STATE OF CALIFORNIA

Supplement Two

COMMISSION ON PERSONAL PRIVACY

Securing privacy through law and education

DECEMBER, 1982

BURT PINES
CHAIRPERSON

THOMAS F. COLEMAN
EXECUTIVE DIRECTOR

Supplement Two:

This supplemental document contains topical reports and surveys that pertain to privacy in medical and mental health services, as well as issues of particular concern to elderly and disabled persons. Authors and titles are listed below:

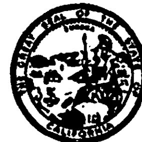
Title: Report of the Committee on Aging and Disability
Author: Commission Nora J. Baladerian

Title: Report of the Task Force on Aging
Author: Commissioner Nora J. Baladerian

Title: Privacy Rights in Alcohol and Drug Programs
Author: Kiernan Prather and Mike Cronen

Title: Continuing Sex Education for Physicians
Author: Commissioner Wardell B. Pomeroy, Ph.D.

Title: Personal Privacy and Hospital Visitors
Author: Commissioner Audrey Mertz, M.D.

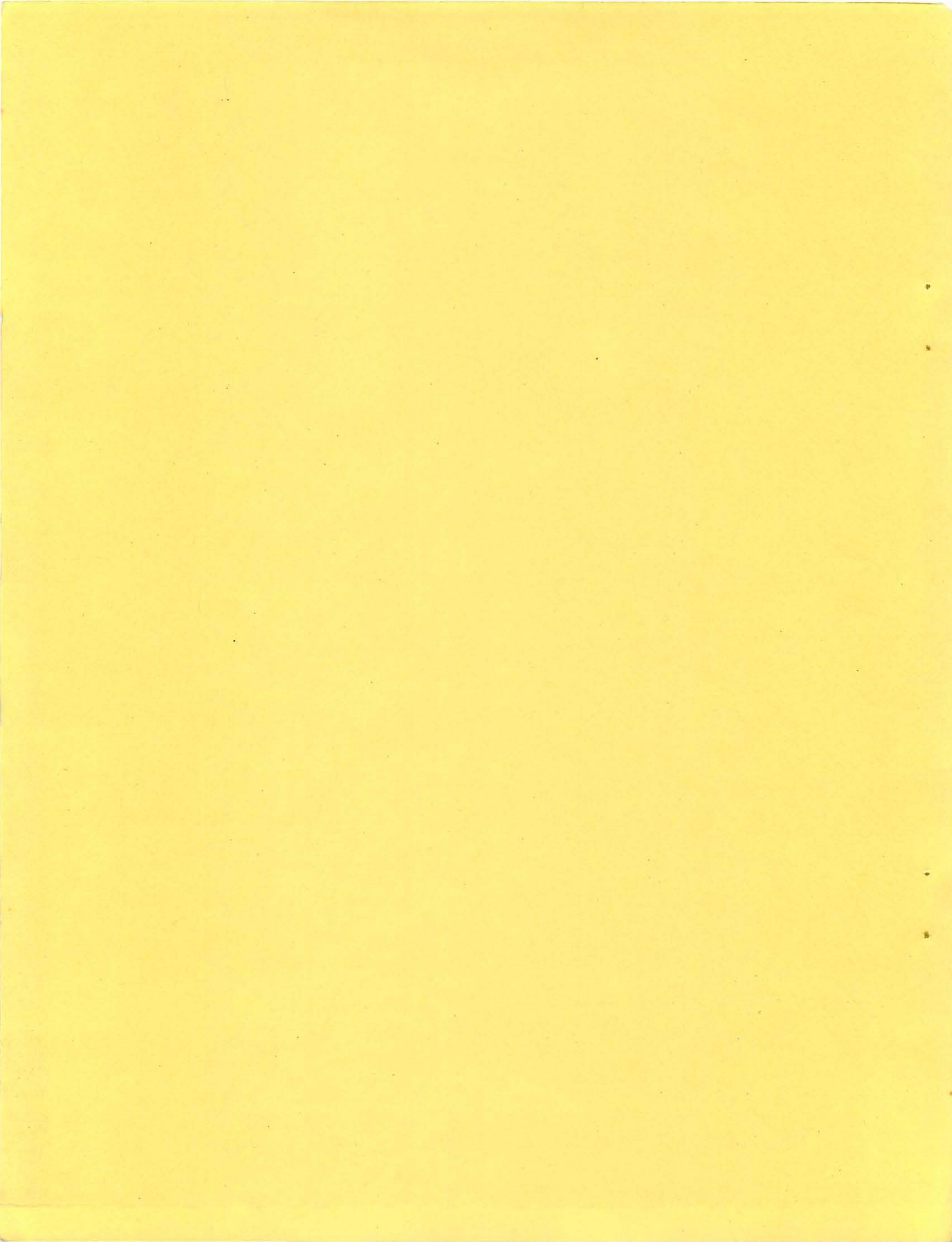


DISCLAIMER

The views stated in the topical reports contained in the Supplements published by the Commission on Personal Privacy are the views of the authors of those reports and do not necessarily reflect the views of the Commission as a whole.

ACKNOWLEDGMENT

The Commission is grateful for the research done by the authors of the topical reports contained in the Supplements. The Commission found these reports helpful in its deliberations and in many cases adopted the recommendations suggested in these reports, either in whole or in part.



COMMITTEE ON AGING AND DISABILITY

REPORT TO THE COMMISSION ON PERSONAL PRIVACY

Committee on Aging and Disability
Nora J. Baladerian, Chair

December, 1982

MEMBERS OF THE COMMITTEE ON AGING AND DISABILITY

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Mental Health Consultant
Culver City, CA

Stanley Fleishman
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Patty Blomberg
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Bruce Gitter
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Daniel Brzovic
Western Center for Law and the Handicapped
Los Angeles, CA

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Whittier, CA

Ellen McCord
State Personnel Board
Sacramento, CA

Dolph Fursee
Retired
Fortuna, CA

TABLE OF RECOMMENDATIONS FROM THE COMMITTEE ON AGING AND DISABILITY

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127	Amendment of Administrative Code to Support Rights to Personal Privacy and Sexual Conduct	
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131	Standardization of Monitoring Patients/Clients Rights Through Development and use of Approved Rights Checklists and Procedures	

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A. MINUTES OF COMMITTEE ON AGING AND DISABILITY

B. REPORT OF LICENSING VIOLATIONS, PREPARED BY ELLEN McCORD

C. TESTIMONY OF ANNE BERSINGER, DEPARTMENT OF SOCIAL SERVICES

D. "MARRIAGE DISINCENTIVES IN GOVERNMENT BENEFIT PROGRAMS FOR DISABLED INDIVIDUALS" BY DANIEL BRZOVIC

E. SENATE CONCURRENT RESOLUTION NO. 30: NORMALIZATION DECLARATION

F. LEGISLATIVE CITATIONS FOR CONFIDENTIALITY AND PRIVACY

G. UNITED NATIONS DECLARATION OF THE RIGHT OF DISABLED PERSONS TO SEXUALITY EDUCATION

H. LETTER FROM DEPARTMENT OF HEALTH SERVICES ALERTING COMMISSION TO POSSIBLE LOSS OF RIGHT TO CONFIDENTIALITY FOR TEENAGERS SEEKING MEDICAL CARE

I. STATEMENT OF PHILOSOPHY ON SEXUAL RIGHTS OF DEVELOPMENTALLY DISABLED CITIZENS, ADOPTED BY THE CALIFORNIA COMMITTEE ON THE SEXUALITY OF THE DEVELOPMENTALLY DISABLED, NOVEMBER 19, 1975

J. STATE COUNCIL ON DEVELOPMENTAL DISABILITIES, REPORT OF OPPOSITION TO AB 603 (STERILIZATION)

K. STATE COUNCIL ON DEVELOPMENTAL DISABILITIES, DRAFT POLICY ON STERILIZATION SEPTEMBER 2, 1982

COMMITTEE ON AGING AND DISABILITY REPORT
FROM COMMISSIONER NORA J. BALADERIAN

INTRODUCTION

The Committee on Aging and Disability was created from a recognition that the potentials for abuse of personal privacy and sexual orientation discrimination are peculiar to persons of these two groups. While many issues of the general population also apply, these groups have factors in common that made it sensible to combine them. Some of the more obvious: higher utilization of residential and health-care residential programs, high level of participation in social service systems, financial support systems (SSI, SSA, Medicare-Cal/Medi-Caid), representation by advocacy groups (Grey Panthers, Protection and Advocacy, Inc., etc.), and a special vulnerability to abuse because most require assistance from others (strangers, agencies) for their life care and intimate needs.

The Committee on Aging and Disability noted many major areas of abuse which could be studied. The reports (Attachment A) of the Committee's meetings are included herein. They include discussion and illumination of the diversity, seriousness and pervasiveness of intrusive and sometimes cruel actions on the part of licensed or State-authorized representatives. Discussion of reports of experiences demonstrating discriminatory or abusive treatment, legal challenges, and dilemmas, and explorations into complex issues of privacy rights are illustrative of the problems that require study and exposure. These reports indicate the extent of the problems of the disabled and aging citizens of the State of California, and the enormity of the task of discovering and studying these invasions of personal privacy and sexual orientation discrimination problems.

A Task Force on Aging was formed to conduct a study on one or two aspects of concerns relating to personal privacy and sexual orientation discrimination for the aging population. The Task Force produced an excellent report on problems that occur in residential programs (intermediate care, skilled nursing facilities, and at home, for persons receiving home health support services). Their findings and recommendations apply equally to disabled persons who find themselves in similar residential and treatment or service programs. The Task Force report follows this report. The members of the Committee on Aging and Disability discovered that a lack of sufficient resources to conduct investigative research resulted in a dismaying inability to submit a thorough piece of research to the Commission. Although initial meetings and planning took place, and a great deal of time was spent by all members of the Committee, the continuing support required for follow-up on research plans was absent. It fell to each Consultant and Commissioner to assume total responsibility for completion of a report, from research to completion. For reasons of other responsibilities and commitments, this was not possible. However, the Chair with the extensive support of the Executive Director Committee was able to spend the time required for organizing, convening and directing the Task Force on Aging.

EXISTING LAWS AND REGULATIONS: IMPLEMENTATION

The above statements do not imply that thorough study of discriminatory and abusive practices is not indicated. Quite to the contrary - we believe that it is, and that a thorough study should be undertaken. We suggest that the Department of Aging, in concert or with the cooperation of licensing agencies or departments conduct a thorough study of practices in residential facilities. This could be undertaken by the Inter-Agency Committee on Personal Privacy, recommended for convening herein. It is the opinion of members of this Committee, based on the limited research conducted and the extensive professional experience represented, that although many protections already exist for persons who have disabilities, these require review and modifications. The attached list of protections describe already mandated regulations. (Attachments C and D of Task Force Report.) What is critical at this time is the assurance of implementation of these existing rights and protections. This is where the gap exists between law and practice. A study of licensing infractions was conducted that revealed serious neglect of the law (see Attachment B). Beyond this documentation, Committee members described experiences in their daily practices indicating that our experience may be the proverbial "tip of the iceberg". We believe that only with regular, thorough, standardized training and monitoring can implementation of existing statutes and regulations be assured.

THE COMMISSION RECOMMENDS that the Governor issue an Executive Order creating an Inter-Agency Committee on Personal Privacy in Health and Social Services. The Inter-Agency Committee should consist of representatives from the following departments: Aging, Social Services, Health Services, Developmental Services, Rehabilitation, and Mental Health. The Director of one of these departments should serve as Chairperson, as designated by the Governor.

The Inter-Agency Committee, with appropriate staffing, should perform the following functions:

1. <u>Training</u>: (a) develop, conduct, and evaluate training programs for service provider agencies regarding personal privacy rights, freedom of intimate association, including lawful sexual conduct, and protections against sexual orientation discrimination; (b) develop standardized training and materials that allow for updating as laws and regulations change, that are thorough in the areas identified; and (c) prepare the materials in the languages of the persons receiving the training if they are not conversant in the English language but are providing direct patient care.

