AWARENESS AND BETTER COMMUNICATIONS. NO DISCRIMI-NATION PRACTICED AGAINST HOMOSEXUAL EMPLOYEES"; #3 "FACILITIES SHOULD HAVE WRITTEN POLICIES DEALING WITH SEXUALITY OF ANY KIND. IN-SERVICE TRAINING MUST DEAL WITH STAFF'S SEXUALITY, MUST BE PROVIDED BY WELL-QUALIFIED PERSON. REGULATIONS WILL HAVE TO DEAL WITH TRAINING. NO ONE WANTS MORE REGULATIONS, THERE ARE MANY PARTS THAT COULD BE ELIMINATED WITHOUT AFFECTING PATIENT CARE. SEXUALITY TRAINING AND AWARENESS WILL BECOME MORE AND MORE IMPORTANT. NON-PROFESSIONAL STAFF OFTEN HAS LITTLE EDUCATION AND AWARENESS, STRICT RELIGIOUS UPBRINGING AND ARE NOT READY TO ACCEPT PEOPLE WITH OTHER MORES. NEXT GENERATION OF NURSING HOME PATIENTS WILL MAKE VERY DIFFERENT DEMANDS AND STAFF MUST BE READY. IN-SERVICE TRAINING AS IT IS GIVEN NOW BY PROFESSIONAL WHO WAS ACTIVE IN PLANNED PARENTHOOD MOVEMENT, CONTAINS MUCH NEED TO UNDERSTAND OTHERS' SENSITIVITIES. PEOPLE TO TOUCH, BREAKING ISOLATION OF ELDERLY. MANY YOUNG PEOPLE OF DIFFERENT CULTURES ARE AFRAID TO TOUCH, PARTICULARLY LEAVING OUT ELDERLY MEN WHO SEEM TO HAVE ILL-EFFECTS OF THIS SEVERE ISOLATION. STAFF WILL HAVE TO UNDERSTAND THAT TOUCHING LEADS TO SENSE OF INTIMACY. EVENTUALLY WILL CONNECT TO SEXUALITY IF TRAINING IS PROPERLY PROVIDED. THIS FACILITY PROVIDES PRIVATE ROOMS READILY, ATTEMPTS TO HAVE NON-JUDGEMENTAL ATTITUDE, IT IS NOT THE INSTITUTION'S PLACE TO JUDGE MORALS OR BEHAVIOR OF 90 YEAR-OLDS. FACILITY DOES NOT INTERVENE IN FAMILY RELATIONSHIPS WHEN THEY ARE CONSERVATIVE OR OTHERWISE, DOES NOT ENCOURAGE TAKING ANY VIEWPOINT AS TO BEHAVIOR OF PATIENTS OR FAMILIES. FACILITY ENCOURAGES PARTICIPATION OF FRIENDS, PATIENTS THEMSELVES AND FAMILIES, IN MAKING CHOICES AND TRIES TO GIVE INFOR-MATION AS IT IS PERMISSABLE, BENDING SOME RULES, TO FRIENDS (WHICH WOULD INCLUDE GAY MEN AND LESBIANS)."

ATTACHMENT D

"PATIENTS' RIGHTS"

A SUMMARY OF SKILLED NURSING FACILITY REGULATIONS,

§72523

PATIENTS' RIGHTS

(A Summary of S.N.F.R. Section 72523)

Each patient admitted to a nursing home has the following rights:

- 1. To be fully informed of his rights and of all rules and regulations of the nursing home governing patient conduct.
- 2. To be fully informed of the services available in the facility and of the charges for services.
- 3. To be fully informed by a physician of his medical condition*; to have the opportunity to participate in the planning of his medical treatment and to refuse to participate in experimental research.
- 4. To refuse treatment to the extent permitted by law and to be informed of the medical consequences of refusal.
- To be transferred or discharged only for medical reasons, or for his welfare or that of other patients or for nonpayment for his stay and to be given reasonable advance notice.
- 6. To be encouraged and assisted through his period of stay to exercise his rights as a patient and as a citizen, free from restraint, interference, coercion, discrimination or reprisal.
- 7. To manage his personal financial affairs, or to be given at least quarterly an accounting of financial transactions made on his behalf if the facility accepts this responsibility for him.
- 8. To be free from mental and physical abuse and from chemical and (except in emergencies) physical restraints except as authorized in writing by a physician for a specified and limited period of time, or when necessary to protect the patient from injury to himself or to others.
- 9. To be assured confidential treatment of his personal and medical records.
- 10. To be treated with consideration, respect and full recognition of his dignity and individuality, including privacy in treatment and in care for his personal needs.
- 11. Not to be required to perform services for the facility that are not included in his plan of care for therapeutic purposes.

The patient's rights followed by an asterisk (*) may be limited by a physician where their exercise is not medically advisable.

- 12. To associate and communicate privately with persons of his choice, and to send and receive his personal mail unopened.*
- 13. To meet with and participate in activities of social, religious, and community groups at his discretion.*
- 14. To retain and use his personal clothing and possessions as space permits, unless to do so would infringe upon rights of other patients.*
- 15. If married, to be assured privacy for visits by his/her spouse and if both are patients in the facility, to be permitted to share a room.*
- 16. To have daily visiting hours established.
- 17. To have members of the clergy admitted at the request of the patient or person responsible at any time.
- 18. To allow relatives or persons responsible to visit critically ill patients at any time.*
- 19. To be allowed privacy for visits with family, friends, clergy, social workers or for professional or business purposes.
- 20. To have reasonable access to telephones both to make and receive confidential calls.

A patient's rights as set forth in Section 72523(a) may be denied for good cause only by the attending physician. Denial of such rights shall be documented by the attending physician in the patient's health record.

The patient's rights followed by an asterisk (*) may be limited by a physician where their exercise is not medically advisable.

Further references:

- Long-Term Care, Health, Safety & Security Act of 1973 -Health and Safety Code Sections 1417 through 1439.
- Skilled Nursing Facilities Regulations California Administrative Code Title 22, Division 5, Chapter 3 (copies may be ordered from the State Office of Procurement, Publications Section, P.O. Box 20191, Sacramento, CA 95820).

ATTACHMENT E

PATIENT'S BILL OF RIGHTS FOR
HOME HEALTH SERVICES USERS

PATIENT'S BILL OF RIGHTS

Each patient receiving care from Home Health Services shall have the right:

- 1. To privacy, respect, dignity, courteous and individualized health care that is equitable, humane and given without discrimination as to race, color, creed, sex, national origin, source of payment, ethical or political beliefs.
- 2. To be fully informed of services available in the agency and of related charges, including any charges for services not covered under Titles XVIII or XIX of the Social Security Act.
- 3. To receive the care necessary to help regain a maximum state of health and to expect that the care will be administered by Home Health Services personnel who are qualified through education and experience to perform the services for which they are responsible.
- 4. To receive appropriate information from a physician, within the limits determined by the physician, law or regulation, regarding the diagnosis, prognosis and treatment.
- 5. To be taught about the illness so that the patient can help himself/herself, and the family can understand and help the patient.
- 6. To be assured confidential treatment of personal and medical records and to approve or refuse their release to any individual outside the agency, except in the case of transfer to another health facility, or as required by law or third-party contract.
- 7. To be able to participate in the planning of his/her medical treatment and to refuse to participate in experimental research.
- 8. To refuse treatment to the extent permitted by law and to be informed of the medical consequences of such refusal.

If a problem arises regarding the services provided by Home Health Services, please notify:

Health Facilities Division
Department of Health Services
1st Floor
2615 South Grand Avenue
Los Angeles, CA 90007
(213) 744-3656

I understand that any communication will be treated confidentially.

ATTACHMENT F

REPORT ON THE TORRES-FELANDO ACT
PREPARED BY JOHN ALAN COHAN

THE TORRES-FELANDO ACT State Department of Aging and Long-Term Care

Existing law provides for the Department of Aging, which administers programs to provide services to the elderly. bill would expand the Department of Aging by creating a State Department of Aging and Long-Term Care, which would administer existing programs and new health and social programs to provide long-term care to the elderly as well as to functionally impaired persons. There would be two divisions in the Department: Term Care Division and the Aging Division. The bill allows allocation of money from the current long-term care system to community long-term care agencies. Also, the Department would be able to receive recommendations from the community long-term task forces by January 1, 1985. The scope of long-term care services is detailed in the bill, which sets forth specified needs to be met. The bill also sets forth requirements to be met by the community long-term care agencies in carrying out their responsibilities for long-term care. Long-term care community advisory groups would also be established.

It is the intent of the bill to continue the legislature's 10-year co-mitment to improving programs and developing a long-term care delivery system that provides both social and health support systems. The bill acknowledges that the four state agencies and nineteen governmental units administering a total of 29 different service programs for the elderly--with separate eligibility and needs assessment criteria--has led to an ineffective use of resources and unnecessary premature insittutionalization. The bill also acknowledges that funds have been spent on inappropriate and expensive services even though less expensive and more humane service approaches could have been utilized instead of care in medical institutions.

