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Dear Reader,

If you have not paid 1989 subscription yet, consider paying both 1989 and 1990 now. The forms are attached to Fall 1988 and Winter 1989 DSQ's. In the fall when we attach our regular subscription forms the price alas will go up.

This issue done with the assistance of Barbara Waxman has the theme Gender and Sexuality with a dual emphasis on concerns facing women and concerns facing all of us, AIDS. The Fall 1989 (deadline Sept. 1), coedited with Kate Seelman is on Communication Technology and Hearing Impairment. Winter 1990 (deadline Dec. 1) will be our regular generic one. Spring 1990 (deadline March 1) will return to the theme of Comparative and Cross-Cultural matters. Dr. Nora Groce (43 Free St., Hingham, MA 02043) will again be the coeditor. Other themes for 1990 will likely be Disability Demographics and The Media.

This issue will mark the end of decade long collaboration with Joanne Seiden. Without her there would be no DSQ. I will always appreciate her. I hope you will also.

Irv Zola

P.S. to Readers

This will indeed be a final word for me as Managing Editor for DSQ. Irv and I go back nearly 9 years of working together, but it will now have to be long-distance (Japan) for the next 2-3 years. It's been a fantastic experience being on the "ground floor," seeing DSQ grow in concept, distribution, and enthusiasm. Each issue seems to touch so many lives, generate more ideas, excite "old hands." I wish you all well and continued growth!

Joanne Seiden

FOCUS

The Politics of Sex and Disability

by Barbara Faye Waxman, Stu-

dent, Graduate School of Urban Planning, UCLA
and Anne Finger, Senior Lecturer, Wayne State University

Simone de Beauvoir wrote of the relation of the male body to the female:
". . . just as for the ancients there was an absolute vertical with reference to which the oblique was defined, so there is an absolute human type, the masculine . . . ."

Let us hear all of de Beauvoir's quote with the word "able-bodied" substituted for the word "male" and the word "disabled" substituted for the word "female."

"The able-bodied person thinks of his body as a direct and normal connection with the world, which he believes he apprehends objectively, whereas he regards the body of the disabled person as a hindrance, a prison, weighed down by everything peculiar to it. . . . Thus humanity is able and the able-bodied person defines the disabled person not in herself but as relative to him . . . . She is defined and differentiated with reference to the non-disabled person, and not he with reference to her; she is the incidental, the inessential as opposed to the essential. He is the Subject, he is the Absolute--she is the Other."

Simone de Beauvoir
From the introduction to <u>The Second Sex</u>

The parallel between male and female and non-disabled and disabled is immediate and striking--especially as it applies to our sexual lives. We represent the negative of sexuality. Our sex role is "the asexual," "the sexually undesirable," "the sexual deviant."

Although the disability rights movement has never addressed sexuality as a key political issue, many disabled people find sexuality to be their area of greatest oppression. We are more concerned with being loved and finding sexual fulfillment than getting on a bus.

HOW WE ARE MADE DEVIANT

This article cannot explore in depth the reasons for our being cast into this asexual role. Certainly, the eugenics movement played a role in the formation of this sexual identity. In our culture, sexuality is closely linked with aesthetic ideals that emphasize symmetry and wholeness on a superficial level. As Michel Foucault points out, a single locus of sexuality creates illegitimate sexualities. This sexual minority status has been ascribed to those of us who are considered to exist outside the boundaries of reproduction.

Medicine and its progeny, social work, have set themselves up as supreme authorities in matters of our sexual health. These professions proclaim society's aversion to our sexuality. They promise to treat our sexuality, to manage it, to cure it. Penile implants, plastic surgery, and counseling which assumes that disabled people ought to function sexually like non-dis-

abled people are all examples of this.

Public policies play a significant role in keeping us deviant: The Library of Congress refuses to print "Playboy" in braille; the Supreme Court says states can outlaw "unnatural sex acts" which may be the only ways our unnatural bodies can have sex; institutionalized people may be denied to have sex of any sort; sex education and AIDS education may exclude us, and when they do, the services are too often aimed solely at keeping us from having children; disabled gay men and lesbians receive almost no services and social support.