2. <u>Regulation</u>: (a) monitor the practices of providers as they impact consumers in the areas of privacy, sexuality, and sexual orientation; (b) receive, investigate, and remedy complaints arising from invasions of

privacy and sexual orientation discrimination; and (c) propose legislation and administrative regulations/ amendments as needed to assure personal privacy protections.

During the 1983-84 budget year, the Inter-Agency Committee should function within the existing resources of its member departments. The Legislature should provide funds for its continued operation thereafter.

(#s 124-125, Supplement __, Report of the Committee on Aging and Disability)

RIGHT TO PRIVATE SEXUAL CONDUCT

Testimony of Anne Bersinger to the Commission (Attachment C) points out that under the licensing regulations, each licensed Community Care Facility has the option to adopt whatever (or no) policies regarding the sexual activity of its client that it chooses. Our experience indicates that the absence of an expressed right to engage in legal consensual sexual conduct for facility residents has:

1. Lead to a fear on the part of facility operators that if they "permit" their residents to engage in lawful, consensual sexual activity, that community outrage may put them out of business;

2. Denial of rights of citizens in their own home to engage in sexual activities (home being the place of residence of the individual);

3. Facility operator confusion/uncertainty of what they are supposed to do regarding sexual activity of the residents; and

4. A majority of the agencies known to Committee members suppress (and some punish) those engaging in sexual conduct through "house rules" prohibiting same.

In the absence of an approved recognition of the right to engage in lawful consensual sexual conduct while residing in a licensed facility, facilities have gone to great lengths to extinguish the sexuality of its clients. For example, two cases in particular exemplify this "sexophobic" attitude, that are noted in Attachment B which describes conduct in licensed facilities that lead to a revocation of the license:

1. "Licensee held knife to head of resident and threatened to cut "Z" in penis if resident did not discontinue certain behavior (unspecified)." (The Committee consensus is that the offensive behavior was probably masturbation.)

2. "...residents forced to wear athletic supporters to control masturbation..."

Additional violations, not noted herein including prohibition of sexual conduct, have been discovered. Others, even more serious were gruesome, exploitative and inhumane. The sexual abuse of clients in the care of others, widely recognized as a serious problem, further demonstrates the need for expressed statements of rights of residents in licensed facilities.

We urge that legal, consensual and private engagement in sexual conduct be expressly stated as a right of an individual living in a licensed residential care program. This could easily be included in "activities of daily living" as noted in the Administrative Regulations. It is the opinion of the Committee that the current Administrative Regulations (California Administrative Code Title 22, Division 6, Chapters 1, 2, 3 and 6) and Constitutional protections do provide for legal private consensual sexual activity in licensed facilities, to wit:

1. Consensual Adults Act of 1975.

2. Right of Privacy Amendment to the State of California Constitution, Article 1, Section 1, passed by the voters in 1972.

3. Senate Concurrent Resolution No. 30 (July 26, 1972) on Normalization (Appendix E).

Based on the above, we believe that the right to full human expression exists in the law, but not in practice. To correct this ommission, amendment of the Codes is indicated.

THE COMMISSION RECOMMENDS that state departments that license health care facilities, community care facilities, and continuing care facilities, such as the departments of Health Services, Social Services, and Mental Health, promulgate regulations amending Title 22 of the California Administrative Code to support the following legislatively mandated rights: (1) every adult person has the right to engage in consensual sexual conduct in the privacy of one's home or other private location; (2) every mentally ill and every developmentally disabled adult has the same rights as every other adult of the same age regardless of disability, unless medically contraindicated; (3) every patient and other adult resident of licensed facilities has basic privacy rights; (4) a residential facility is reasonably considered to be the temporary or permanent home of an individual residing therein. Specific regulations are needed to articulate the following rights:

1. <u>Personal and Patient Rights</u>: Every adult residing in a health care, community care, or continuing care facility, has the right to engage in private sexual conduct with other consenting adults. For this purpose,

the location of the conduct shall be deemed "private" if it meets the following criteria: (1) the area is outside of the view of others: (2) no other area within the facility is available for such purpose, which is accessible to the patient/resident.

2. Personal Accommodations: Marital status discrimination should be eliminated from sections of the code regulating equipment and supplies necessary for personal care and maintenance, such as §80404(a)(3)(A). Presently the code requires "[t]he licensee shall assure provision of . . . '[a] bed for each resident, except that married couples may be provided with one appropriate size bed.'" All sections regulating bed size selection should be free from marital status discrimination and should read as follows: "The licensee shall assure provision of 'a bed for each resident, except that consenting adult couples shall be provided with one appropriate size bed, regardless of the marital status or gender of the individuals, unless medically contraindicated.'"

(#127, Supplement __, Report of the Committee on Aging and Disability)

ECONOMICS

The issue of intimate relationships with others has an important determining factor: Economics. This is true for most everyone, but remains a matter of personal decision. In the case of the elderly or disabled individual, whose income is derived from Social Security Administration, Supplemental Security Income, Social Security Disability Income, or other government programs, the matter of personal choice in intimate relationships is eroded. The regulations covering amount and eligibility to receive benefits intrude into one's personal choices regarding marriage, who shares one's home, and who assists in one's personal care. Betty R. and Jimmy E. testified at the Commission Public Hearings in Los Angeles (see p. 79 Los Angeles Public Hearing Testimony). Betty and Jimmy are two developmentally disabled adults who wished to marry; however the financial punishment of getting married, due to regulations of Supplemental Security Income benefits, prohibited them from doing so...living together without being married was unthinkable, and against their religious convictions. Betty R. died two months after presenting her testimony, never having had the opportunity (at age 27) to experience marriage "like other people".

Surely it was not the intent of the Social Security Administration to keep people from getting married, but this has been the result for many persons dependent upon this agency for their income. Daniel Brzovic of the Western Law Center for the Handicapped further clarified this problem in his testimony at the Los Angeles Public Hearings (p. 80) and in his written report on the subject (Attachment D). Based on testimony and the report of Mr. Brzovic, that describe invasions into personal privacy by way of economic sanction, remedial action is required.

THE COMMISSION RECOMMENDS that economic disincentives which penalize persons who are married and which discourage persons from becoming married be eliminated from health and welfare benefits programs operated by the federal government, such as Social Security, Supplemental Security, In-Home Supportive Services, Medicaid, and Medi-Care. The Commission urges members of California's congressional delegation who serve on committees that oversee these programs to review "marriage-penalty" regulations and proposed remedial legislation.

(#129, Supplement __, Report of the Committee on Aging and Disability)

CONFIDENTIALITY AND ASSURANCE OF PROTECTIONS

Confidentiality protections are written into numerous laws and regulations (see Appendix F) for the protection of confidentiality of client records and the person. Protection and Advocacy, Incorporated, monitors compliance to these measures for persons with developmental disabilities in the State of California, and relates closely to the Departments of Developmental Services and Education, particularly Special Education Division. This agency provided the materials contained in Appendix F. We note that persons charged with assuring the civil rights of clients, including confidentiality protections, personal privacy protections, sexual orientation discrimination protections, protections related to other aspects of personhood and privacy, are not required to receive training in implementation procedures, monitoring or evaluation techniques, or the specifics of the law itself! We suggest that this gap be filled through specifications built into the job requirements.

THE COMMISSION RECOMMENDS that the departments of Developmental Services, Social Services, Health Services, Mental Health, and Rehabilitation take the following actions:

1. Require reviewers to utilize a comprehensive patients-rights checklist during the annual or periodic review of client/patient progress conducted for state licensed programs or facilities; and

2. Require reviewers to utilize the department-approved checklist in the following manner: (a) each right specified in statutes and administrative regulations (as indicated on the checklist) should be individually

communicated to the client; (b) after each right is so communicated, the reviewer should ask the client if this right has been denied or limited in any way since the last review; and (c) the reviewer should record the client's response separately for each right.

The Clients/Patients Rights Advocates within each of these departments should prepare a standard checklist to be used for the periodic reviews required by the department. The checklist should clearly indicate each patient right which has been legislatively or administratively declared. Routine use of such checklists should begin no later than January 1, 1984.

(#131, Supplement __, Report of the Committee on Aging and Disability)

STERILIZATION OF RETARDED/DEVELOPMENTALLY DISABLED INDIVIDUALS

Historically, persons who have disabilities, particularly developmental disabilities (mental retardation, cerebral palsy, epilepsy, etc.) have been considered automatically proper subjects for sterilization procedures, by persons taking it upon themselves to judge who shall and who shall not have the opportunity to bear and raise children. The authorization and promotion of sterilization on this mass basis has been a result of a number of myths, fears and stereotypes including:

- Fear that more disabled/retarded children will be brought into the world.
- Judgment that disabled persons cannot properly parent children.
- Judgment that "those people" really do not understand about parenting.
- Genetic control is "better" and only certain persons or types of persons "ought" to be allowed to have children.
- And many more...a treatise could be presented...

As late as 1962 sterilization was required prior to discharge from State hospitals in some states, where the patient had mental retardation. Currently, it is illegal to perform a sterilization procedure on a mentally retarded individual where informed consent cannot be assured. This presents a conflict for the civil rights of individuals with limited understanding: They are being denied access to a form of permanent contraception available to all other citizens, simply based on the intelligence, rather than the needs and desire of the individual. On the other hand, prior to this law, sterilization was being conducted en masse to persons without informing them of the procedure, its consequences, purpose or dangers.

To equalize access to this procedure, AB 603 was introduced in the Legislative Congress of 1980-81, in an effort to adequately protect mentally retarded individuals from undergoing a sterilization procedure without proper protections, while affording access to the procedure for those who desired it. The bill was defeated and recommendations for an improved version with more protections is being proposed. This Committee supports these efforts to equalize access to sterilization procedures, and protection of individuals from the sterilization procedures occurring at the decision of persons in charge of another, who may not be aware of or wish to recognize, the client's right to informed consent. We urge the Legislature to pass the legislation introduced that is supported by Protection and Advocacy, Incorporated, the Association of Retarded Citizens, the State Council on Developmental Disabilities, and other advocacy groups.

The Committee has reviewed the Recommendations proposed in the main body of the Report and would like to express our support and approval of the following Recommendations:

NO.	TITLE	PAGE
17	Medical Decision Making	193
18	Hospital Visiting Practices	198
19	Patient's Right to Designate Family	202
20	Patient's Access to Health Care Records	203
21	Limited Disclosure to Patient's Household	205
22	Wrongful Disclosure of Health Care Information	206
23	Mental Health Care	215

We would like to refer the reader to the excellent testimony regarding persons with disabilities that was presented during the Public Hearings in Los Angeles and San Francisco as follows:

PAGE	TITLE
30	Patient's Rights
32	Sexuality and Disability
79	Marriage Penalty in Government Benefit Programs
80	Marriage Penalties
55	Sex and Disability
61	Sexual Rights
66	Protection of Disabled Persons
75	Sex Education for Developmentally Disabled Clients

PARTIAL REFERENCE LIST OF MATERIALS USED BY COMMITTEE ON AGING AND DISABILITY:

1. Sex Code of California, A Compendium of Laws and Regulations, 1981, Planned Parenthood Affiliates of California

2. "Year of the Consumer" Report published by the Citizens Advisory Council of the State Department of Mental Health, 1981

3. Mental Health Law Project Summary of Activities, 7/79-6/81; Washington, D.C.

4. United Nations Assertion of the Rights of the Disabled Individual to Sexuality Education

5. Letter from Beverlee Myers, Director of the Department of Health Services, regarding confidentiality erosions for teenagers

6. Commonwealth of Massachusetts Task Force on Privacy, Human Sexuality and Sex Education for Developmentally Disabled Persons, Report: 2/24/81

7. Regulations relating to Foster Family Homes, excerpts from the California Administrative Code, Title 22, Division 6, Chapter 6, effective 10/26/80

8. "The Nature and Trends of Abuse of Mentally Retarded Persons in Residential Institutions", a report prepared for the President's Committee on Mental Retardation, 9/26/79

9. President's Committee on Mental Retardation Site Visit Report Florida, June 1980

10. The White House Conference on Handicapped Individuals

ATTACHMENT A

MINUTES OF COMMITTEE ON AGING AND DISABILITY

Minutes of the First Meeting of the
Committee on Aging and Disability of the
COMMISSION ON PERSONAL PRIVACY
August 14, 1981, Sacramento, California

Members Present: Nora Baladerian, Barbara Waxman
Members Absent : Stanley Fleishman

Guests Present : Ida Horner, Dept. of Mental Health
Patty Blomberg, Dept. of Developmental Services
Kay Coulson, Commissioner
Godfrey Lehman, Commissioner
Ms. Lehman, invited guest

I. Presentation by Ellen McCord, Commission Liaison in Sacramento

Ellen presented an overview of the Agencies related to the work of the Commission, their mandates and functions and contact persons. Ellen's telephone numbers are: (916) 322-2809, 445-2174 (messages). She will be working with us for 90 days, i.e. through the end of October.