It is the purpose of the bill to foster independence and self-reliance, maintain individual dignity, and allow long-care services to be community and family based as much as possible.

An "older person" under the bill is someone 60 years or older. A "functionally impaired person" is someone 18 years or older with restricted self-care capabilities. "Long-term care" means diagnostic, therapeutic, rehabilitative, supportive and maintenance services addressing the health, social and personal needs of persons covered by the bill. "Community long-term care delivery system" means community-based programs and services that meet long-term care client's needs.

All departments administering programs that have an impact on older persons are to consult with the Department and adopt formal interagency policies to integrate services and information.

The Long-Term Consolidated Fund is to be created in the State Treasury, effective January 1, 1983, to provide the means for the Department to carry out its duties. The Department is to also seek other additional funding from local and federal sources as well as private foundations.

Controls are to be used to assure that only those persons in need of services are granted access to services, and only those services appropriate and responsive to the participant's needs will be granted, at the least possible cost.

Provision is made for entering contracts with community long-term care agencies. The Department is to establish procedures for application and criteria to be met, as well as rules, policies and procedures governing the administration of services and use of funds by the community long-term care agencies. Performance standards are also to be established by the Department.

The Department is to conduct periodic random sample reviews of the community long-term care agency's programs to ensure providers are in compliance with the standards, particularly to assure that the care and services are of sufficiently high quality to meet the needs of participants, that the services conform to standards of health, decency and safety, and that the services protect participants from hazards and dangers. The Department is also to develop of sliding fee schedule.

Technical assistance is to be provided to community longterm care agencies which may be necessary to improve and enhance the administration and delivery of services.

The Department is to plan and evaluate activities to assure continued development of long-care services throughout the state and to improve and efficiency and effectiveness of such services. The Department will randomly survey participants to obtain their evaluation of the services they are receiving.

Community long-term care agencies must be capable of responding to participant needs on a 24-hour, seven-day-a-week basis. They must have a staff (or consultants who are available) to conduct comprehensive assessments in accordance with one of the provisions of the bill. They must have capability of communicating in languages other than English if a substantial number of participants in the service are do not speak English. They must also institute a grievance procedure. Each agency must have ways of meeting such primary needs as nutrition, mobility, psychosocial, financial, shelter, security, safety and health needs.

REPORT PREPARED BY:

ATTACHMENT G

"WHAT HEALTH CARE PROFESSIONALS SHOULD KNOW ABOUT OLDER LESBIANS"

BY SHARON M. RAPHAEL, PH.D.

WHAT HEALTH CARE PROFESSIONALS SHOULD KNOW

ABOUT OLDER LESEIANS

BY

SHARON M. RAPHAEL, Ph.D. California State University Dominguez Hills

Presented at American Public Health Association Meetings

Detroit, Michigan

October 20, 1980

Research on the topic of Lesbian and Gay aging is a very recent development in the field of social gerontology. The majority of the articles and papers written to date (most of these since 1975) focus on Gay male aging. Since 1978 a small but significant number of articles and other written works have appeared which address the issue of aging within the Lesbian population.

Social service and educational projects designed to serve the needs of both older Lesbians and older Gay men are also just beginning to implemented or explored in various locations in the U.S. including the East Coast, The Midwest, and the West Coast. The Midwest project is primarily educational in objective, designed to inform professionals in aging and the health fields about the existence and needs of the older Lesbian and Gay population. (Project Director, Judith Scott, Gay Community Services, Minneapolis, Minnesota.) Other projects can be described as inhome services for the frail Lesbian and Gay male elderly. The first such project is operating in New York City; (S.A.G.E.-Senior Action in a Gay Environment). Another in San Francisco is in the planning stage.

It is important to note that no projects have been planned or introduced which are designed to serve only older Lesbians or only older Gay men.

One major concern that professionals raise who are interested in developing programs to serve this target population, older Lesbians, is how to best reach individuals who are assumed to be "nearly invisible, very closeted, and not Gay or Lesbian identified". Although there is historical evidence that suggests that Lesbians in the U.S. have not had the same degree of access to the same types of public places that Gay men have typically frequented such as bars and clubs, it appears that

Lesbians have created informal social networks and alternative systems of support which have helped older Lesbians and Lesbians of previous generations to maintain an in-group identification with women who share the same sexual-affectional preference. The Robinson (1979), Raphael and Robinson (1980) and Wolf (1978) research on support systems and friendship ties tends to reinforce the notion that Lesbians have formed alternative support systems to replace weakened or non-existent family ties that often exist for their non-Lesbian counterparts.

The mythical picture of the totally isolated and lonely older

Lesbian is not what health professional or other service providers should have in mind when developing proposals for special projects or to broaden general services to include the needs and sensitivities of this population group. There also exists the probably mistaken notion that because those who have appeared most actively involved in Gay Liberation, Feminism, and Lesbian Feminism are "younger persons", that these movements have not had much of an impact on the older generations of Lesbians and Gay men. We also need to be reminded that it has been more than a decade since these movements appeared on the scene and that these "younger persons" in many cases are now experiencing the advent of middle age.

Although it is probably the case that there are significant numbers of older women who might from a clinical or psychological testing standpoint be considered Lesbians, despite the fact that they do not identify as Lesbians, it would be a mistake to develop speical programs for these "invisible" women that would treat these women as somehow different from other Lesbians, and implement strategies in order to make even the most minimal contact with them possible. Let us instead take a lesson from the history of the development of the Gay Centers across this country when similar concerns were being expressed. Specifically, the question

was asked, "How can Gay Centers reach the most closeted of the potential target group out there?" After all, it was assumed these were the people who needed the most help. That kind of logic led to program developers suggesting that, perhaps, these centers should not be called Gay or Lesbian Centers. Finally it became clear to most that a service organization or movement cannot represent the best interests of its constitutency by co-opting itself or its ideas in the name of an invisible collectivity that may only exist in the minds of the organizers. Gay service workers and professionals found they had to solve the problems and serve the needs of the hundreds of thousands who actually did walk through the doors of the agencies and centers that had advertised they were there to serve Gay and Lesbian people, not some euphemism for Gay or Lesbian. The so-called "very closeted" got the message and soon followed the lead of the others who were less afraid.

I suggest the same strategy will work for the older population of Lesbians and Gay men. Begin serving those groups who obviously need and want your services, and then others will follow. Not to take this appoach is to do a disservice to the generations of older Lesbians and Gay men who have survived against incredible odds in this society.

This leads us logically to another question that service providers often ask about this population group. Are older Lesbians and Lesbians of all ages already utilizing existing services or are they staying away in large numbers because of the heterosexual bias inherent in the existing service systems i.e. nursing homes, nutrition sites, recreation centers, retirement villages, health care clinics.

The Robinson research included questions that asked older Lesbians over fifty years of age if they would consider moving to a retirement village i.e. Leisure World . All responded, no. But when the question was posed, "If it were a Cay or Lesbian or all women retirement village?"

the responses were quite different. Some examples were "Do such places exist?""How can I find out more about this?" "Yes, I'd be interested if it were a Lesbian or Gay retirement community". (Robinson, 1979) The idea of having an option of living in a Gay or Lesbian identified environment was seen as an attractive possibility.

Although we do not have answers to the question of degree of utilization of existing health care services by this population, it is apparent that practically nothing has been dome in this country to understand the special needs and specfic issues of Lesbians as they come in contact with the health care system and medical establishment and its complex myriad of institutions. The article by Elaine Pogoncheff titled "The Gay Patient" published in R N magazine breaks through the silence as she details so cogently the many difficulties that Lesbians and Gay men encounter in the hospital setting.

One common pitfall that aging specialists often do not avoid in the attempt to counter stereotypes and myths about old people is to unintentionally give the impression that old people are quite well adjusted and so well functioning that special legislation and massive aid is not necessary. The same problem exists for the researcher who examines the Gay and Lesbian population. Just because the older Lesbian is not typically living out some homophobic nightmare that ends in self-destruction does not mean the older Lesbian is not in need of the same complement of public services that other groups deserve and require. The point is to work with the strengths and positive coping mechanisms already exisiting in the groups being provided services rather than approach a potential target population as totally dependent or devastated.

Just as we have become aware that old people cannot be lumped into one homogeneous group that has as its overriding common denominator, age, it also holds that we cannot describe older Lesbians as one distinct group

without considering the very heterogeneous nature of the Lesbian and Gay population in general. All the same variables that exist for the general population and that appear to set people in society apart from each other i.e. class, race, ethnicity, religion, and regionalism also set Lesbains and older Lesbians apart from themselves.