Disability activism has taken a liberal/reformist approach to access and enfranchisement. Psycho-social practitioners have concentrated on the effects of segregation and stigma on disabled people, without understanding the underlying dynamics. Both spheres argue, though not always in explicit terms, for the reduction of the polarization between the disabled and nondisabled worlds, and both point to the replacement of this polarization with societal integration through the adoption by the minority of majority values.

Disabled people still attempt to adapt themselves to the majority's social and sexual structure. Since we do not find our lives reflected in the dominant sexual imagery, and we do tend to feel sexually marginal, illegitimate, even furtive, adopting majority values is how we assume sexual legitimacy is gained. The examples are many: We may seek out able bodied people as sexual partners to get validation of ourselves as sexual beings. Ellen Stoll, the disabled woman who posed for Playboy magazine, made the point of her own erotic appeal by emphasizing her similarities with conventional erotic imagery, thus reproducing society's contempt for the disabled parts of our bodies. Women with hip contractures who cannot have conventional intercourse, may have hip surgery so they can have 'regular sex.' Some of us put off sexual encounters for fear of experiencing a rejection of our bodies.

The anthology, "Sexuality and Physical Disability" includes the article 'Basic Issues in Sexual Counseling . . .,' which reflects the usual matters about which disabled 'clients' seek validation, reassurance, and encouragement. They want to know whether someone will ever find them attractive, or if they are having intercourse in the right position.

We seek from the expert sexual affirmation and promises that our sexuality falls within the boundaries of health. These questions are rather an acknowledgement of the repression of our sexuality, as measured against what we are supposed to know if we had sexual freedom. Ultimately, our uncertainty cannot be relieved through these relationships.

AN AGENDA FOR SEXUAL FREEDOM

As Karl Marx said, "Philosophers have interpreted the

world. The point, however, is to change it."

The disability community has not politicized our sexual problems as we do transportation or housing. In general, we don't yet understand our sexual position to be socially constructed. We don't speak out about it because we are afraid that we are ultimately to blame for not getting laid; that it is somehow a personal inferiority. And in this culture, that secret is a source of personal embarrassment rather than a source of communal rage against the sexual culture itself.

But how do we politicize our sexual pain? Do we unfurl banners that read "GIVE ME MY SEXUALITY OR GIVE ME DEATH!"? On which institutions do we march? To whom do we make our demands?

First of all, to ourselves. The feminist slogan of the second wave of the women's movement--"the personal is political" can be adopted by the disability rights movement with regards to sex. Disabled people must begin to share their personal sexual oppression with one another so that we can see that the problems we think of as idiosyncratic are a part of a pattern. The source of authority about the sexual lives of disabled people then must be disabled people ourselves.

Secondly, as sexuality becomes a disability issue via this process of disclosure, the disability community's goal must be to infuse the sexual culture with the richness of our experience. Sex must then be approached with the same passion as other human rights.

Foucault says that power's hold on sex is maintained through language. The forging of our own sexual identity means the redefinition of such words as "sex" and "impotence"; the rejection of those words which perpetuate the medicalization of our sexuality: "sexual options," "sexual rehabilitation," "sexual adjustment"; and the possession of sexually affirming words: "pleasure," "passion," "erotic," "romance," and "lust."

We must develop a movement for sexual freedom that is broadly based. By this we mean, not only one which reflects the ethnic and social diversity of our population, but one which also speaks to all of our individual needs: for love, for orgasm, for being desired. The feminist movement can provide an instructive model for this. In fact, we see that disabled feminists, such as Adrienne Asch and Michelle Fine have brought a rich perspective to their work on how sexism and ableism intersect. Unfortunately, such a thoroughgoing analysis, both personal and political at the same time, has not been done for or by disabled men. Discussions of disabled men and sexuality almost always begin and end with erection and infertility.

We must put on our agenda access to reproductive health care, disability relevant sex education, social insurance covering sexual counseling and therapy, legalization of prostitution which will allow direct payment of sexual surrogates and live sex ed. mod-

els where appropriate for blind children.

We must learn to value what arises out of the disability experience. As the disability movement becomes less reformist and more culturally rooted, active on a number of different fronts, we see the need for transformation rather than reform. In dialectical fashion, our differences in appearance and function which are the sources of our degradation, also contain the seeds of our sexual liberation. We must celebrate our differences from those without disabilities. Sexual planning plays a considerable role in the achievement of good sex by especially physically disabled people. This disproves the myth of sexual spontaneity and requires direct, honest and clear sexual communication. We expand the meaning of sex from sole genitality to polymorphous expressions. We can have a greater tolerance of human differences and of unconventional sexual activities. We know and understand our bodies in elaborate ways which makes for more informed love making.