Dept. of Aging: Dawn Rice will/can assist with interagency task forces. She is the Deputy Director of that Section.
Joe Kurtz will also be available from this Dept. to help us.
Dept. of Health Services : This oversees programs including MediCal, MediCare, Licensing of public and private health facilities, family planning.

Dept. of Social Services: This conducts programs such as public assistance, food stamps, licenses facilities such as day programs, child care centers, operates protective services.
Dept. of Developmental Services: Patty Blomberg is the contact person, telephones: (916) 322-7846, TTY 323-5901. Provides services to developmentally disabled persons, evaluates programs, conducts flow of persons into and out of State Hospitals except those under Dept. of Mental Health
Dept. of Mental Health: The mandate they have adopted for this year, as described in their current annual report is to "focus on a wide range of life styles and behavior." This will be helpful to us in employing their support.

** Ellen will provide the Committee with the following:
Agency budgets,
Agency Organization Charts
Copy of Dept. of Mental Health Annual Report

II. Presentation by Tom Coleman, Executive Director, Commission on Personal Privacy

A resource person is available to design, implement and analyze any surveys we desire to undertake. Also, the Institute for Local State Governments is available, in addition to the Aging Dept. Tom will assist in coordinating these efforts.

III. Participation by Ida Horner, Affirmative Action Analyst, Dept.of Mental Health
Ms. Horner identified the following persons as possible resources for our Committee:
Chuck Ropple, Chief, Mental Wellness Promotion Project of the Human Resources and External Relations Section. This Section has both a Legislative Liaison and an Advisory Liaison.

III. Participation by Ida Horner (cont'd)

Eileen Goodman is the liaison to the DDS Family Life Policy Task Force with Patty Blomberg,from Mental Health.

Cheryl Blakely is the Chief of Community Services, the Section which oversees the 6 Service Areas. Persons who staff these areas are all PSW's (Psychiatric Social Workers).

The Research and Evaluation Branch will be available to assist with any research on existing policies.

Ken Slavney is the current Patient's Rights Specialist. This position was previously held by Bill Weidner, author of "10 Patient Rights". Each of the 58 counties in the State has a Patient's Rights Advocate...however, there are areas in the State not covered by these county designations, who have their own Patient's Rights staff. Patient's Rights Advocates and/or Analysts do monitoring of programs, and recieve and handle complaints. Charlene Salazar is the individual who recieves the complaints.

The Chief of Hospital Divisions is charged with operations of the two State Hospitals under Mental Health, Metropolitan and Atascadero. Some of Patton also.

IV. Participation by Patty Blomberg, Chair, Family Life Task Force Policy Development

Patty described the efforts and history of the Task Force on which she serves, including the support that she is receiving for these efforts from Dave Loberg, Chief, Dept. of Developmental Services. She has access to the legal opinions which have been issued in the past, and can access sexuality related programs operated (or not) within the Department, as well as any complaints and support from the community.
The Dpt. is responsible for the training of care providers...Patty can hook us up with those staff. She distributed the following items:

- "Regional Center Family Life Needs" (list)
- "Programs in Progress or Attempted by each Regional Center"
- "ARCA Task Force on Family Life and Sex Education"
- "State of California...Family Life Resource Center"
- "Training in Sexuality"
- "Sexuality Training"

V. Other Business

It was decided to adopt all of the items listed on the Committee descriptions under "Issues Contractually Required", in addition to other issues the Committee elects to study, which will be defined at our next meeting. We will be meeting semi-monthly to conduct the business of the Committee. Announcements of these meetings will be mailed to the Commission office, in accordance with the legal requirements governing our meetings.
Barbara Waxman will be in contact with the Department of Rehabilitation to assist us with our work. This Department has extensive contact with and responsibility to persons in the disabled community.

NEXT MEETING: Date: 8/31/81
Time: 6:oo P.M.
Place: Office of Stanley Fleishman
433 N. Camden Drive Ste. 900
Beverly Hills Tel. 5507460

COMMITTEE ON AGING AND DISABILITY
MEETING: 8/31/81

MEMBERS PRESENT: COMMISSIONER BALADERIAN, CHAIR
COMMISSIONER FLEISHMAN
COMMISSIONER WAXMAN
BRUCE GITTER, COMMITTEE MEMBER

The meeting began with a (rambling!!) discussion of the mandated issues and issues in addition to these that the Committee is interested in pursuing:

1. Skilled Nursing Facilities (SNFs) and other institutions in which disabled and elderly persons reside:

   a. What are existing regulations these institutions operate under in terms of assuring privacy and sexual freedoms according to all citizens?

   b. How is actual implementation assured/monitored regardless of staff attitudes?

   c. What exactly are the types of residential facilities operated in the State (including State, County and municipally chartered facilities)?

   d. What policies have been developed (or are absent) in facilities to implement regulations regarding personal privacy and sexual freedom?

   e. What barriers exist to implementing the policies (i.e., scheduling, staff cooperation/attitude, programming, physical plant)?

   f. What if any is the extent of staff/administration/board resistance to implementation of regulations found in "A" above?

   g. What is the situation regarding access to private cause of action for clients/patients covering attorney's fees for complaints?

2. Social Security Administration (SSA) regulations' impact on private and personal marital/relationship decisions [i.e., living together (considered unacceptable by many elderly persons) vs. income reduction as a consequence of marriage] as this also applies to disabled persons who require home health care for independent living, which is discontinued upon marriage. What is the place of SSA to be involved in personal decisions such as these? What are the financial implications of alternate relationships in regard to: SSA, pension awards, etc?

3. Medical records: issues to be considered:

   a. Regulatory and legislative control.

   b. Confidentiality regulations including Federal, State, local; accreditation requirements.

   c. Actual implementation of controlled access.

   d. Facility policies implementing the laws and regulations; consequences for staff who fail to comply with policies and regulations.

   e. What if any are current abrogations of client rights at facilities and service agencies?

   f. What is the level of implementation of patient rights to access own records?

   g. What is the level of patient awareness of rights to see own record?

   h. What is documented in regards to privacy and sexuality that is not pertinent to patient care and treatment (i.e., private correspondence content, sexual activity, sexual orientation, etc.)?

4. Training of professional, para and nonprofessional and administrative facility staff; also indirect service providers and vendors of service: What is the content, extent, effect and pervasiveness of training regarding personal privacy and sexuality including sexual orientation.

5. Licensing regulations, laws, policies, interpretations, legal opinions, re: privacy and sexuality:

   a. All citations (or sample) of abuses of personal privacy and individual sexuality, patient rights to dignity, privacy and humane treatment for the past three years.

   b. What is the follow-up on these citations?

6. Sex surrogates as a legal part of the treatment/habilitation plan of physically disabled patients for individuals who need this therapy approach for real rehabilitation. (Strategy: begin with veterans as the "first wave", then other disabled persons right's can easily follow.) Should veterans have a complete rehabilitation program including consideration of the "whole person", including sexual rehabilitation, films, education, therapy, surrogates. If so, should this apply to other disabled persons as well?

7. The issues of persons with disabilities who wish to adopt children. This includes the family relationships being disrupted by adventitious disability and the issue of sterilization.

8. Identify citizen rights to sex education, including:

   a. Identification of barriers to sex education for the general population.

   b. Interview disabled individuals as to their sexual education experience.

   c. Obtain reports on a complaint now pending with OCR (Office of Civil Rights) against Planned Parenthood, Alameda and family planning agencies.

   d. Review mandates regarding sex education (coordinate with Committee on education and counseling).

9. Is appropriate medical care provided to disabled and elderly residents of institutions?

   a. Are gynecological visits regularly scheduled for women (annual at least)?

   b. Are the medical exams conducted according to standard medical practice including privacy, dignity and patient education?

   c. Is contraception discussed and offered to clients both male and female?

   d. Is sterilization as an option offered free of bias?

   e. Is sexual orientation considered for all of above?

10. Nursing and convalescent hospitals: discrimination against patient privacy and sexuality which denies patient need for human contact regardless of sexual activity or implication.

    a. What are nursing home policies and practices regarding sleeping together on a voluntary basis of adults?

    b. What if any assistance is provided for married couples and relationship partners to share a room or bed?

In addition to the issues listed above, the Committee decision was to focus our energies on institutionalized persons to facilitate access to the desired information. We are well aware that only 10% of the elderly population reside in facilities operated by the State, and will request that the Task Force, when convened, will assist in gathering information for the majority of elderly persons not found in institutions.

The staff will be asked by this Committee to develop a Task Force on Aging, to deal specifically with personal privacy issues not shared by the population of persons with disabilities.

The next meeting was scheduled for:

Thursday, September 24, 1981
6:30 pm
Office of Stanley Fleishman
Suite 900
433 North Camden Drive
Beverly Hills, CA

Attachments:

1. Action Plans

ACTION PLANS

1. Development of planning report to the Executive Director to be shared with our contracting agencies and to serve as our activity plan instrument to focus the energies of our Committee effectively.

2. On adoption of children by disabled parents:

    a. Stan will locate and supply books on this topic.

    b. Barbara will interview persons who have attempted adoption proceedings who are disabled.

3. On licensing violation citations re: personal privacy:

    a. Nora will:

        (1) Contact local County and State licensing offices.

        (2) Request assistance from staff, including Ellen and Kathy.

4. On legal rights to sex education:

    a. Barbara will:

        (1) Request information on current complaint pending with OCR against Planned Parenthood Alameda.

        (2) Identify barriers to sex education for the general population.

        (3) Review PL 94-142 and AB875 for laws relating to sex education; will also contact the Legal Aid Foundation, Special Education Task Force, resource person Cathy Blakemore.

        (4) Will request assistance from Patty Blomberg (etc.) in Sacramento.

    b. Staff will be asked to:

        (1) Conduct a survey of sex education practices in institutions for clients with disabilities including: State Hospital Representatives on sex education to determine extent of sex education for clients and staff cooperation/implementation.

        (2) Determine facility policies on sexuality at the residential facilities: What sexual activities are permitted/prohibited? How is this done?

(3) Where sex education programs are provided, what policy changes occur to allow the adult individual to experience sexuality?

5. Regarding appropriate medical care:

   a. Nora will request Regional Centers to review a sample of records to indicate annual medicals including sexual health care.

   b. Staff with Nora and Barbara will conduct a survey of institutions' adherence to principles of privacy and sexual conduct, including issues covered in 504.

   c. Barbara and Nora will request staff assistance and determine extent of provision of sexuality counseling, education, rehabilitation and therapy in rehabilitation programs, and the inclusion of sexuality in the medical treatment plan.

6. Regarding SNF discrimination precluding privacy and human closeness and sexuality:

   a. Nora will:

      (1) Contact Ed Feldman of the Nursing Home Abuse Section, County DHS.

      (2) Contact Ida Horner of DMH in Sacramento for assistance.

7. Regarding access, recording and confidentiality of medical records:

   a. Bruce will:

      (1) Seek laws relating to confidentiality of client records.

      (2) Seek regulations by accrediting agencies.

      (3) Call Patty Blomberg for information and resource persons.

8. Regarding the use of surrogates in sex therapy for clients with disabilities:

   a. Stan will:

      (1) Identify applicable laws, court cases, regulations.

      (2) Seek laws relating to approved medical treatment plans and their statements re: sexual health rehabilitation, beginning with V.A. Benefits.