At the same time, Lesbianism as a common experience and identity, if understood in all its various dimensions can serve as an extremely . important heritage and living reality that binds these women together as a complex social force and many faceted community of persons. What health care providers should know about older Lesbians in a period when little systematic research has been completed on this topic is not to assume too much or too little about who the older Lesbian is. If the older Lesbian appears invisible to the picneer researching in this area, this does not necessarily mean she is invisible to herself or to her sisters. On the other hand, there may be significant age cohort effects and historical factors that have created for the older Lesbian of today a unique view of the world and of herself. Future generations of older Lesbians will undoubtably be affected by the legacy of those who came before and in what ways they were treated by the larger society.

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Robinson, Mina. "The Older Lesbian". Master's Thesis. California State University Dominguez Hills, Carson, California, July, 1979.

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ATTACHMENT H

"SUPPORT SYSTEMS FOR OLDER LESBIANS"
BY MINA K. ROBINSON, M.A.

SUPPORT SYSTEMS FOR OLDER LESELANS

BY

MINA K. ROBINSON, M.A.

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Carson, California 90747

Presented at American Public Health Association Meetings

Detroit, Michigan

October 20, 1980

The necessity for and the availability of support systems for older Lesbians has been a topic of interest to me for some time. Today I would like to share information with you that I learned through research conducted for my Master's Thesis on The Older Lesbian (1979) and on data collected since then in working with individuals and groups in the Los Angeles area.

Studies have shown, that in the population as a whole, 68% of women over the age of 65 had seen one of their children the same or previous day.

32% live with one of their married or unmarried children. 81% of the women who had never been married had seen a sibling during the previous week. 70% of unmarried men and women who do not share a household with their children live within a 30 minute journey of their nearest child. 70% of the men and women say they receive help from their children. 75% of the women had received help from their children and relatives. (Stehouwer, 1968) The types of help that are referred to in Stehouwer's study includes services, gifts, advice, help in emergencies, transportation, and to some extent, financial aid.

In my research I found that the older Lesbian in my sample did not have the support of family unless she was out of the closet with her family and the family "approved" of her Lesbianism. This was true of relationships with siblings and in relationships between those Lesbians who were mothers and their children (one third of the sample). If a Lesbian was in the closet with her siblings or her own children or if she was out of the closet but her siblings or her children "disapproved" of her Lesbianism, there was little or no relationship. It was not unusual to find closeted Lesbians who had not spoken to siblings in 30 years. Only one in 20 of those sampled had a good relationship with siblings.

I did find, however, a pattern of close friendship ties which had replaced the missing kinship networks.

In research conducted for my thesis and in groups conducted at various Lesbian conferences in the Los Angeles area, older Lesbians were found to have friendship networks that they relied upon to meet their emotional needs as well as many of the types of aids mentioned in Stehouwer's study.

In August, 1980, Sharon Raphael and I Lacilitated a workshop in Los Angeles titled "Lesbian Aging = Creative Aging". The 20 women attending, ranging in age from 23 to 75, (most were middle aged or older) were asked to write down their fantasy of what they would like to be doing when they were 65 or, in the case of women already 65, what they wanted to be doing in five or ten years. These were to be done anonymously.

One of the oldest women in the group wrote of wanting a collective living situation. "At 75 I'd like to be living in a Gay retirement colony of women. Life presently is fine, at 68, sculpting, fishing, belonging to an older Lesbian group, traveling, reading, playing". Another woman wrote, "When I'm 65 I'd like to be in a small urban environment, a defined and operating womanspace, linked with other networks of women around the country and around the world. I will have a nurturing "home-base" community, be -involved in a business that economically maintains our community". Still another woman said. "I hope my lover and I will be living in a house that has other Lesbians living nearby or on the same property. We will be sharing meals with friends of ours, and doing many projects together collectively. Public transportation will be available and easy to get to. The car will be obsolete. Vans will be operated by Lesbian collectives to take us to beautiful retreats where my sisters and I will spend time getting renewed". Another women wrote "I would like to be living with my lover and other women in a collective situation in which we all share and care about each other and take care of all of our needs".

When the women were through writing we read each others fantasies and talked about what we'had heard from each other. We talked about some of the pitfalls of collective living, particularly country living for women raised in the city, which several women had written about.

one 52 year old woman shared a recent experience with us. She had moved to a rural farm collective in Mexico with other Lesbians who were considerably younger than herself. They were all poor women, some Mexican and some, like herself, an American of Mexican heritage. She was an artist who had always lived in the city. Their intent was to grow their own crops and live "off the land". That year there was a drought and they lost most of their crops. She wasn't used to the drinking water. Their food rations were minimal and did not include all the necessary vitamins and minerals. She became ill and was unable to get medical treatment as there were no doctors in the area. Unconscious, she was finally taken several hundred miles to a clinic where it turned out they could not help her. It was arranged to have her flown back across the border when she was close to death. She recovered in a San Diego hospital.

We talked about the importance of being realistic in our expectations of ourselves in middle and old age. Is it realistic to expect an older woman who has been used to a thermostat in her living room to chop wood for her cooking and warming needs? Is it reasonable to expect someone who may have grown some roses and perhaps a tomato vine to be able to produce all of her own food? Can we who are used to modern conveniences easily make the transition to handheld scrubboards and outhouses? Does a woman who has held white-collar jobs all her life and who has led a sedintary urban lifestyle have the physical strength and endurance to live "off the land"? Should we entering middle or old age leave the easy accessibility to the medical establishment? These questions need to be

carefully examined by each of us entertaining utopian thoughts of "returning" to the land.

The collectives of older women that do exist on the west coast appear to exist for a very privileged class of women. The women do not "work" the land, although most do maintain a small vegetable garden. The women have had the capital to enable them to buy large acreages of land, either with houses already on them or they were able to afford to have houses built. The women did not need to earn any money, therefore locating near to possible workplaces was not an issue. Poor women, and any woman unable to put up her equal share of money for the land were systematically excluded.

I believe that opportunities are being overlooked that can enhance or create support systems for older Lesbians of other economic classes where they do not presently exist. All of the current collective living situations that I am aware of on the west coast are rural and owned by the collective members. But why not develop urban collectives, where paid work situations would be more available, and why not encourage rental housing collectives, particularly usefull for women now occupying S.R.O.'s (single room occupany)? There are also other types of collectives which could be important such as eating collectives. As we know we tend to eat less nutritionally as well as more expensively when we eat alone.

Intentional families, that is a group of people who decide to commit themselves to meeting regularly to give supports to each other which are stereotypically supplied by relatives, may offer to each other various aids and supports mutually agreed upon such as food and T.L.C. during illnesses, transportation when needed, and ongoing emotional support. It is not necessary to live together to enjoy a well functioning support system. The informal support systems existing between friends should not be undervalued, but taken into account when evaluating an

individual's situation.

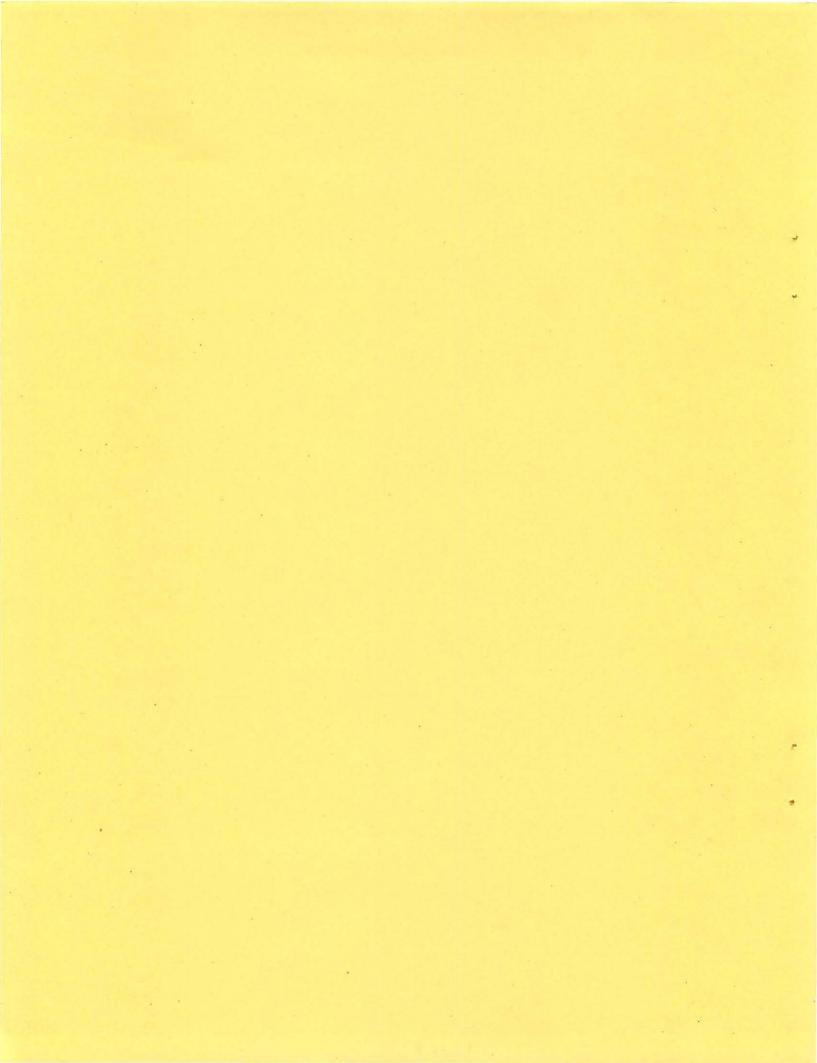
ADJUSTMENT TO AGING

In writing their fantasies most of the women made reference to continuing to participate in activities that interested them at younger ages. Those who were involved in physical pursuits wanted to continue that part of their lives. Those who were artistic spoke of continuing to paint and sculpt and weave. Some women who were people-oriented in their vocations and avocations planned on continuing their social involvements. Continuity in life activities and interests makes for a posivive adjustment to old age. (Atchley, 1971)