Rather than seeking to minimize the polarization, we acknowledge our differences. We find our strength in this acknowledgement.

SOURCES

The Second Sex by Simone de Beauvoir, Bantam Books 1961

The History of Sexuality by Michel Foucault, Vintage Books 1980

Sexuality and Physical Disability: Personal Perspectives by David Bullard and Susan Knight, Eds., CV Mosby Co. 1981

COMING EVENTS

A. August 9-13, American Sociological Association, 84th Annual Meeting. San Francisco Hilton, San Francisco, California. The theme of AIDS will appear in a plenary session and on 6 other program slots, so also will there be one session on disability and six others on the general theme of medical sociology.

B. September 12-15, Third International Congress on Ethics in Medicine, Nobel Conference, Karolinska Institute, Stockhom, Sweden. "The Individual Versus Society." Main topics: Priorities in Health Care; Clinical Freedom; Ethical Problems in Epidemiological Research; Integrity and Autonomy; Ethical Aspects of HIV Infection. Will take place at the Huddinge Hospital, Stockholm, Sweden. The offical language of the Congress will be English. Local Organizing Committee: Third International Congress on Ethics in Medicine, Department of Development, Beth Israel Medical Center, First Avenue at 16th Street, New York, New York 10003. 212/420-4082. Congress Secretariat: Ethics in Medicine, c/o Congrex, P.O. Box 5619, S-11486 STOCKHOLM, SWEDEN. Phone: +4687234230, Telex: 14969.

C. September 14-December 11, Boston University School of Public Health will hold its

third annual 12 week course on "Financing Health Care in Developing Countries." The course is intended primarily for professionals from developing countries who currently have or anticipate having responsibility for financial management, program planning, project management or policy analysis. Applications must be received no later than **August 15, 1989**. Contact: Boston University School of Public Health, 80 East Concord Street, Room A-310, Boston, MA 02118-2394 USA.

D. September 17-22, Gender and Science and Technology Fifth International Conference, Technion, Haifa, Israel. Contact: Secretariat, GASAT 5, c/o Atzeret Ltd., PO Box 3888, Jerusalem 91037, Israel.

E. September 18-20, International Colloquium, Women and Society Program, University of Antwerp, Belgium. Theme: "Gender and Class: International Developments in Theory and Research." Contact: Alison E. Woodward, Department of Political and Social Science, University of Antwerp, Universiteitsplein 1, B-2610 Wilrijk, Belgium; 3-233-9393.

F. September 21-23, Multidisciplinary Perspectives of Menopause, sponsored by the New York Academy of Sciences, Sheraton Centre, New York City. Contact: Wulf Utian, Dept. of Obstetrics & Gynecology, Mt. Sinai Medical Center, University Circle, Cleveland, OH 44106.

G. October 27-29. The Henry A. Murray Research Center of Radcliff College workshop on creative approaches to secondary analysis of longitudinal data, Radcliff College, Cambridge, MA. Theme: "Working with Longitudinal Data; New Questions for Old Data." Contact: Evelyn Liberatore, Murray Research Center, 10 Garden Street, Cambridge, MA 02138; 617/495-8140.

H. November 4-8, National Council on Family Relations 1989 Annual Conference, New Orleans. Theme: "Families and Sexuality." To receive an abstract application containing complete instructions, please contact: Cynthia Winter, Conference Coordinator, National Council on Family Relations, 1910 W. County Road B, Suite 147, St. Paul, MN 55113; 612/633-6933.

I. November 9-12, Twenty-Second Annual Chacmool Conference, The Archeology of Gender, Calgary, Alberta. Conference will generate discussion and stimulate new research on the roles and interactions of men and women in prehistory. Contact: Prog Committee, Dept. of Arch. U Calgary, Alberta, Canada T2N 1N4.