(3) Identify the extent to which services are currently rendered, type of services currently rendered and therapist relationship to the surrogate.

(4) Analyze a need (if any) for legislation to regulate the use of surrogates and avoid violent abuse.

(5) Detail application of findings to other disabled/elderly patient groups who require this therapy.

9. Hospital/institutional privacy:

a. Bruce and Nora will work with staff to:

(1) Develop a survey instrument for use at agencies; and

(2) To interview posthospital clients regarding their hospital experience as it related to personal privacy and sexuality.

COMMITTEE ON AGING AND DISABILITY

MEETING 9/24/81

MEMBERS PRESENT: COMMISSIONER BALADERIAN, CHAIR
COMMISSIONER FLEISHMAN
COMMISSIONER WAXMAN
COMMITTEE MEMBER BRUCE GITTER

Minutes from the meeting of 8/31/81 are not yet completed: upon completion they will be mailed to each Committee member.

Plan for study with timetables also not yet completed: upon completion will be mailed to each Committee member.

Bruce Gitter was officially appointed to the Committee on Aging and Disability, as a Committee member.

A report on activites begun and/or accomplished since the last meeting was requested of each member, as well as plans for continuation of the study.

Stan Fleishman

The major issues on which he has focussed are:
1. Surrogates as a part of the treatment plan
2. Custody of children of parents with disabilities
3. Sterilization of persons with disabilities

ACTIVITIES TO DATE:
1. Surrogates: None yet
2. Custody: None yet
3. Sterilization:
   Reviewed current laws regarding sterilization in general. Any male or female may be sterilized following a "due process" hearing. In the event of a profound disability which precludes informed consent, a bill is currently in the State legislature proposing steps to afford consent by representatives legally recognized by the court who could authorize a sterilization procedure. This is known as the "Duffy Bill.
   Reviewed most recent issue of the "Mental Disability Law Reporter". Found that the current feeling in the nation is that the courts have the inherent power to authorize sterilization with "due process".
   A review of current laws relating to sterilization reveals that the law is silent in regards to persons with disabilities.

   Nora recently received two opinions on Duffy, from the Developmental Disability community. These will be forwarded to Stan for analysis.

PLANS:
1. Surrogates: Will contact resource persons suggested by Barbara, including Jay Kohorn, Patty Blomberg and Cecily Greene.

2. Custody: Requests Chair to submit request to staff to "shepherdize" the Carney case to find court use and application in cases in California and nationwide. (Carney, Marriage of; Stanley Moss wrote the opinion for the California Supreme Court. Relates to parental rights of parents with disabilities.)

3. Sterilization: Will continue the review of the "Mental Disability Law Reporter." Will review legal opinions published by the developmental disabilities community upon receipt from Nora. Will contact the ACLU regarding their opinion on the Duffy Bill. Also, upon receipt will review of the opinion of the PROTECTION AND ADVOCACY, INC. agency in Sacramento.

<u>Barbara Waxman</u>

The major issues on which she has focussed are:

1. Sexual health care of disabled persons including family planning, ob-gyn
2. Parenthood of disabled persons, adoption and sterilization
3. Institutional living

ACTIVITIES TO DATE:

1. Sexual health care: Has discussed this issue with persons cognizant of the practices of the Department of Rehabilitation, and discovered an incident of invasion of personal privacy and choice. This involved an individual who is receiving vocational placement services from DR: she was told that she must become a family planning method user, discuss/reveal her contraception plan with the DR counselor, and maintain a contraceptive regime <u>in order to</u> maintain DR eligibility and employment.

   Barbara met with a representative cognizant of the policies and practices of the Center for Living and Learning, a residential program for individuals with disabilities who stated that this Center requires that female applicants be on a contraceptive regimin prior to approval of admission to the program.

   She attended the Office of Family Planning Advisory meeting, on which she serves as a member. She presented information on the Commission, and requested input from this body.

2. Parenthood: Barbara has made contact with a group of persons in San Diego who meet regularly to discuss the issue of parenthood for persons with disabilities. Some of the members are parents with disabilities, some are individuals planning to become parents. When she goes to San Diego in October, she will meet with this group. There is another group of this type in Northern California which she has discovered and will contact.

3. Institutions: None yet, except as indicated in #1 above.

PLANS:

1. Sexual health care: Will meet with Nora to plan an approach to this study

2. Parenthood: Will meet with the groups described above. Also will contact Carol Rosensteel, a resource person in this field.

3. Institutions: Will develop an approach to this study with Nora. Meeting scheduled for 10/14/81.

<u>Bruce Gitter</u>

The major issues on which he has focussed are:

1. Legal protections of privacy for disabled persons
2. Legal protections for confidentiality of records of disabled persons

ACTIVITIES TO DATE:

For both activities he has: contacted Patty Blomberg in Sacramento, local educational and legal agencies, and made contact with Carolyn Schneider in Sacramento of the Protection and Advocacy Agency, Inc., who provided him with the laws and regulations relevant to privacy protections, including: (following is a brief synopsis of the analysis Bruce conducted of the materials)...

Welfare and Institutions Code: provides for the right to dignity, privacy and humane treatment, a right to be free from harm, including unnecessary physical restraint or isolation, excessive medication, abuse, or neglect; (how does this relate to sexual privation? restraints to prohibit auto-sexuality? prevention of intimacy regardless of sexual interest or activity?) The document states that "services should be available to enable persons with developmental disabilities to approximate the pattern of everyday living available to nondisabled people of the same age. (How does this apply to privacy? sexuality? including the life styles options available to nondisabled persons including non-marital and same-sex partnerships?)

Will be receiving additional materials from individuals contacted and conduct a similar analysis.

PLANS:

1. Will acquire additional information regarding confidentiality included in laws, regulations, and accreditation requirements.
2. Will, with the assistance of staff investigate the application of these laws, regulations, and accreditation requirements.
3. Will, if time permits, or through the assistance of staff, determine the daily routine of facilities and the implementation of above concerns.

Nora Baladerian

The major issues on which she has focussed are:

1. Violations of personal privacy regulations cited by Licensing for persons living in institutions, and patient rights violations en toto.
2. Training of direct and indirect service persons involved in the care and treatment of individuals with disabilities
3. Application of issues to the elderly population

ACTIVITIES TO DATE:

1. Violations of personal privacy: Has worked with Ellen in Sacramento to elicit information regarding citations of this type from the Departments of Social Services and Health Services. Ellen has yet to contact the Department of Mental Health and the Developmental Serv ices contacts. Nora met with a member of the Los Angeles County Patient Rights Advocates and has requested from this group a list of the violations/complaints they have received re. personal privacy/sexual rights. Also a meeting of the full group has been requested. She met with the Directors of two of the local Regional Centers who have been very open to providing support services in the form of clerical, copying and research assistance. She and Tom will be making a brief presentation to the Southern California Association of Regional Centers Directors to strengthen our resource base and familiarize them with the Commission. Two complaints of privacy violation have been handled by Nora that arose from Camarillo State Hospital. Nora spoke with the Unit Psycholo t who is in charge of the treatment offered there. She will

continue the follow-up required. A third complaint has been filed with the Commission regarding employee housing privacy violations. Nora will follow up on this with the assistance of Tom.

2. Training: None yet

3. Aging: Has met with two experts in the field and acquired a list of resource persons who may be willing to assist by serving on the Task Force. However, these persons have not yet been called.
Has begun research efforts in this area.

PLANS:
1. Patient rights violations:
   1. Will continue efforts to cite personal privacy violations in publicly operated/regulated residential/treatment facilities. Add V.A. Hospitals.
   2. Will meet/set meeting together with Patient Rights Advocates group; also Statewide
   3. Will contact P&A group locally for research assistance and citations they have received, in particular, Cathy Blakemore.
   4. Will request research assistance from staff.
   5. Will meet with Regional Center Directors.

2. Begin investigations regarding regulations and practices for training of direct-service and in-service service providers regaridng privacy and sexuality considerations.

3. Request staff to assist with development of the Task Force on Aging.

Chair requested Committee input for Public Hearing issues to be presented to the Commission Chair meeting 9/26/81. The following were suggested for Public Hearing focus:
1. Veterans to discuss use of surrogates for rehabilitative therapy. (Resource persons could be Jim Turk and Cecily Greene).
2. Training of personnel for hospital/residential facility care: privacy and sexuality concerns.
3. Medical misinformation regarding sterilization which biases uninformed patients to accept a sterilization procedure.
4. Biased OB-GYN practice used for referrals out of the CMA to disabled callers.

Chair will make requests to the staff for information described during this meeting. Requests follow minutes.

The next meeting was scheduled for:

Wednesday, October 14

6:30 P.M.

Office of Stanley Fleishman: 433 N. Camden Drive Suite 900
Beverly Hills, CA.

STAFF REQUESTED TO ASSIST AS FOLLOWS: (ACTION REQUEST FORMS SUBMITTED TO THE OFFICE)

1. "Shepherdize" Karney case
2. Determination of application of WIC 4503 to prior sections 4501, 4502
3. Does WIC 4501 include assistance for homosexual community familiarization
4. Does the Genetics Unit of the Department of Health have any policies relative to sterilization? Includes Departments of Developmental Services and Mental Health, which may have units concerned with genetics.
5. Assembly of all of the following regarding sterilization:

   Statutes
   AG opinions
   legislative histories
   court decisions
   interpretations

6. Are there any regulations pertaining to Acute Care Rehabilitation programs (i.e. Northridge, Glendale Adventist, Daniel Freeman) that dictate/imply sexual morality for choice of partner for overnight stays? (NOTE: IT is becoming the practice of Rehabilitation Institutes fo encourage married patients to practice sexual contact prior to release.) What are laws, policies, discrimination???
7. What is the right to sue for violation of confidentiality laws?
8. The Department of Rehabilitation requires a complete medical examination prior to approval of eligibility. Does this include sexual health? How? What information is required/documented/appropriate?
9. What is the content of WIC Sec. 5326.1: Investigate and receive reports
10. What training programs are required for hospital line staff? Especially regarding privacy and sexuality rights.
11. Does the Dept. of HEALTH Services have a policy statement regarding facilities that receive Medi-Cal funding?

AGING AND DISABILITY
(issues under consideration)

1. Care/treatment provider training

What is the content, extent, and implementation of training for individuals who are charged with the direct or indirect care of elderly and disabled persons in regard to privacy and sexuality (laws, regulations, policies)? This would include training for physicians, nurses, paraprofessionals, non-professionals, indirect service providers, vendors approved by state or local agencies.

2. Right to receive appropriate medical care and treatment

Does having a disability preclude, in practice, access to appropriate medical care and treatment, particularly including sexual health care, incidence reporting and treatment of sexual abuse?

3. Right to sex education for persons with disabilities

Is adequate and accurate sexuality education experienced by the majority of persons with disabilities? What are the laws and regulations governing this aspect of training? What is the level of implementation? Are there barriers to implementation?

4. Institutional living: preservation of rights

Are the rights to intimate association and personal privacy waived upon entering a residential or treatment program, either as a matter of law or in actual practice? Are existing legal protections effective?

5. Confidentiality of client records

What laws and regulations exist regarding confidentiality of client records? What is the level of implementation of such laws and regulations, especially with respect to the content of documentation, access to review records, and purging of records?

6. Comprehensive sexual rehabilitation

What are the treatment options for disabled persons who require sexual rehabilitation? Are disabled persons denied options available to non-disabled persons?

STATE OF CALIFORNIA EDMUND G. BROWN JR., Governor

COMMISSION ON PERSONAL PRIVACY
107 South Broadway, Room 1021 • Los Angeles, CA 90012
13) 620-5269 • ATSS 8-640-5269

Committee on Aging and Disability

Minutes of Meeting, October 14, 1981

Present: Commissioners Baladerian (Chairperson), Fleishman, and Waxman; Kay Coleman (Guest), Thomas F. Coleman (Executive Director), Cathy Gardner (Staff), Bruce Gitter (Consultant).

I. Introduction:
Introduction of those present; presentation of agenda (attached).

II. Comments and approval of minutes from prior meetings:
Minutes of the meetings of 8/14/81 and 8/13/81 were approved as written.