Additional comments which relate to adjustment to aging include thoughts of being a positive role model for younger women. One woman wrote "I will be a legend in my career field and the wise woman my younger friends come to for support." Another woman wrote "I also would have finished writing a book pertaining to my life as a success working with the elderly and my confusing but creative life being Gay", Another writes "I want to play some sort of leadership role in the political scene".

The women who currently had lovers wrote of these relationships continuing throughout their lives while some of the single women wrote of continuing to live alone (or with pets) as their choice of life style. Regardless of relationship status almost all the women mentioned the importance of friends in their lives.

These Lesbians clearly intend to leave their mark on a world of their own making. Setting new trends, breaking new ground, with a little help from their friends they can well serve us as role models for the future.



Privacy Rights in Alcohol & Drug Programs

by Kieran Prather & Mike Cronen

INTRODUCTION

The purpose of this report is to study the policies and practices of some county and private programs funded by the ADP, to see if any invasions of personal privacy exist, and to make recommendations to correct any unreasonable violations.

Research for this study was conducted by Mike Cronen and Kieran Prather, under the supervision of the commission's executive director, with the consultation of Commissioner Audrey Mertz, chairperson of the Medical and Mental Health Services Committee of the Commission.

The following methods of research were used to obtain information for this report: study of Federal, State, and county regulations for ADP and ADP-funded programs that touched on areas concerning personal privacy; interviews with administrators and staff members of such programs, and interviews with clients who had participated in these programs; and written and telephone contact with other programs. Research resources were limited to programs in the Los Angeles County area, with some information about programs in San Diego and San Francisco. However, our findings led to recommendations that are of value to the ADP on a statewide basis.

In general, we found that governmental rules and regulations are in effect and are reflected in the programs, policies, and procedures used by ADP at the State, county and private levels.1/ However, we also found that some procedures that are not specifically regulated leave room for potential invasions of privacy. This report will examine four such areas, and will make recommendations for improvement: (1) information provided during intake procedures; (2) physical condition of the area for intake; (3) use of phone calls in reference to a client's case; and (4) computer use of identification numbers. We did not find widespread disregard for these concerns, but we found that safeguards were employed arbitrarily. Our recommendations offer uniform procedures for dealing with these areas.

RESEARCH

Research was initiated by a review of the ADP budget. 2/ This review was used as a means of identifying ADP-funded programs throughout the State, especially in Los Angeles County. Our research

^{1/}Public Records Act, California Government Code, § 6253.1 et seq.
U.S. Public Health Code, Title 42, Chapter 1, Part 2,
Confidentiality of Alcohol and Drug Abuse Patient Records.
2/1981-82 Governor's Budget, submitted by Edmund G. Brown Jr. to the California Legislature 1980-81 Regular Session. Health and Welfare 420, Appendix A, page 23.

indicated that the overwhelming majority of ADP funds are distributed to the county governments for subsequent allocation to specific county and private programs. While these programs are guided by State and Federal laws and regulations, county governments are most actively involved in the administration of the programs. Once it was established that the county plays the major administrative role in the allocation of State funds, our research dealt with ADP-funded programs in Los Angeles County, with additional information regarding programs in San Diego and San Francisco.

The first procedure was to examine the rules and regulations that apply to programs that are funded, or partially funded, by the ADP. Federal requirements are from the Code of Federal Regulations. 3/State regulations come from the California Administrative Code, 4/ and are affected by legislation such as the Public Records Act, the Information Practices Act, and Article I, Section I, of the California State Constitution. Additional regulations may be in effect because of county ordinances, but the above constitutes the minimum requirements for every ADP-funded program.

The next procedure was to look at a sampling of eight individual programs. No attempt was made to obtain a thorough analysis of all programs available. With the time and resources we had available, we were able to spot check different kinds of programs. Our findings and recommendations should be read in this light. We sought information about programs in four ways: (1) review of written information; (2) interviews with administrators and staff members; (3) interviews with clients; and (4) written and telephone contact with other programs. We had two main objectives in our research-gathering process. Primarily, we wanted to see how programs implemented the regulations regarding privacy. Secondly, we wanted to see how gay and lesbian clients were treated by different programs. We felt this strongly tested the privacy rights concerning life styles.

Two types of written information were examined. The first was official forms: waivers, employee oaths, application forms, and intake forms. These were considered in light of the existing regulations regarding personal privacy. The second type of information was promotional material, both brochures used to advertise the program and information given to clients seeking general information. Our only purpose with this second review was to see if any statements were made that might suggest a violation of privacy rights.

^{3/}Code of Federal Regulations, Title 9 4/California Administrative Code, Title 22, § 80341

Interviews were made with two staff members at the Los Angeles County Office on Alcohol Abuse and Alcoholism, the directors of three residential programs, the directors of three nonresidential programs, the director of a drinking driver program, and the director of a facility that refers clients to other programs. 5/ In each of these interviews, the questioning followed the same pattern. The director was asked to explain how regulations concerning client privacy were implemented, how records were stored and disposed of, the nature of the intake procedure, and how the physical environment considered privacy. The directors were also asked how they worked with clients who were gay or lesbian: what services the facility offered, special problems they encountered working with gay and lesbian clients, and the process of referral when it seemed indicted. Lastly, the directors were asked for comments and suggestions they might have concerning the area of privacy rights.

Casual interviews were made with a counselor at a residential facility, a counselor with a nonresidential program, and an aide at a nonresidential program. Questioning was more general, asking for impressions about privacy as it affected the program, or as it affected that person's position. The counselors were asked about the treatment of gays and lesbians by staff members and other clients in the program.

Six clients were interviewed, commenting on five residential programs and three nonresidential programs. Clients were asked questions concerning their privacy rights in the program in general, and questions about their treatment in the counseling process. Lastly, they were asked for general observations about the programs they had participated in.

A telephone survey was made of residential facilities to ascertain how a gay client seeking help would be treated. The facilities were selected from the directory of alcohol programs put out by the Los Angeles Office of Alcohol Abuse and Alcoholism. Ten centers were interviewed. We wanted to know what differences, if any, the client's choice of lifestyle seemed to make in obtaining information about specific programs.

^{5/}Residential Facilities: Van Ness Recovery House, Volunteers of America, and Raleigh Hills. Nonresidential Facilities: Gay and Lesbian Community Service Center, United American Indian Involvement Crisis Intervention, and Salvation Army. Community Services Organization: Drinking Driver Program. Referral Service: Gay and Lesbian Community Service Center.

Finally, a questionnaire was sent to 42 directors of drug and alcohol rehabilitation programs throughout the State. This letter asked for comments and suggestions concerning the area of personal privacy. There was little response to this inquiry. Because of the low numbers of responses the materials were not included in developing this study.

FINDINGS/RECOMMENDATIONS

On the completion of our study of the ADP-funded programs, we found that on the level of official statements and written information, governmental confidentiality requirements are satisfactorily in effect at all levels - State, county, and private. Each director and staff member interviewed demonstrated a thorough understanding of State and Federal regulations concerning confidentiality, and was sympathetic to the client's privacy needs. This situation was further verified in the interviews with clients. While negative criticisms of programs and staff persons were given, no client expressed the feeling that privacy rights had been violated. None of the complaints voiced touched on policies concerning privacy rights and confidentiality.

We know, of course, that violations must occur, and that sometimes these violations will be intentional and malicious. But these seem to be isolated acts of one individual, not the accepted standard of any program.

A high level of attention has been given to privacy rights, especially in terms of confidentiality of records and client identification. This seems to be related to the nature of alcohol and drug programs generally. Confidentiality is not only legally required and desirable for the client, but it is also a necessary element in the successful continuance of any drug and alcohol program. If program providers are unable to maintain the confidence and trust of the client, the voluntary nature of these programs would allow the client to select a more understanding facility for treatment. it is also true that rehabilitation can only begin when the client trusts those who work with the program; compliance with the confidentiality regulations offers a basis for that trust. Therefore, it is mutually beneficial for the provider to maintain high standards of confidentiality and respect for privacy rights.