III. Presentation, by Chair, of reports submitted to Executive Director:
The following reports had been submitted to Tom Coleman, in "draft" form, since the last meeting of this committee:

1. Minutes of 8/31/81 and 9/24/81 meetings.
2. General issue identification form.
3. Priority plan of action forms.

The following had been submitted to Cathy Gardner, since the last meeting of this committee:

1. Committee mmeting notice forms.
2. Action request forms. (See list attached to minutes of 9/24/81.)

The above were discussed in detail and approved with these comments on the issue identification items:

Issue 1 - Care/treatment provider training (DDS-C-4)
- A. Resources suggested by Barbara Waxman:
  - Bill Bronston (Health and Welfare)
  - Ed Roberts (Dept of Rehab.)
  - Judy Tingley (Deaf Community)
  - Ed Rogers (So. Calif. Deaf Agency)
- B. Barbara will present cases related to training issue.
- C. Question for research: What orientation to the client population do workers receive re: personal privacy, sexuality, and sexual orientation?

Issue 2 - Institutional Living (Aging-D-2)
- A. Recommendations that may result from study:
  1. Identify laws
  2. Educate service providers
  3. Attitude restructuring
  4. Monitor behavior

III. (continued)

Issue 2 - (continued)

B. Stan will identify the rights of the general population in regard to sexuality. We can then extrapolate application to specific groups, ie. institutionalized persons, minors, disabled persons gays, the elderly, etc. For example, legal issues pertaining to masturbation, consensual sexual activity of minors, of adults, abortion, and birth control. Does application of these general laws preclude application regardless of mental age or other status? Does this imply application to inclusion of sexuality as an intergral part of an "individual/habilitation/program/ treatment/ education plan"?

C. "Congregate Homes" was added to the list of residential programs.

D. Additional step (issue?) of study was approved as follows: "Determine what the reporting procedure is for documenting failure to implement laws protecting privacy. What follow-up is t here to assure compliance?"

Issue 3 - no changes

Issue 4 - no changes

Issue 5 - Confidentiality

A. Identify forms used for documentations, IPP's.

B. Add research step to identify record keeping procedures.

Issue 6 - Comprehensive sexual rehabilitation

A. Determine what the implications are for third party payments, ie. Blue Cross/ Blue Shield, Medi-Caid (medi-cal) and Medicare.

IV. Report of activities from each Committee member

Tabled until meeting of 10/28/81.

V. Plans for continued study

Tabled until meeting of 10/28/81

VI. Report on Public Hearings and Brochure

Cathy Gardner reported on the Public Hearings; November 13th in Los Angeles at the State Office Building, Room 1138,and November 20th in San Francisco, location TBA. Tom Coleman suggested that Commissioners focus their activities on prep-aration for the hearings.

The Commission Brochure is being delayed until 12/81 and will require volunteer assistance.

COMMISSION ON PERSONAL PRIVACY

VII. Other Business

Task Force on Aging: Cathy Gardner is assembling a Task Force on Aging. A letter (draft attached) will be sent to all persons whose names have been submitted by Nora.
Letter was approved by the Committee.

VIII. Schedule for next Meeting

Wednesday, 10/28/81
6:30 pm.
Office of Stanley Fleishman
433 No. Camden Drive, Suite 900
Beverly Hills, CA

COMMITTEE ON AGING AND DISABILITY

AGENDA

October 14, 1981

1. Introduction
2. Comments and approval of minutes from two prior meetings
3. Chair presentation of reports submitted the Executive Director
4. Report of activities from each Committee member
5. Plans for continued study
6. Chair report on Public Hearings and Brochure
7. Other Business
8. Schedule next meeting.

TO: TOM COLEMAN

FROM: NORA BALADERIAN

RE: STUDY AGENDA FOR COMMITTEE ON AGING AND DISABILITY

DATE: 1/29/82

THE FOLLOWING REPRESENT THE STUDY PLANS FOR THE MEMBERS OF THIS COMMITTEE, CONSULTANTS TO THE COMMITTEE AND TASK FORCE MEMBERS OF THE TASK FORCE ON AGING.

1. Nora Baladerian:

Will assume responsibility for the completion of a report that fulfills the format and content requirements as described by your memos on this topic:

> "Care/Treatment Provider Training Received by those who provide services to persons with disabilities, in the areas of personal privacy and sexual orientation discrimination." [Include special education, as this impacts on most developmentally disabled children; NRA, CCS, RC, DVR, MH (cite requirements for training content).]

Target groups (populations effected) include the physically disabled and the developmentally disabled citizens of our State, minors and adults. Insofar as possible, persons with mental illness will be included, but will not be considered a major population to be studied.

A review of the legislative protections will be made, a review of training requirements and programs (both prior to certification and in-service types), and implementation of the training and legislation. Where deficits are located in these content areas in training programs, recommendations will be made in light of abuses that citizens suffer as a result (if proven) of the lack of awareness/training/implementation that is contributory.

I will expect SPB to do the typing and final typing of the report. I will enlist the support and assistance of community members to provide information for the research portion of the study. I will request the assistance of you (through your resources) in the development and conduct of a survey for this study. Editing of my report will be done by Bruce Gitter, Consultant to our Committee.

This topic fulfills one of the requirements of the contract we have with DDS.

2. Barbara Waxman:

Will assume responsibility for the completion of a report that fulfills the format and content requirements as described by your memos on this topic.

a. Right to receive sex education and how training is provided.

b. "Right to Receive Appropriate Medical Care", with subtopics:

(1) Identify existing rights through legislative review and review of court cases.

(2) Study actual availability of family planning and sexual health care through the Office of Family Planning service delivery system.

Barbara will utilize resources available to her through her position at Planned Parenthood, and the assistance of Patty Blomberg and others at the Family Life Education unit of the Department of Developmental Services and her position as an Advisory Board Member of the State Office of Family Planning.

Typing and final typing will be requested of SPB. Nora will assume responsibility for editing of the report and providing any technical assistance that Barbara can benefit from. Barbara will be responsible for the research and writing of the report. Barbara has obtained a verbal commitment from Patty Blomberg of the Department of Developmental Services to provide typing and xeroxing for these reports.

2. Stan Fleishman:

Stan will develop and submit a Consultant Report in a format <u>not</u> of the depth required by the "report" standards, but which is substantial in nature on the topic.

"Comprehensive Sexual Rehabilitation", reviewing the equitableness of sexual rehabilitation service accessibility, particularly in regard to persons with disabilities. Questions of equal access to these services will be discussed with an eye to discrimination on the basis of economics or status (physical disability in particular).

Assistance for the project will be provided by Nora and Barbara in the form of informational resources, persons to be used as resources, etc.

Final typing will be provided by Stan (through resources available to him), and final editing provided by Nora with assistance requested from Tom Coleman.

4. Bruce Gitter:

Bruce, a Consultant to the Committee, will submit the findings of his research already conducted in the area of confidentiality of patient records for persons with developmental disabilities. Nora will develop this into a written Consultant Report, without the formality or depth required of a "report". Final editing of this will be provided by Bruce, typing can be provided through Nora.

5. Monte Rosen:

Monte, a Consultant to the Committee, together with other experts, will prepare a formal report on the topic:

> Right to Sexuality Education for Persons with Developmental Disabilities/Reduced Mental Capacity. This report will be totally developed by this group led by Monte. The members that he selects already have extensive resources and expertise that they can apply to this effort. Nora will assume responsibility for the final typing of their report, once submitted in draft form, and for the editing of their report. Any technical assistance that can be rendered by Barbara or Nora, as needed, will be provided upon request.

6. TASK FORCE ON AGING

See attached report.

ATTACHMENT B

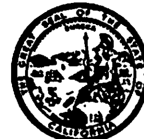
REPORT OF LICENSING VIOLATIONS

PREPARED BY ELLEN McCORD

STATE OF CALIFORNIA

EDMUND G. BROWN JR., Governor

COMMISSION ON PERSONAL PRIVACY
107 South Broadway, Room 1021 • Los Angeles, CA 90012
(213) 620-5269 • ATSS 8-640-5269



January 7, 1982

Commissioner Nora Baladerian
4571 Inglewood Boulevard, Suite 4
Culver City, CA 90230

Dear Commissioner Baladerian:

At long last, here is the summary of licensing violations you requested. This report covers all instances of what I could loosely construe as "personal privacy" violations. I have summarized those cases that involve one's "personal dominion over one's own body", as you suggested.

Also included is the report on child care facilities that Steve Schulte requested for the Education and Counseling Committee.

It is important to note that these summaries are somewhat out of context. In most cases, the violations noted were extracted from a laundry list of horrors including rotten food, dangerous conditions in the facility, violations of personnel provisions in the regulations and gross negligence on the part of the facility operator(s).

Also, to give you an idea of how representative this set of cases is as compared to all the cases I read, there are 101 total cases in the files. The total number of cases summarized for you and Steve is 36, 17 of which were adult facilities.

Although it may not be apparent from reading these summaries, there were many more cases of sexual abuse and exploitation in facilities licensed for the care of children. The most common problems in the adult cases were dangerous conditions in the facility, neglect of residents and lack of compliance with personnel regulations.

I hope this is helpful to your committee. Please call me if you have any further questions [(916) 322-2809].

Sincerely,

/s/Ellen E. McCord

ELLEN E. McCORD
Governmental Liaison

cc: Steve Schulte
Anne Bersinger

AGING AND DISABILITY COMMITTEE

LICENSING VIOLATIONS REPORT (Summary of Actions Against Licensed Community Care Facilities for Aged and Disabled Persons for February through December, 1981)

A. Actions Completed

1. Adeline's Board and Care Home (Adeline and Agepito Alvarado)
   Target Group: Aged Adults (6)
   Applicable Regulation Section: California Administrative Code (CAC), Title 22, Division 6, Section 80341
   Violation: Bruising of resident caused by Mr. Alvarado pulling and dragging client to toilet; fracturing/bruising of other client; no information as to how caused.

2. Goodlow Adult Family Home (Ivy Goodlow Brown)
   Target Group: Adults (number or exact client group not indicated)
   Applicable Regulation Sections: CAC, Title 22, Division 6, Sections 81055 and 80403
   Violation: Resident suffered burns, overall physical condition became so deteriorated he was hospitalized.

3. Hinkle Home (Mr. and Mrs. Orville L. Hinkle, Jr.)
   Target Group: Ambulatory children or adults (6)
   Applicable Regulation Sections: CAC, Title 22, Sections 80341 and 80404
   Violations: Making resident sleep in hallway because he had wet his bed; residents forced to wear athletic supporters to control masturbation; one occupied bedroom being used as a passageway to another bedroom.

4. Hughes Family Home (Shirley M. Hughes)
   Target Group: Family home - adults (2)
   Applicable Regulation Sections: Health and Safety Code (HSC) Section 1550 and CAC, Title 22, Sections 80341, 81055 and 81057
   Violation: Not allowing resident to change dirty clothes to clean clothes after vomiting or spitting on self; yelling at resident in demanding manner in front of other persons.

5. Heritage Range, East: Heritage Ranch, West (Marjorie and Donald McKissick)
   Target Group: West: Group home, adults (32); East: Group home, adults (24)
   Applicable Regulation Section: CAC, Title 22, Section 80341(a)
   Violation: Licensee held knife to head of resident and threatened to cut "Z" in penis if resident did not discontinue certain behavior (unspecified).

6. The Academy (George and Rozalia Moisi)
   Target Group: Large family home - adults
   Applicable Regulation Section: CAC, Title 22, Section 80341
   Violation: Various nonconsensual sexual advances by male licensee toward female residents.

7. Hillside Haven (Harold and Inez Waybright)
   Target Group: Developmentally disabled adults (6)
   Applicable Regulation Section: HSC, Section 1550(c)
   Violation: Licensee beat a resident with cut off water hose; struck residents with hand; threw one resident's clothes out of the window and told her to leave and not come back; threatened resident that she would kill her if she told anyone how she was treated.