However, our investigation did lead to observations concerning areas which are not covered by existing regulations. We explain these situations and offer recommendations below. We emphasize that these are observations rather than across-the-board criticisms. Some of our suggestions are already in effect in some programs. We offer them as procedures that should be implemented in programs that are not currently using them.

During our interviews with program directors we learned that many gays and lesbians are reluctant to reveal their sexual orientation at the time of intake. The reasons for this seem to be either that they do not believe that their sexual orientation is relevant to their drinking, or that they are afraid of difficulties in the program should their life style be known. According to the directors, an individual's sexual orientation is often discovered while they are in the program.

We also found that the directors of some general programs were either unaware of, or poorly informed about special programs available for gays and lesbians. While there are programs of this type in the major urban areas of the State, prospective clients are not always informed of them because the intake centers are not aware of the needs of the client or are not aware of the programs available. We believe it is important that clients be informed about special programs which might help them.

RECOMMENDATION. All clients and potential clients at every facility should be informed of the availability of these programs as a routine part of the intake process. This might be achieved by use of printed lists indicating all programs that are directed to a target group, such as specific ethnic groups. If this is not realistic, the clients should at least be given a card indicating that such groups do exist, and directing them to a location for more information about them. What is important is that the client be advised of the availability of these programs without having to reveal sexual orientation.6/

Section 80341, Title 22, of the California Administrative Code requires that clients be advised of their personal rights. It further states that these rights must be posted in facilities that are licensed for seven or more persons. One of these rights is to be informed of the agency to contact regarding complaints about the program.

We find that clients are frequently advised of their rights verbally during the intake procedure. Many clients are not able to understand or comprehend the importance of the statement of rights at that time. In interviews with clients, we found that many of them did not know how to file a complaint, or even that they had the right to file a complaint. Yet these same clients remembered that their rights had been explained to them.

^{6/}See Appendix A for the recommendations adopted by the full Commission, based on this report.

RECOMMENDATION: As a part of the intake procedure at every facility, whether residential, nonresidential, or referral, all clients be given a printed copy of their rights, along with the process for filing a complaint. This would enable them to refer to the statement of rights at a time when they felt a violation might have occurred. We suggest that this be done by the State Department of Alcohol and Drug Programs, and be distributed by the department to individual programs, to ensure that a uniform statement is issued to all clients.

At each of the sites we visited, there was an area set aside for the purpose of client intake interviews. Often, these areas were not partitioned off, and were located in areas of heavy traffic and high visibility.

After discussion with personnel at these locations, it was agreed that the intake process should be confidential. However, clients frequently come for the initial interview intoxicated, or in highly emotional conditions. The safety of the intake interviewer must be an important consideration. The intake environment needs to be sensitive to both of these needs.

Given the need for staff safety, ordinary confidential conditions may not be possible. Secluded rooms, closed doors, etc., do not allow for the necessary safety of the staff member. On the other hand, it is possible to accommodate the need for confidentiality and keep safety precautions. Portable partitions might satisfy both needs. Possibly an area that is clearly visible, yet separated from other work areas might solve the problem. Specific recommendations are not possible since each facility will be different, but we do wish to call attention to this concern.

RECOMMENDATION: As the physical layout permits, each program facility should provide a private area and atmosphere for client intake interviews which would allow for the privacy of the client while maintaining sufficient safety standards for the intake interviewer.

From conversations with program directors, it was learned that client information is often freely exchanged between directors and personnel of different programs for the purpose of referral follow-up. In situations where an individual comes to a referral facility for information regarding available programs, the staff member involved with the intake will subsequently contact the recommended program to find out the status of the referral. If a client entering a program has participated in another program, the directors might discuss the client's case. While these situations don't in themselves constitute a violation of privacy rights, the indiscriminate use of this procedure could be problematic. Employers or family members could obtain private information by claiming to be involved with an alcoholic rehabilitation center. We believe that conscientious staff members

will be wary of phone calls, and will be sure that they are speaking with appropriate callers. But we also feel that every precaution should be taken to protect the client's right to privacy.

RECOMMENDATION: All phone calls concerning a client's case be documented with the following information: name and position of the caller and the facility represented; name of person releasing the information; date; and summary of information released. This additional safeguard should take little time, but will provide a check on the indiscriminate release of information.

Furthermore, we wish to emphasize the need for proper release forms signed by the client when any information is to be released. Staff members should be aware universal waivers are not valid and should not be accepted. We make no new recommendations; we only want to support the existing regulations.

Currently, Los Angeles County assigns an identification number to all clients receiving treatment in ADP-funded programs. The number consists of the client's initials and birthdate. The identification number is used for follow-up of referrals, for statistics gathered by the county, and for tracking the individual.

Tracking is the term used for following the progress of a particular client over a period of time. Studies indicate that alcoholics tend to drift to certain areas. Tracking enables the ADP to identify areas of heavy concentration. It also enables the ADP to identify concentration by ethnic background, economic levels, and sexual orientation. Tracking is important in understanding the sociology and demographics of alcohol and drug addiction.

Plans are being made to make use of computers for tracking, as well as for gathering other types of statistical information. This, no more than the use of identification numbers, does not constitute a violation of privacy rights. Yet we feel the need to comment on this area. In the Information Practices Act of 1977, the California legislature makes it clear that the indiscriminate collection, maintenance, and dissemination of personal information is a violation of personal privacy rights. We feel there is a potential danger of other agencies gaining access to records that should be reserved for the use of the ADP, once this information has been programmed into a computer system.

RECOMMENDATION: The current practice of assigning identification numbers should be reexamined to be sure that this method does ensure the confidentiality of the client, and would ensure this confidentiality if the computerized information were obtained by another agency. Secondly, every safeguard available should be used to ensure that access will be limited to offices with legitimate right to the information.7/

^{7/}California Government Code § 1798.24(d)

CONCLUSION

We find that sufficient safeguards do exist with the present rules and regulations concerning confidentiality and the rights of privacy. We also find that it is the actual practice of the programs we surveyed to carry out these regulations effectively. Violations do occur, however, these seem to be the random acts of individuals rather than matters of policy.

In addition, we find that programs directed to gays and lesbians exist in the large urban areas of the State. We further find that many individuals obtain more successful recovery in these special programs. However, potential clients are frequently not informed about these programs.

We offer our recommendations in four areas: (1) intake procedures; (2) physical area for intake; (3) use of telephone calls; and (4) safeguards with computerization. We feel they can be readily integrated into existing programs with little administrative change or expense. We feel that they would effectively improve the level of service provided to clients in the areas of confidentiality and privacy rights.

ADDENDUM

Even though our purpose was not to single out individual programs, we feel that one group deserves recognition for the work they have done and for the service they could offer in the implementation of some of our suggestions.

In 1981, the Los Angeles County Office on Alcohol Abuse and Alcoholism (OAAA) convened a gay task force to act as an advisory board to the county in matters concerning gays and lesbians in drug and alcohol rehabilitation programs. This task force is composed of interested personnel and directors from gay programs, and includes a representative from the OAAA. To date, the task force has sent a questionnaire to county programs requesting information about their intake procedures and the services they offer to gay and lesbian clients. Immediate plans are to design an intake form that would aid in the identification of gay clients, and to offer their services for workshops for general programs working with gay and lesbian clients.

We commend this volunteer task force for their work, and we encourage programs in the Southern California area to make use of the services offered by the task force. It is in a unique position of being able to offer advice for the treatment of gay and lesbian clients, while keeping within the framework of the ADP administrative structure. We encourage the offices of the ADP in other areas to examine the possibility of creating similar task forces for other parts of the State.

Appendix A

The following additional recommendations have been adopted by the Commission based upon its research and the materials located in the Supplements published herewith. (See Report of the Task Force on Alcohol and Drug Abuse Programs.)

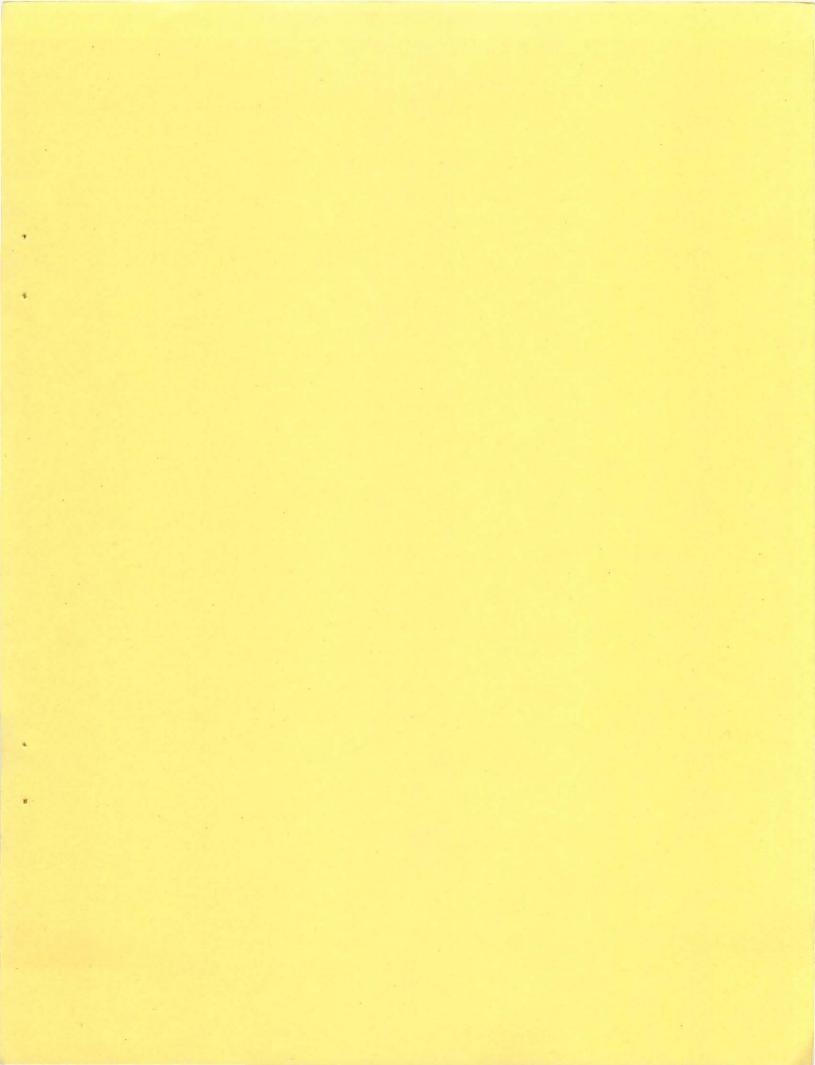
THE COMMISSION RECOMMENDS that the Department of Alchol and Drug Programs require State-licensed or funded-programs to include the following procedures during the initial interview with a prospective client:

- (a) provide all prospective clients with written information regarding personal rights, and the process for filing complaints should their rights be violated;
- (b) provide information to all prospective clients about local programs targeted for special groups, including programs for lesbians and gay men.

THE COMMISSION RECOMMENDS that the Department of Alcohol and Drug Programs should require each State-licensed or-funded program to provide a private area for client intake interviews. Such an area should accommodate the need for confidentiality while maintaining sufficient safety standards for the intake interviewer.

THE COMMISSION RECOMMENDS that the Department of Alcohol and Drug Programs require that all telephone calls regarding a client's case which involve personnel at a state licensed or funded program must be documented with the following information: name and position of the caller/receiver and the facility represented; name of person releasing client information; date; and summary of information released. This safeguard will provide a safety check on the indiscriminate release of personal information concerning a client.

THE COMMISSION RECOMMENDS that the Department of Alcohol and Drug Programs study and monitor the assignment and use of client identification numbers by local ADP-funded agencies. Agencies which assign identification numbers to clients, especially those using computerized systems, should be required to certify annually the security methods which are taken to ensure confidentiality and privacy for client information and records.



CONTINUING SEX EDUCATION FOR PHYSICIANS

BY

WARDELL B. POMEROY, PH.D.

Privacy in one's sexual life is a very important part of the mores of our country. There is a basic difference, however, from considering sex as private and considering it as shameful. Some people confuse these two concepts believing they go hand in hand. There is also a difference between engaging in sexual behavior in a nonprivate way and in talking about one's sexual behavior. Kinsey found that if confidentiality and a nonjudgmental attitude by the interviewer is established, people are quite free in talking about what they have done sexually but would be very reluctant to engage in sexual activity in front of the interviewer. Although Masters and Johnson were successful in observing sexual behavior with a few hundred subjects, this is definitely an exception to the accepted (and actual) mores of our culture.

What opportunities do people have to talk about their sexual behavior, especially when that behavior becomes a problem? Traditionally they have gone primarily to their physician and to a lesser extent, to their minister, friends or acquaintances. The great majority in all of the above categories do not keep confidences, are judgmental and are poorly informed about sexual matters. As a step in overcoming this dilemma, the State of California from 1976-1978, through the Board of Medical Quality Assurance, established mandatory continuing sex education for licensed social workers, psychologists, marriage counselors and nurses. This continuing education amounted to only ten hours a year, a mere pittance in relation to the amount of time that is needed. Physicians were exempted from learning about sex although they were allowed to take such courses on a voluntary basis.

Let us look at what preparation physicians receive in the field of sex during their medical education. The following tables and text are taken from the July 1977 task force on Instruction in Human Sexuality in the Division of Licensing - Board of Medical Quality Assurance:

Table I: Format and length of Introductory courses or course segments on Human Sexuality in California Medical Schools

Schools	Format	Hours
Loma Linda	Segment of OB/Gyn Clerkship	8
Stanford	Separate course	30
U.C. Davis	Segment of core course in Human Reproduction Separate course	8-16 20
U.C. Irvine	Segment of core course in Behavioral Science	10
U.C. Los Angeles	Segment of core course in Behavioral Science	16

TABLE I - contd.

Schools	<u>Format</u>	Hours
U.C. San Diego	Fall segment of core course in Behavioral Science	9
	Spring segment of core course in Behavioral Science	3
U.C. San Francisco	Separate course Separate course	20 9
U.S.C.	First academic period Second academic period	12 8

In addition to the hours of instruction on human sexuality offered in introductory courses or course segments, most schools reported single lectures and sessions on aspects of human sexuality spread throughout the preclinical curriculum. Estimates of the number of hours of instruction offered in this format ranged from 15 to over 50.

Finally, all but one school reported some instruction on human sexuality in the clinical years. Of those schools reporting the number of hours involved, the University of California, Davis, offers 18 hours of clinical instruction, 6 of those hours in a separate elective course; the University of California, San Francisco, offers a separate clinical clerkship of 160 hours; the University of California, Irvine, offers 15 hours of instruction, and the University of Southern California offers 12 hours of instruction within more general courses.

It should also be noted that the University of California, San Francisco, offers two courses open to residents, interns, and health and helping professionals as well as medical students. One of these parallels the 20 hour introductory course for second year medical students. The other is a 50 hour introduction to sex counseling which includes some experiental learning.

Table II shows the medical specializations represented on the teaching staff of each school's introductory course(s) or course segment(s) on human sexuality. Psychiatry, obstetrics and gynecology, and urology are the specializations most commonly represented.

In addition, in the case of Stanford, Davis, Irvine, Los Angeles, and San Francisco, the primary teacher and some or all of his supporting staff have had training in human sexuality and experience in sex therapy.

Several schools also include nonmedical specialists on the staff of their introductory human sexuality course(s) or course segment(s). At Stanford the roster of guest speakers includes nurses and social workers. At

Davis, the supporting staff this year included a marriage and family counselor who treats sexual dysfunctions, particularly of women. One of the supporting staff at Irvine is both a lecturer in psychiatry and an MSW/LCSW. Specialties represented on the staff at San Francisco include psychology, public health, social work, education, and relationship counseling.

Finally, several schools report the use of community resource persons. Stanford's guest speakers include representatives of alternative life-styles—a chaplain, a prostitute, a homosexual, a lesbian, a sadomasochist, and a transsexual. Davis' supporting staff this year included 3 representatives from a gay task force. San Francisco uses presentations and panel discussions by individuals and couples representing various sexual lifestyles and problems.

TABLE II: Medical specializations represented on the teaching staff of each school's introductory course(s) or course segment(s) on human sexuality.

School	Psychia- try	OB/GYN	Pedi- atrics	Urology	Endocri- nology	Physi- cal Medicine	Ortho- pedic Surgery	General Practice
Loma Linda		Х		Х				
Stanford	x	X	x	х				
U.C. Davis	x		x		х	x		
U.C. Irvine	x							
U.C. Los Angeles	X							
U.C. San Diego	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
U.C. San Francisco		х		х			x	X
U.S.C.	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
								
Number of Schools	4	3	2	3	1	1	1	1

TABLE III: Areas of knowledge covered in each school's introductory course(s) and course segment(s) on human sexuality.