B. Actions Pending

1. Capitol Guest Home (Zoilo C. and Luz F. Cendana)
   Target Group: Group home - adults, age 18-64 (26)
   Applicable Regulation Section: Multiple regulation violations; most pertinent one: CAC, Title 22, Section 80311
   Violations: Not filing reports on certain incidents including: one resident brutally striking another; same resident threatening to kill another resident; same resident was discovered having sex with a sixteen-year-old boy.

2. Bonnie Brae Board and Care (Cyngizer, Adam and Sofia, and Glosman, Moisei and Sofia)
   Target Group: Group home - mentally disordered adults (83)
   Applicable Regulation Section: Multiple; most pertinent: CAC, Title 22, Section 80341
   Violations: Sheer curtains were used on the windows in the resident's rooms and did not allow privacy. (This is among a laundry list of serious deficiencies in meeting the requirements of sanitation, record keeping, personnel and safety regulations.)

3. Claremont Sheltered Care Center (Helen Fitch)
   Target Group: Group home - adults (49, of which a maximum of six may be nonambulatory)
   Applicable Regulation Section: CAC, Title 22, Section 80404
   Violations: Belongings and clothes of residents were piled in front room where residents live; used as passageway for six residents living in back room.

4. (See Henderson's Home in Education and Counseling Committee Report)

5. Belmont Heights Manor (David J. and Ketta Kane)
Target Group: Group home - adults (27)
Applicable Regulation Section: CAC, Title 22, Section 80341
Violation: Residents not informed of personal rights.

6. Lee's Guest Home (Helen Lee)
Target Group: Ambulatory adults (6)
Applicable Regulation Sections: CAC, Title 22, Sections 80341, 80321 and 80404
Violations: Severe physical abuse; slapping, hitting, beating up resident; forcing resident to sleep on couch in facility that is a different one than the one in which she resides.

7. Willowick Comples (Keith I. and Shirley L. Petty)
Target Group: Group home - developmentally disabled, ambulatory adults (84)
Applicable Regulation Section: Multiple, most pertinent: CAC, Title 22, Sections 81255(a), 80051(a)
Violations: Various violations in finances, medical needs, medication storage and dispensing, and condition of facility; violation pertinent to above section involves lack of personal hygiene care to clients and insufficient assistance in dressing clients in appropriate clothes and undergarments.

8. Roan's Rest Home (Elizabeth and Pierre H. Roan)
Target Group: Aged (14, 5 of which may be nonambulatory)
Applicable Regulation Sections: CAC, Title 22, Sections 80341, and 80403
Violations: Personal hygiene needs of clients not met (client not bathed); refusal to allow visits by daughter of client and refusal of visits by friends/family to other clients; use of physical restraints on clients.

9. Satori Home #1 and #2 (Satori Community Homes, Inc.)
Target Group: #1 ambulatory adults (20); #2 ambulatory adults (5)
Applicable Regulation Sections: CAC, Title 22, Sections 80321 and 80341
Violations: Caretaker (Ruby Rowland) sexually abused female resident by pushing her on bed, rubbing her between the legs and in the face with a toy snake and making references to the resident having sexual relations with her father; placing her hands inside resident's clothing and making sexually exciting comments; corporal abuse and demeaning remarks are also cited.

10. Townsend Care Home (Carolyn A. Townsend)
Target Group: Developmentally disabled adults (4)
Applicable Regulation Sections: CAC, Title 22, Sections 80321 and 80149
Violations: Corporal punishment of residents including hitting them with hands and a broomstick.

STATE OF CALIFORNIA

EDMUND G. BROWN JR., Governor

COMMISSION ON PERSONAL PRIVACY
107 South Broadway, Room 1021 • Los Angeles, CA 90012
(213) 620-6269 • ATSS 8-640-5269

January 7, 1982

Commissioner Stephen Schulte
1213 North Highland Avenue
Los Angeles, CA 90028

Dear Commissioner Schulte:

Attached are the summaries of licensing violations for your committee and for the Aging and Disability Committee. These are brief summaries of legal documents that comprise the files on facilities whose operators have so grossly violated licensing regulations as to warrant closure of the facility or denial of a license to operate a facility.

Some of the violations are taken out of context and often represent only one of many violations of licensing regulations. However, with the facilities involved in the care of children, when a license has been suspended, revoked or denied due to sexual abuse or exploitation, that was frequently the only gross violation of the regulations.

The total number of cases in the licensing files was 101. Thirty-six of these were summarized for you and Nora. Nineteen of the thirty-six were in facilities licensed for the care of children.

Is it important to note that the incidences of sexual abuse and exploitation were more frequent and more severe in the facilities licensed for the care of children. Also, as you may recall from our Youth Authority visits, most of the youthful offenders have previously resided in a foster family or group home setting such as these.

I hope this information is helpful to you in your study of institutionalized youth. Please call if you have any further questions [(916) 322-2809].

Sincerely,

/s/Ellen E. McCord

ELLEN E. McCORD
Governmental Liaison

cc: Nora Baladerian
Kay Coulson
Anne Bersinger

EDUCATION AND COUNSELING COMMITTEE

LICENSING VIOLATIONS REPORT (Summary of Actions Against Licensed Care Facilities for Preschool and Foster Care Facilities for February through December, 1981)

A. Action Completed

1. American Youth Foundation (Hilltop House, Normandie House and Westmoreland House)
   Target Group: Foster Youth
   Applicable Regulation Section: General Authority of the California Adminstrative Code (CAC), Title 22 and the Health and Safety Code (HSC).
   Violation: This is a stipulation that puts the facility on probation and stipulates the requirements for the facility to retain its license. The points in the stipulation may be proposed by either the facility or the department and may not relate to a regulation provision, but relates to the nature of the problem with the facility. Stipulation states in part: "AYF will maintain an intake policy which shall include: (a) not accepting residents whose histories indicate violent behavior, drug dependency, homosexuality, developmental disabilities, or arson..."

2. Celebsation House (Celebration, Inc.)
   Target Group: Group home - children (48)
   Applicable Regulation Section: CC, Title 22, Sections 80321 and 81207
   Violation: (1) Nude bathing with residents and staff; (2) sexual relationship between resident and staff condoned by staff; (3) payment of two residents to be photographed while participating in sexual activity; and (4) facility operator placed hands on breasts and between legs of resident.

3. Carter Family Home (Marilyn A. Carter)
   Target Group: Small family home - children (2)
   Applicable Regulation Section: HSC Section 1550(c); Penal Code Sections 261, 288 and 288a
   Violation: Resident male of facility had sexual intercourse with nine-year-old client of facility.

4. Winfred and Claudia Cobleigh
   Target Group: Day care - children (approx. 4)
   Applicable Regulation Section: CAC, Section 86037
   Violation: Alleged sexual misconduct toward female child under care of the facility by the licensee's 16 year-old son.

5. Isabel's Nursery School (E. James and S. Isabel Meachem)
   Target Group: Day care - children (45)
   Applicable Regulation Section: CAC, Title 22, Section 80341(a); Penal Code 647(a)
   Violation: Licensee had photographed young female clients (age 3 to 5 years) in the nude; licensee was witnessed fondling young client's buttocks and kissing young female client on lips while holding her on his lap.

6. New Trails Residential School, Inc.
   Target Group: Group home - children
   Applicable Regulation Section: CAC, Title 22, Section 80404
   Violation: Residents were required to use an occupied bedroom as a passageway to get to the bathroom.

7. Stanley and Lanova Premer
   Target Group: Foster family home - 1 child
   Applicable Regulation Section: HSC, Section 1520(b)
   Violation: Licensee (Stanley) sexually molested six-year-old foster child placed in home.

8. Richard and Cicely Stafford
   Target Group: Foster family home
   Applicable Regulation Sections: CAC, Title 22, Sections 80341, 85129, 8513_, 80323, 85123, 80407, 85121, 85127, 85171, 80409, 81005, 85141
   Violations: Extreme emotional and physical abuse of three-year-old, five-year-old and nine-year-old foster children, some of which involve the children's privacy, such as: not providing clean underwear, threatening and demeaning children and not allowing children to telephone or visit natural parents.

9. Stratton Family Home (Ronald William Stratton)
   Target Group: Foster family home - children (5)
   Applicable Regulation Section: HSC, Section 1550(c)
   Violations: Kept sex paraphernalia in a bag in a closet where accessible to boys in home and boys in neighborhood. Licensee had three minor boys tie him down and told them to do anything they wished to his body, including pouring hot wax on it.

10. Maxine L. Watts
Target Group: Child day care (41)
Applicable Regulation Section: CAC, Title 22, Section 80807(a) (Violation had occurred when applicant was in charge of family foster home in 1976 and 1977).
Violation: Not meeting personal hygiene needs of foster children under her care. (Children were not adequately bathed or clothed.)
Note: This was a denial of a license for the child day care center based upon this and other violations under previous licenses.

11. Kiddie Corner Christian Preschool (Patricia Frances Young)
Target Group: Preschool children
Applicable Regulation Section: CAC, Title 22, Section 31239(d)
Violation: Corporal punishment and demeaning remarks used to control behavior of children.

B. Actions Pending

1. Joe L. and Elizabeth H. Cornejo
Target Group: Small family home - children (6 max)
Applicable Regulation Section: CAC, Title 22, Section 80149(a)(3)
Violation: Male licensee engaged in sexual intercourse with 13 year-old female foster child and attempted sexual intercourse with a 15 year-old female foster child.

2. Henderson's Home (Carrie Henderson)
Target Group: Small family home - mentally disordered children (6)
Applicable Regulation Section: CAC, Title 22, Section 80341 and 80403(f); HSC 1550
Violations: Several episodes of severe corporal punishment including slapping, whipping and throwing clients; one incident involved spouse of licensee (Richard) using a resident as a shield while in argument with licensee who was threatening Richard with a gun; locking residents in closets.

3. Evergreen Christian Preschool (Rodney W. Long)
Target Group: Preschool center - children 2 to 5 years old (24)
Applicable Regulation Section: CAC, Title 22, Section 80341(a); HSC, Section 1550(c)
Violations: Incidents of sexual abuse and corporal punishment by licensee and employees to a number of children, male and female, ages three to five years.

4. Grandma's Place (Myrl Maxwell)
   Target Group: Large family day care home
   Applicable Regulation Section: HSC 1550(c)
   Violation: Son of licensee was allowed or permitted to sexually molest male children aged three to ten years, while children were receiving care and supervision in the facility.

5. Ann Osorno
   Target Group: Family day care home
   Applicable Regulation Section: HSC, Section 1550(c) and CAC, Title 22, Section 86027(a)(3)
   Violation: Spouse of licensee (Guillermo) committed a lewd or obscene act in the presence of two minor females in the facility.

6. Tara Hills Child Care Center (Timothy Townsell)
   Target Group: Day care center - children (19)
   Applicable Regulation Section: HSC, Section 1550 and CAC, Title 22, Sections 3113, 31199, 31200, 31201, 80321, 80323 and 80341
   Violations: Licensee's 19 year-old son sexually abused a three-year-old male in the facility by ejaculating into the boy's mouth; licensee sexually assaulted and attempted to rape a 15 year-old female who had contacted the facility for potential employment.

7. George and Lois Twyman
   Target Group: Child day care - children 0-6 years old (6)
   Applicable Regulation Section: HSC, Section 1550; CAC, Title 22, Section 86037
   Violation: Licensee sexually abused a five-year-old and a six-year-old client of the facility (both females).

8. John Yoder
   Target Group: Foster home
   Applicable Regulation Section: HSC 1550(c); CAC, Title 22, Section 85119(a)(3)
   Violation: Licensee sexually molested male children, ages 13 to 18 years old, while these children were in his facility.

ATTACHMENT C

TESTIMONY OF ANNE BERSINGER

DEPARTMENT OF SOCIAL SERVICES

STATE OF CALIFORNIA—HEALTH AND WELFARE AGENCY

DEPARTMENT OF SOCIAL SERVICES
744 P Street, MS 19-50, Sacramento, CA 95814
(916) 445-3284

November 20, 1981

Mr. Thomas F. Coleman, Executive Director
Commission on Personal Privacy
107 South Broadway, Room 102
Los Angeles, CA 90012

Dear Mr. Coleman:

Thank you for the opportunity to provide testimony to your public hearings regarding the rights of residents to privacy in community care facilities. I am sorry that I cannot attend the hearing. However, I am enclosing a statement regarding the protection of residents' rights which I understand will be read into the record at the public hearings.

I appreciate the opportunity to be of assistance.

Sincerely,

ANNE BERSINGER
Deputy Director
Community Care Licensing Division

Attachment

As Deputy Director of the Community Care Licensing Division in the State Department of Social Services, I am taking this opportunity to identify the protections established to safeguard the privacy of the approximate 500,000 children and adults who receive care from one of the nearly 50,000 community care facilities licensed in the State of California. Licensing services are provided through ten field offices situated throughout the State and by contracts with 47 county welfare departments.

Licensed community care facilities provide "care and supervision" to persons who require some degree of assistance with the activities of daily living and in the assumption of responsibility for their health, safety, and well being. The determination of the need for care in a community care facility involves a medical assessment and the gathering of other personal and confidential information regarding the individual resident/client. Regulations require that all such information and records obtained by the licensee in the course of providing services shall be confidential. Each licensee is responsible for storing confidential records and for ensuring that confidential information is released only upon the written consent of the person, or his/her guardian or conservator. Regulations also establish personal rights for persons who receive services from community care facilities. For example, residents of a facility must have access to telephones to make and receive confidential calls and to letter writing materials and stamps, and must receive unopened correspondence. These and other personal rights which protect the privacy of residents are the responsibility of each facility and compliance is monitored by the licensing program.

Community Care Licensing does not regulate the permissive sexual activity between consenting adults or the cohabitation of unmarried adults in licensed facilities. We do require that an adult resident of a community care facility be free to leave such facility (unless precluded from doing so by his/her guardian or conservator) so that the resident could conceivably also elect to have a consenting adult sexual partner outside the facility. Community care facilities may elect to establish a program of sexuality for consenting adults. A placement agency's assessment for an individual resident may then include a program of sexuality for adults as part of a "normalization" process. The licensed facility is free to permit such activity. Licensing regulations require that the licensee cooperate with the placement agency or with any treatment program participated in by the client and that the licensee provide reinforcement within the facility to those services provided to residents from community resources. However, under no circumstances are activities in the facility allowed to impinge on the rights of other residents/clients being served.

The licensing program is primarily concerned with ensuring that the health and safety of residents is protected and that residents are not abused (sexually or physically) in facilities. The largest number of enforcement actions (suspension or revocation of a license) that we take against facilities are the result of an incident of such abuse.

Thank you for this opportunity to explain our personal privacy protections.

ATTACHMENT D

MARRIAGE DISINCENTIVES IN GOVERNMENT BENEFIT PROGRAMS

BY DANIEL BRZOVIC

A. MILTON MILLER MEMORIAL FUND, INC., dba
WESTERN LAW CENTER FOR THE HANDICAPPED

February 16, 1982

Commission on Personal Privacy
107 South Broadway, Room 1021
Los Angeles, California 90012

Re: Invasion of privacy: Marriage disincentives in government benefit programs for disabled individuals.

Dear Commission:

The Western Law Center for the Handicapped represents individuals who have legal problems relating to their disability. A number of our clients have problems related to their receipt of government benefits. This includes benefits based on earnings such as Social Security Disability Insurance and Medicare, and benefits based on need such as Supplemental Security Income, In-Home Supportive Services, and Medi-Cal. Most of these programs treat married individuals differently from unmarried individuals. In most cases, benefits for a married couple are lower than benefits for two unmarried individuals in similar circumstances. The differential treatment seems to be based on two separate ideas: First, two people living together can live more cheaply than one. Second, spouses have a legal obligation to support each other, and should discharge that obligation before the government is asked to provide assistance.

We do not feel that these considerations are necessarily inappropriate. We do feel that government programs should be neutral with respect to marriage regardless of how the benefit levels are structured. In other words, the benefit payment levels should neither encourage nor discourage marriage. Unfortunately, there are many programs which penalize married individuals unfairly. In many cases individuals are discouraged from marrying or are encouraged to separate.

1. Disincentives in the Social Security program.

Social Security payments, including disability insurance payments are paid on the basis of earnings records. Social Security Child's Disability benefits are payable to individuals who became disabled during childhood and whose wage earning parent(s)are either deceased or retired. For some odd reason, these benefits are, in most cases, terminated when the individual marries. There is now an exception to this if an individual marries an individual receiving Social Security benefits. An exception to the exception is for a woman who marries a man receiving disability benefits and the man recovers from his disability. In that case, the woman's benefits are terminated even though a man's benefits would not be terminated in similar circumstances.

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While the exception is good, (apart from the unconstitutional and discriminatory exception to the exception), it does not go far enough in protecting the incomes of disabled individuals who receive the benefits. It protects individuals who marry an individual receiving Social Security, but it does not protect the income of an individual who marries a wage earner, no matter how low the wages. Even worse, it does not protect the income of an individual who marries another disabled individual who does not receive Social Security but who has an income so low that they receive Supplemental Security Income (SSI).

As an example, two developmentally disabled individuals could marry and not lose benefits if they both receive Social Security. If one of the individuals receives SSI, the other individual will lose Social Security and will receive an SSI benefit instead which is equal to one-half the SSI benefit of the other individual. If the individual is receiving a Social Security payment which is higher than the SSI payment marriage will result in a financial loss. In some cases, the loss may be substantial. Equally bad, the individual will lose Medicare benefits along with the Social Security. In some states the lsot benefits may be fully replaced by Medicaid, but in most they will not. Even in states like California with a comprehensive Medicaid program, there will be a loss because fewer doctors will accept Medi-Cal than Medicare.

There is no reason that marriage should force a Social Security recipient to become an SSI recipient. In fact there is no reason that marriage should affect the receipt of Social Security disability payments at all. Social Security is designed to replace lost income. In this era where the two wage earner family is the rule rather than the exception, receipt of replacement income should continue after marriage.

2. Disincentives in the Supplemental Security Income Program.

SSI, like the IHSS and Medi-Cal programs which will be discussed later, is a program of assistance based on need. This means that an individual's income and resources are taken into account in determining the amount of the grant. This is the type of program which has been traditionally been called welfare. The SSI program provides a minimum guaranteed income to disabled individuals.

A couple on SSI receives one and one-half times the benefit of an individual on SSI. Congress seems to feel that this is a marriage disincentive because it has provided rules for considering individuals in certain circumstances who are living together to be married. It has also provided for payment at the reduced rate for individuals who have separated and have not been living apart for six months.

It is entirely possible that the reduced rate is a price which people

are happy to pay for marriage. If so, it is notnecessarily bad since it may be justified by other valid reasons. Such differential treatment is bad only to the extent it influences individual decisions as to whether or not to marry or separate.

An SSI rule which does have a serious effect on individual choices is the attribution of income rule. For two spouses living in the same household, the income of one spouse is deemed to be the income of the SSI recipient spouse. Exclusions from deemed income are provided so that the nonrecipient spouse can keep an amount of income which he or she could keep if he or she were an SSI recipient.

The deeming rule is an attempt to force a spouse with income to support the spouse who requires public assistance. This may be an appropriate governmental goal. Unfortuantely, deeming is often applied in ways that create hardships and tensions which sometimes cause the disintegration of families. For example, income is deemed from a Social Security recipient to an SSI recipient. Individuals who receive fixed incomes are less able, typically, to handle a reduction in their spouses benefits than an individual with earning capacity who may have hopes of supporting their spouse by earning a higher wage. In addition, we have seen tremendous tensions develop when SSI overpayments are sought to be recovered on the basis of deemed income. The mechanical application of the deeming rules also creates a hardship for families with a severely disabled member who has medical or other expenses which may not be reimbursed by Medi-cal or other programs. The financial hardships created by such expenses together with the loss of benefits through deeming creates financial problems and tensions which very often lead to the disintegration of families.

In the past, the deeming rules have produced a strange and extremely inequitable result when the sole source of income of a nonrecipient spouse is IHSS received to provide attendant care for the recipient spouse. Even though the family receives nothing but SSI and IHSS, the SSI is reduced on account of the IHSS. The attached letter explains the problem more fully. Fortunately, this issue has been resolved since the Reagan administration, in the only Social Security regulatory action which will cost the government more money, has stopped deeming in this limited circumstance. See attached regulation.

3. Disincentives in the In-Home Supportive Services Program (IHSS)

IHSS is payable to SSI eligible individuals as a supplement to the basic SSI payment when the recipient needs homemaker services, chore services, or attendant care in order to remain safely in his or her own home, in order to avoid loss of employment, or in order to avoid medical out-of-home placement. Payments are paid on the basis of individual need consistent with the annual appropriations in the annual state budget act.

Under the IHSS program, individuals are affirmatively punished for being married. The situation is especially severe in cases where an individual's disability is so severe that attendant care can be provided to them only by their spouse.

The deeming process for SSI has already been described. The same rules apply to IHSS. If an IHSS recipient has too much income, including deemed income, to receive an SSI payment, (e.g. the recipient receives a Social Security payment which is higher than the SSI payment level) the income is deducted from the IHSS payment after first subtracting the SSI payment amount. Since IHSS payments to a spouse provider were deemable income, an individual who received no SSI would have the IHSS payment itself reduced on account of receipt of the IHSS. Fortunately, the unjust policy is no longer followed because of the new federal regulation eliminating deeming in this circumstance.

Even though the injustice of deeming IHSS payments is gone, there is a new injustice which is even worse. Last June, in order to give welfare recipients a 9.2% cost of living increase, the Legislature took money from the IHSS program. This is so that the most severely impaired recipients would have to give money to the least severely impaired recipients of SSI, or to those who are not impaired at all. As part of the reduction, the legislature provided that when a spouse is "able and available" to provide services, a disabled individual shall not be entitled to receive IHSS except for nonmedical personal services and paramedical services. This is so even if the spouse is the only individual qualified to be the provider, and even if the failure to provide the services would result in inappropriate institutionalization.

In enacting the able and available spouse provision, the Legislature seemed to be concerned that spouses discharge their legal obligation of support. Unfortunately, the provision does not address itself to the financial obligation (as deeming does) but cuts back payment for services even if the spouse is precluded from working outside the home because he or she must provide those services. As can be seen, an individual who can receive services only from his or her spouse will not have the financial means to hold the family together. For many of these individuals, institutionalization will be the only alternative. This is particularly true in the case of mentally disabled individuals who require protective supervision. The Western Law Center has two such clients.

The goals of the program would be better served if payments to spouse providers were made on the same basis as payments to aprent providers. Parent providers may be paid if the parent had to leave employment to provide the services, no other suitable provider is available, and failure of the parent to provide the services may result in inappropriate institutionalization or inadequate care. Financial controls are

maintained by means of the IHSS payment maximums, and, for parental income which is not received through IHSS, the deeming rules. By limiting the circumstances under which a relative may be a provider, rather than what services may be paid for, the legislature has insured that inappropriate institutionalization of children will be avoided by maintaining the income of the family.

Unfortunately, there has been an extreme lack of sensitivity to the problem. Barbara Schleueter, attorney for the State Department of Social Services, maintains that the able and available spouse provision is appropriate since the services will still be provided. She maintains that the state simply will not pay for them. This ignores the fact that if a spouse must quit work to provide the services, the spouse will not have the income which will enable the family to remain together. The choice will either be starvation or institutionalization. Misaco Dolan, Administrative Assistant to Senator John Garamendi, the author of the able and available spouse provision, maintains that no changes should be made in the provision because any additional money given to married people will have to come from somewhere else. This ignores the fact that, if money is to be saved, married people should not bear a disproportionate burden. It also ignores the fact that only 2.5% of the IHSS recipients have "able and available" spouses. It also ignores the fact that the able and available standard is administratively unworkable. Finally, it ignores the fact that the standard now in use for parent providers would save money by taking into account legal obligations of support while at the same time insuring that program goals are met.