Schools	Nosology and Etiology of Sexual Dys- functions	Anatomy, Physiology, Psychology of Sexual Functioning	Variations in Sexual Behavior	Sexual Effects of Disease, Disability, and Medical Intervention	Socio- cultural Deter- minants	Child- hood and Adoles- cent Sexuality	Sex and Aging
Loma Linda	X			х			X
Stanford	X	X	x	х	x		
U.C. Davis	X	x	x	х		x	x
U.C. Irvine	x	X	X	x	x	x	X
U.C. Los Angeles	X	X	x		x		
U.C. San Diego	X	X	X			x	
U.C. San Francisco	x	X	X	x	x	x	
U.S.C.	x	X	x	X	x	x	X
				·			
Number of Schools	8	7	7	6	5	5	4

Table III shows the areas of knowledge most frequently covered in introductory course(s) or course segment(s) on human sexuality. All schools cover the nosology and etiology of sexual dysfunctions. All but Loma Linda cover the anatomy, physiology and psychology of normal sexual functioning, and 'normal' and 'abnormal' variations in sexual behavior.

Table IV shows the number of schools teaching skills and/or skill related knowledge and the number of schools attempting affective learning.

TABLE IV: Schools teaching skills and skill-related knowledge, and attempting affective learning in their introductory course(s) or course segment(s) on human sexuality.

School	Sexual History Taking	Office Management of Sexual Problems	Intensive Treatment Models	Student Self-Assessment of Attitudes and Values	
Loma Linda	x				
Stanford		X	x	x	
U.C. Davis	x	X	X	х	
U.C. Irvine	x	x	x	x	
U.C. Los Angeles	x	X			
U.C. San Diego					
U.C. San Francisco	x	X	x	x	
U.S.C.	x	х	x	x	
Number of Schools	7	6	5	5	

TABLE V: Teaching Methods and Materials Used in Courses or Course Segments

Schools	Instructional Films, Slides, Etc.	-	Small Group Discus- sions	Demonstration Interviews, Case Presen- tations, Etc.	Skill Develop- ment Through Role Playing	grammed	No. of Methods or Materials Used
Loma Linda							0
Stanford	x	x	x			-	3
U.C. Davis	X	x		X		•	3
U.C. Irvine	X	x	x	X			4
U.C. Los Angeles			x		X		2
U.C. San Diego	x						1
U.C. San Francisco	X	x	X	X	X		5
U.S.C.	X	x	X			x	4
					· · · · · · · · · · · · · · · · · · ·		
Number of Schools	6	5	5	3	2	1	

INSTRUCTION IN HUMAN SEXUALITY

IN U.S. MEDICAL SCHOOLS

The most recent published, comprehensive survey of instruction in human sexuality in U.S. Medical Schools was carried out by the Center for the Study of Sex Education in Medicine (CSSEM) in 1973. Of the 114 medical schools in the U.S., 110 were contacted for this survey. Of these, 105 responded to the questionnaire. A summary of this survey follows.

Format of Instruction

All of the responding schools had programs in human sexuality; 72 percent taught human sexuality in a separate course; 28 percent taught human sexuality within a more general course.

Length of Instruction

Of the responding schools, 16 percent offered less than ten clock hours of instruction in human sexuality; 35 percent offered 10 to 19 hours; 28 percent offered 20 to 29 hours; 21 percent offered more than 30 hours.

Staff

Of the responding schools, 95 percent reported representatives on their teaching staffs from psychiatry, 87 percent from obstetrics and gyne-cology, 49 percent from psychology, 31 percent from urology, 27 percent from nursing, and 19 percent from family medicine. About 47 percent of the responding schools reported that other disciplines were involved-social work, theology, education, marriage counseling, etc.

Content

Ninety-five percent of the responding schools included aspects of normal sexual behavior; 88 percent included variations and deviations in sexual behavior; 81 percent included sexual dysfunctions; 79 percent included some psychosexual development; 75 percent included aspects of treatment; 72 percent included aspects of cultural variations, and 70 percent included biological aspects. Seven out of ten medical schools covered all of the above items.

All schools but Stanford teach techniques for taking a sexual history. (Students at Stanford learn how to take a sexual history in a separate course on physical diagnosis.) All but Loma Linda and the University of California, San Diego, teach techniques for the office management of sexual problems. Five schools attempt some sort of affective learning.

^{1.} Reported in: Lief, Harold I and Arno Karlen, <u>Sex Education in Medicine</u>. Spectrum Publications, New York, 1976. Ch. 3, pp. 25-34.

Teaching Methods and Materials

Aside from lectures, syllabi and printed texts, the principal methods and materials employed in California medical schools to teach human sexuality appear to be: instructional films, slides, etc.; explicit sexual films; demonstration interviews, case presentations, panel discussions, presentations by individual patients, homosexuals, etc.; small group discussions; student role playing; programmed manuals.

Table V shows the principal teaching methods and materials used by each school. Only Loma Linda relies exclusively on lectures in its course segment on human sexuality. All but Loma Linda and Los Angeles employ both instructional audio-visual material and also explicit sexual films. All but Loma Linda reported devoting some class time to small group discussions. Three schools, Davis, Irvine, and San Francisco, present some material by means of demonstration interviews, case presentations, panel discussions, presentations by individual patients, representatives of various sexual life styles, etc. Two schools, Los Angeles and San Francisco, use role-playing to develop student skills in sexual history taking and therapy techniques. The University of Southern California employs a programmed manual as part of its program.

Placement in the Curriculum

All but one school, Loma Linda, offer their introductory course(s) or course segment(s) in the preclinical years. Stanford offers its course once every other year, in the spring, so that some students will be taking it at the end of their freshman year, some at the end of their sophomore year. The University of California, Los Angeles and San Diego, offer their introductory course segments on human sexuality in the first year. The University of California, Davis, Irvine, and San Francisco offer their introductory courses and course segments on human sexuality in the spring of the second year.

As noted above, all but one school report some coverage of human sexuality material in the clinical years. Only the University of California, Davis and San Francisco offer separate courses on human sexuality in these years.

Teaching Methods and Materials

Ninety percent of the schools used lectures; 87 percent used small group discussions. Seminars were used by 54 percent, case demonstrations by 47 percent, and workshops by 13 percent.

Films were the commonest teaching aid, used by 94 percent of the medical schools. Four percent reported using erotic films only; 13 percent reported using nonerotic informational films, and 84 percent used both erotic and informational films. Slides were used by 79 percent of the schools, audio-tapes by 48 percent, and live or taped television by 42 percent. Guest lecturers were used by 66 percent of the medical schools.

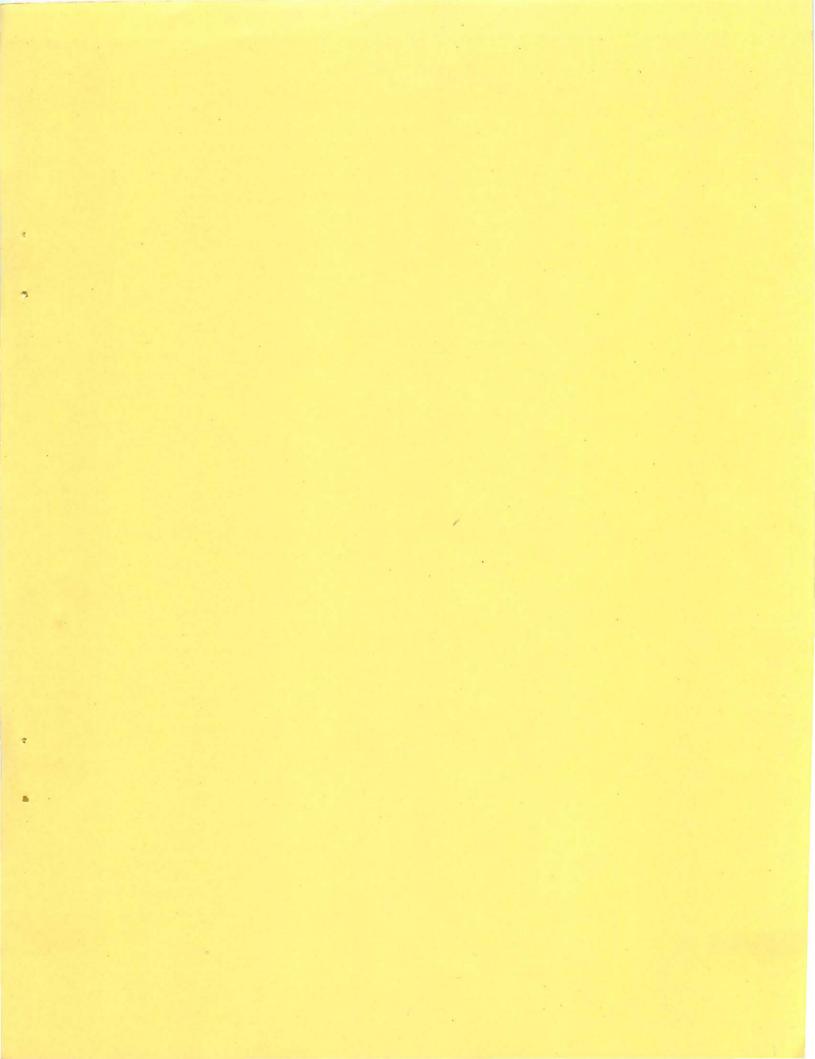
DETERMINATIONS

Having reviewed the written and verbal testimony, and in order to ensure adequate instruction in human sexuality for applicants for a physician's and surgeon's certificate, the Division of Licensing determines:

- 1. That each applicant shall show by evidence satisfactory to the Board that she/he has successfully completed a medical curriculum extending over a period of at least four academic years in a school or schools located in the United States or Canada and approved by the Board, or in a school that is under the charter of a university located in the United States and that is, or was at the time an applicant seeking a certificate pursuant to this chapter entered the school, and institutional member of the American Association of Medical Colleges approved by the Board, and total number of hours of all courses shall consist of a minimum of 4,000 hours which shall include at least one identifiable and separate course in human sexaulity.
- 2. That the total length of the course or courses on human sexuality be at least 30 hours long.
- 3. That the course on human sexuality be taught by a multidisciplinary faculty, including, but not limited to, representatives from the departments of psychiatry, obstetrics and gynecology, pediatrics, and urology.
- 4. That the course on human sexuality cover the following topics: sociocultural determinants of sexual attitudes and values, variations in sexual behavior, including homosexuality, the nosology and etiology of common sexual dysfunctions, techniques for sexual historytaking and for the office management and appropriate referral of sexual problems and sexual trauma.
- 5. That the course on human sexuality include explicit sexual material such as films, slides, interviews, etc.
- 6. That, at the end of the course on human sexuality, the student be able to take a sexual history and develop an appropriate patient management plan which may include appropriate patient referral.
- 7. The Division of Licensing hereby establishes a task force on human sexuality to facilitate the implementation of these standards in the undergraduate medical curriculum and to consider the inclusion of human sexuality in the continuing education of physicians.

The above data shows us how poorly prepared physicians are in the field of sex and how important it is for them to have continuing education of more than ten hours a year in the sexual area. The amount of sex education taught in California medical schools has decreased since 1977 so the above statistics are an overstatement for 1982. For example, the number of sex education films sold or rented teaching sex education in medical schools has been cut in half over the past five years.

I think that health practitioners in general, and physicians in particular, cannot adequately maintain the confidentiality and privacy of their patients without being comfortable with their own sexuality. Without enough knowledge about the sexual attitudes and behavior in society, the physician cannot understand the dire necessity of privacy and confidentiality. Because of the highly sensitive nature of sex in all its forms, the physician, as part of his sex education, must be taught how to be nonjudgmental and confidential with his/her patients as well as having basic information about human sexuality.



PERSONAL PRIVACY AND HOSPITAL VISITORS by Audrey Mertz. M.D.

Acknowledgements: Contributions to this study were made by members of the Sacramento Lesbian and Gay Mental Health Professionals, notably Kenneth D. Brock, M.S.W. A 1980 survey of nurses' feelings about homosexuals by Wendy Patt, RN was used as resource.

Findings

- 1. Many hospital patients wish to have visits by significant other people who are not next-of-kin or members of immediate family.
- Visits by persons other than immediate family are often prohibited by hospital policies, especially in emergency rooms, postoperative recovery rooms and intensive care units.
- Attitudes of hospital staff may be negative to homosexual patients and to visits by their lovers and interfere with nursing care.

Recommendations

- 1. Hospital visiting policies should be changed to include access to patients by significant others.
- 2. Negative attitudes toward homosexual patients and their visitors should be changed by inservice training to staff and by supportive policy statements by administrators.

Introduction

Many homosexual couples fear loss of access to each other in times of medical crisis, when the emotional support and help of the partner is vital to the sick or injured person. Hospital visiting policies usually restrict visiting of patients in emergency rooms, postoperative recovery rooms and intensive care units to immediate family members or next-of-kin. Unless the nurse in charge recognizes non-traditional arrangements as "family" and lovers as "immediate family members" or the doctor specifically orders that visits may be made by the person the patient wants to see, the lover may not be allowed in.

Similar difficulties of access may be experienced by opposite-sex lovers who are not spouses or close friends and neighbors who are especially important to the patient.

Gaining access is the first hurdle. The visitor may then feel negative attitudes from hospital staff who are disapproving or unfamiliar and uncomfortable with alternative families. Nursing staff may find it hard to accept expressions of affection, tenderness and concern between persons of the same sex and may screen this off from other patients and themselves. They may joke among themselves about the patient and lover and void giving needed nursing care.

Body of Text

Hospitals in the Sacramento area were surveyed as to policies and practices regarding visitors. They all have rules about visiting hours, number of visitors at one time and minimum age of child visitors. Visitors to emergency rooms, postoperative recovery rooms and intensive care units are often limited to adult members of the immediate family. Exceptions may be made in policy or in practice, but it is usually the nurse's judgement or the doctor's order that allows in a person who is needed by the patient but is not a member of the immediate family as commonly defined.

The traditional visitor restrictions do not recognize that many people are bonded to persons who do not meet the legal definition of spouse, next-of-kin, or immediate family. These may be close friends, same-sex or opposite-sex lovers. The person most significant to the patient and most needed at the bedside during hospitalization may not be a relative.

Problems that often result from such restrictions are that the person close to the patient misrepresents himself as a spouse or other relative, or is afraid to visit from fear of exposure or fear that the patient will be treated unfairly. The family when they do not approve of the person chosen by the patient, may prevent that person from visiting.

Some problems were reported at an informational hearing at the Human Rights Commission of the City and County of Sacramento on May 28, 1980, about disparate treatment of gay and lesbian couples by hospitals. Gays and lesbians are often refused visitation because they are not "immediate family" of the patient.

Problems found at one Sacramento hospital were:

- 1. Woman who had been living with a man for seven years and never divorced her husband. Both men wanted to visit.
- 2. Lesbian relationship where family did not like the patient's significant other and would not let her visit.
- 3. Middle-aged single woman whose friends were her "significant others". She had cut herself off from her family, but family would not let the friends visit. They were more concerned with the patient's money than with the patient.
- 4. A young couple living together for a short time against family objection. They did not want the live-in girlfriend to visit.

John C. Lawrence wrote in <u>Nursing Forum</u>² "We recognize that hospitalization can be an unpleasant, embarrassing, frightening and even terrifying experience and agree that all patients are entitiled to every available support during this stressful period. Yet the

homosexual patient is often denied the strongest support possible that of his closest loved one. Legally, he cannot list that person as next of kin on hospital admission records. He and his mate cannot hold hands, express affection, or show too much concern for each other lest they incur the wrath, curiousity, or derision of the floor staff. Because of these limitations on caring much psychological pain is superimposed on the physical pain. other hand, if the patient is open about his lifestyle or if his homosexuality is discovered or even suspected while he is hospitalized, he can expect to be avoided by those staff members who are unable to deal with their own anxieties about homosexuality. The presence of a homosexual person can be threatening to everyone, including professionals, who would suppress or deny their own homosexual feelings."... "The loved one finds himself unable to obtain information about the patient or to participate in decisions that relate to his care. At a time when his energy should be channeled into care and concern for someone he loves, it must be expended instead on bureaucratic hassles in dealing with the fact that he is not recognized as having a legitimate role to play in the situation, or on coping with devaluation of the relationship. Whatever energy is left is devoted to hiding his love instead of providing it to dampening his feelings at a time when they most need to be expressed and to censoring what he says and does out of fear that it will offend. To endure a hospital stay may be one of the most bitter and unpleasant of any of the oppressive experiences that homosexual persons are subject to daily."

At a hosptial nursing conference reviewing the discharge of a lesbian patient against medical advice, the nurses came to realize that they had denied the patient comfort, compassion and nursing care because of awkwardness and embarrassment and fear that they might be considered homosexual if they appeared accepting of her. The conclusion was "If there are problems in treating the homosexual patient, they probably stem from the attitudes of the staff. You can't change attitudes overnight — if ever. But you can provide excellent nursing care while dealing with those attitudes."

Suggested ways of dealing with prejudices against homosexuality, or homophobia are self-awareness, examination of assumptions about homosexuality and awareness of attitudes expressed in initial questioning of patients. "You can't assume that all patients are straight, any more than you can assume that your married patient only has sex with his spouse, or that your single patient has relations with only one partner."

Appendix

- 1. Brossart, Jeanne "The Gay Patient: What You Should Be Doing" RN, April 1979
- 2. Lawrence, John "Homosexuality, Hospitalization and the Nurse", Nursing Forum Vol. XIV #3 1975, pp. 305-317
- 3. Patt, Wendy, RN "The views of Registered Nurses toward the Homosexual Patient" Dec. 10, 1980 questionnaire results from 30 nurses of eskaton American River Hospital, Carmichael, CA
- 4. Pogoncheff, Elaine "The Gay Patient: What Not To Do" RN April 1979