The Western Law Center for the Handicapped is most concerned about provisions which discriminate against married people which are not based on financial considerations. Such provisions, including the able and available spouse provision, seem to be designed to punish people for being married to a disabled individual. They are clearly not intended to take into account individual needs.

4. Disincentives in the Medi-Cal Program.

Medi-Cal is payable to individuals who receive SSI or IHSS or who would be eligible to receive SSI except that they have too much income. Medi-Cal income requirements are the same as for SSI and IHSS. This includes deemed income requirements. Medi-Cal provides an income exclusion, up to a maximum, for medical expenses which the SSI and IHSS programs do not have.

There is a serious divorce incentive in the case of a Medi-Cal recipient with community property income who is institutionalized. In such a case, all of the community porperty income of the institutionalized spouse is considered income to such spouse. A small exclusion is provided to meet the needs of the noninstitu-ionalized spouse. Medi-Cal would not count all of the income as income to the institutional-

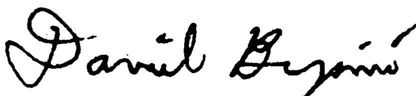
ized spouse if the couple were divorced, since the income would be divided into the separate porperty of each. Only one-half would be income to the institutionalized spouse,hence the incentive to divorce. This incentive could be equitably be eliminated if the recipient were given either the advantage of the community property rule or the federal rule.

Another disencentive concerns treatment of community property resources of an institutionalized spouse. Under the program, a spouse who has been institutionalized for six months is no longer considered part of the Medi-Cal family, which is appropriate. Such an individual needs to spend down only his or her share of the community property for his or her care, which is appropriate. Unfortunately, Medi-Cal has applied this rule in such a way, that the noninstitutionalized spouse must spend down his or her share of the community property also. The way it works is this: A spouse always has control over half of the community property. When he or she spends down his half, he still has half of the half which was not spent down and must therefore spend down that half, and so on and so on until the noninstitutionalized spouse's half is spent down to the exempt amount. Again, the problem could be solved by divorce since the property would be transmuted into separate property, and there would be no spenddown for the noninstutionalized spouse's separate property. In addition, divorce would eliminate the risk that the family home would have to be sold since, under the circumstance described, the home would be included in the spenddown requirement.

5. Conclusion.

As can be seen from the foregoing, many government benefit programs contain disincentives to marriage and incentives to divorce. The problem is compounded by rules taht have no relation to financial responsibility but instead seek to punish individuals for being married to disabled individuals. Disability of a spouse already creates family tensions and hardships without the financial hardships imposed by discriminatory government practices. At the Western Law Center, we find ourselves in the uncomfortable position of counseling clients about the relative financial advantages of being married or unmarried. We do not feel that programs should be structured in such a way that it is necessary for us to do this. We believe that the programs should be neutral with respect to marriage. This does not always mean that benefits should always be the same as for single individuals. It does mean that the advantages of being married should not be outweighed by the advantages, or necessity, of not being married. We would the programs to meet their stated goal of strengthing family life and encouraging individual choice.

Respectfully submitted,



Daniel Brzovic
Senior Attorney

A. MILTON MILLER MEMORIAL FUND, INC., dba
WESTERN LAW CENTER FOR THE HANDICAPPED

Social Security Administration
Department of Health and Human Services
P.O. Box 1585
Baltimore, MD. 21203

Gentlepersons:

We support the proposed revision of 20 CFR 416.1161 to exclude income from deeming received by an SSI ineligible spouse or parent for providing homemaker, chore, or attendant services for an eligible spouse or child.

Deeming of income in this particular circumstance is inequitable for several reasons.

Exclusion of Spouses from Social Insurance Protection

Under 20 CFR 416.1161, as currently interpreted, a spouse providing IHSS for his or her eligible spouse is an employer of the spouse and the IHSS received on account of the eligible spouse is therefore earned income and is deemable. Employment by a spouse is not, however, considered to be employment for Title II purposes. SSA Section 210 (a)(3)(A). IHSS spouse providers are therefore put in the unfair position of being considered employees when it comes time to reduce their income, but not when they themselves need retirement, disability, health care or unemployment insurance benefits.

Spouse providers are almost always locked into the IHSS system because there is no one else with the training, care or love who will provide skilled quality services, often for 24 hours per day at minimum wage, up to a state imposed maximum. They are locked out of the Social Security Insurance system despite the fact that they work long, hard hours throughout their working years. Reducing family income by deeming of this income to the SSI eligible spouse makes it virtually impossible for the provider spouse to purchase replacements for the income security and health insurance which would otherwise be provided by Social Security.

One of our provider clients was forced to give up her Blue Cross when her income was deemed. She is now in the precarious position of hoping that she stays healthy because if she does not, she will not have the means to pay for her medical care. It is this type of situation that Social Security was designed to cure, and the SSI rules should therefore be written to give families security rather than take it away.

Lack of Adequate Alternative Care

Spouses and parents are generally IHSS providers because there is no one else who is able or willing to provide the necessary care. In fact, under California law, a parent can be the IHSS provider only if the parent leaves full-time employment or is prevented from

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obtaining full-time employment because no other suitable provider is available and where the inability of such provider to provide supportive services may result in inappropriate placement or inadequate care. Welf. & Inst. Code, Section 12300. Deeming of IHSS is inequitable because it deprives individuals of adequate care and results in inappropriate placement.

Many of our provider clients have left moderate or high paying jobs to become IHSS providers for their spouse or child. This has resulted in a substantial loss of income. In the typical case, the disability of the spouse or child has made the entire family dependent on the spouses' or childs' benefits. Reduction of these benefits typically makes it impossible for a spouse or parent to be a provider because of the reduction of a total family income. When SSI is reduced, the recipient receives a grant which is less than basic need, while the provider is paid for actual hours of work at only minimum wage, and even then only up to a legislatively imposed maximum. Because of deeming, family income is unconscionably low.

In most cases, unless the spouse or parent can be the provider, there is no way the disabled recipient will get appropriate or adequate care, or be able to live in their own home. One of our clients is so severely disabled that when his wife was sick and could not care for him for a short time, he had to be hospitalized in acute care. Hospitalization in a skilled nursing facility would be inappropriate and expensive enough, but this was acute care!

The State of California provides IHSS not only because it is just and equitable to support the right of handicapped individuals to live with their own families in their own homes and community, but also because it is cheaper than institutionalization. This wise, money-saving program should not be jeopardized by the false economy of deeming.

Disruption of Family Relationships

There is no SSI reduction through deeming for individuals who live with their IHSS providers as long as the providers are not their spouse or parent. The current deeming regulations therefore impose a penalty on marriage. It also imposes a penalty on children living with their parents. (There is no deeming of income to an SSI recipient from foster parents or caretaker relatives). We feel that payment of government benefits should, when possible, be neutral with respect to family relationships. The benefit payment system is supposed to strengthen family ties and enable individuals to live in their own homes in peace, comfort and safety. The present deeming system is encouraging our clients to live together without getting married or, if they are already married, to get divorced. Elimination of IHSS deeming will take the government out of the business of breaking up families.

Frustration of the Purpose of Deeming

We can think of only one reason for deeming: Insuring that the government does not make payments to individuals who have a statutory right to support from their relatives. Deeming of IHSS payments does not promote this objective. Spouses and parents are

entitled to payments for homemaker, chore and attendant care, because they cannot both work and provide for care. Moreover, by spending their lives providing care that no one else can or will provide, they are certainly providing all of the support for their families that can be expected of them. Depriving individuals of the ability to take care of their families does not mean they will provide more support, and it does not save the government any money. It results only in the breakup of families and inappropriate, expensive institutionalization.

Purpose of State IHSS

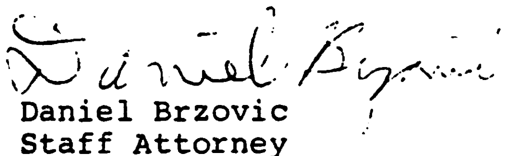
The California IHSS program is operated in accordance with California's Title XX CASP Plan. Consistent with Title XX, the program is designed to enable aged, blind, and disabled individuals to live in their own homes in peace, comfort and safety; avoid inappropriate institutionalization; or achieve or maintain economic self support to prevent, eliminate or reduce dependency. The California program is for those who have individual needs for homemaker, chore or attendant care which they cannot meet with their basic-needs SSI grant. It is therefore intended to supplement SSI.

The California legislature certainly did not intend to have basic need money cut out from under the recipients when it provided them with individual need supplementation. It also did not intend to have the federal government receive a windfall through the payment of state benefits.

Conclusion

For the foregoing reasons, state assistance based on need paid to a spouse or parent provider for homemaker, chore or attendant care, should not be deemed income to the SSI recipient.

Sincerely,



Daniel Brzovic
Staff Attorney

DB/ms

ATTACHMENT E

SENATE CONCURRENT RESOLUTION NO. 30

NORMALIZATION DECLARATION

SENATE CONCURRENT RESOLUTION NO. 30
(Filed with Secretary of State July 26, 1972)

RESOLVED BY THE SENATE OF THE STATE OF CALIFORNIA THE ASSEMBLY THEREOF CONCURRING,

That the Legislature hereby declares that the mentally retarded person has a right to as normal a life as possible despite the severity of his handicap and should be afforded the same basic rights as other citizens of California of the same age;

and be it further RESOLVED, That "normalization" is defined to mean that despite any limitations, each retarded individual shall be provided the maximum opportunity to participate in usual living experiences including education, work and social activities that permit development to his highest potential,

and be it further RESOLVED, That such opportunity for "normalization" is the birthright of every citizen and a proper investment for the good of society.

ATTACHMENT F

LEGISLATIVE CITATIONS FOR CONFIDENTIALITY AND PRIVACY

Protection & Advocacy Incorporated

Designated by the Governor to protect and advocate for the rights of Californians with developmental disabilities.

September 21, 1981

Bruce Gitter
110 Pico, #205
Santa Monica, CA 90405

Dear Mr. Gitter:

You requested information on clients rights in the areas of confidentiality of and access to records, and sexual rights for your subcommittee of the Governor's Committee on the Disabled and Elderly.

I am enclosing the following information:

- rights of persons involuntarily detained by reason of mental illness and consequent disability. Welfare and Institutions Code Section 5325.

- rights of persons with mental illness. Welfare and Institutions Code Section 5325.1. (includes privacy)

- rights of developmentally disabled persons living in state hospitals or community care facilities. Welfare and Institutions Code Section 4503.

- records required to be kept by the Department of Developmental Services. Welfare and Institutions Code Section 4425.

- laws governing release of records and confidentiality for developmentally disabled and mentally ill persons. Welfare and Institutions Code Section 5328 to 5330.

- directives governing the records of developmentally disabled persons who are clients of regional centers. Taken from Regional Center Operations Manual, Sections 3500-3512.

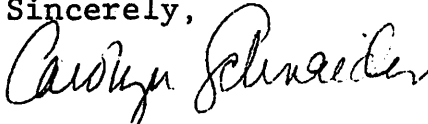
- AB 603, which would allow substitute consent to sterilization for a person found incapable of giving his or her own consent. This bill will be considered next legislative session. PAI opposes it, as does the American Civil Liberties Union.

1400 K Street
Suite 307
Sacramento, CA 95814
916/447-3324
Tollfree hotline
800/952-5746
TTY 916/447-3331

You should also take a look at AB 610, authored by Assemblyman Howard Berman, which allows people access to their own medical records. It should be available from his office, (213) 476-7646.

Let me know if you need further information.

Sincerely,



Carolyn Schneider
Staff Attorney

CS:gh

enclosures

ATTACHMENT G

UNITED NATIONS DECLARATION OF THE RIGHT OF DISABLED PERSONS TO SEXUALITY EDUCATION

File: Commission on Personal Privacy

The United Nations (E/CN, 5/500) states:

> "73. The importance of sexual life to peoples health and well-being is generally recognized. It is as important to the disabled as it is to any other person and an important factor in his or her integration to society. The problems involved have been discussed very little; rather, they have been suppressed until very recently. Guidance in this area is probably not yet available to the handicapped in the majority of countries. The disabled have the same rights as others in the society to being informed and educated in this respect."