J. November 9-12, Sexuality: Expanding the Boundaries. The 32nd Annual Meeting, The Society for the Scientific Study of Sex, Toronto. Contact: Howard J. Ruppel, Jr., M.A., Executive Director, SSSS, P.O. Box 208, Mount Vernon, IA 52314 USA, (319) 895-8407 or Ed Herold, Ph.D., Chair, 1989 SSSS Annual Meeting, Family

Studies, University of Guelph, Guelph, Ontario, CANADA N1G 2W1, 519/824-9313.

K. November 15-19, American Anthropological Assoc. 88th Annual Meeting, Washington Hilton, Washington, DC. Contact: Harriet Klein, Montclair State College, Upper Montclair, NJ 07043.
The Council on Anthropology and Reproduction in Washington, DC is planning 5 symposia for this meeting.

"Men's Roles in Reproduction." Contact: Catherine Leone, 919/966-5987 or Nicholos Townsend, 415/642-3391.

"Cross-Cultural Perspectives on Reproduction Decision Making." Contact: Gisele Maynard-Tucker, 818/985-2954.

"Life After Birth: Structure and Organization of the Postpartum Period." Contact: Barbara Rylko-Bauer, 606/957-2466.

"Politics of Reproduction: Critical Perspectives--The Discussion Continues." Contact: Patricia Antoniello, 212/678-5262.

"Infants at Risk and Public Policy: The Impact of PL 99-457." Contact: Karen Michaelson, 509/359-2201.

RETROSPECTIVE

"People with Disabilities have a need and a want to be loved. The best thing is when someone sees you as a person first, then sees the wheelchair."

Graeme Farmer, who addressed a two day Conference on Sexuality and Men with Disabilities held in Sydney, Australia in June 1988, speaks from experience. He has used a wheelchair since the age of thirteen.

The Conference was organized by the Australian Council on Disability (ACROD) to provide a forum for men with disabilities to discuss matters of mutual concern, to disseminate information and to encourage future action.

Participants, ranging from people with disabilities to rehabilitation and health care workers, had the opportunity to discuss not only the sexual act but also the sexual image--reconciling the macho with the reality.

Specifically, Graeme Farmer spoke of the institutional experience; the difficulties of living a normal lifestyle, meeting people and starting relationships where every move has to be made in front of an audience. "Living life in an institution is like living in a fishbowl." Graeme sees his life as "doubly disabled"; trapped in a disabled body and trapped in an institution.

For Neil Lillicrapp, 42 and the keynote speaker at the Conference, paraplegia has in an odd way been "beneficial." A car accident at the age of nineteen forced him to reevaluate his life. It was a struggle, he said, to discover where he fitted into the male stereotype.

"When it happened, I felt I was no longer a man. My sexual function was no longer the way it used to be. It threatened my whole self-perception."

While the traditional

sexual act may not be possible for many men with a disability, "its okay to explore," he said. "If we (men) are forever doing the seducing, rather than the person being seduced, we are missing out on half the experience."

Different disabilities can impact sexuality in unique ways according to another speaker, Des Lean-Fore. Prior to acquiring his visual impairment, Des played in a band and led an active sexual life. Now loss of eye contact makes it difficult for him to read signals from prospective partners. Inability to drive and restricted mobility also contribute to his difficulties.

Sessions included a discussion on rights for people with disabilities, sexual options including commerical sex and gay options, aids and medical aspects of sexuality and disability.

Procedings of this conference will be published later this year and can be obtained from: John Galvin, Australian Council for Rehabilitation of Disabled, Canberra.
ACROD Limited, P.O. Box 60, Curtin ACT 2605, Canberra, Australia. Telephone: (062) 82 4333. FAX No.: (062) 81 3488.

CALL FOR PAPERS

A. AIDS Education and Prevention: An Interdisciplinary Journal seeks original manuscripts that highlight existing and theoretical models of AIDS education and prevention, including their development, implementation and evaluation; and various public health, ethical, psychosocial, and public policy issues. Contact: Dr. Francisco Sy, Sch of Public Health, Univ. of South Carolina, Columbia, SC 29208. First issue: January 1989.

B. The Chronic Disease and Disability section of the Western Social Science Association invites scholarly and critical papers on disability theory, policy, methods, evaluation research, ethnographies, and advocacy for presentation at the annual meeting in Portland, OR (April 25-29, 1990). Proposals for session topics, session organizers, and roundtable discussions are also encouraged. Submit a two-page typed developed abstract including author(s), affiliation(s), mailing address(es), and title of paper. Proposals will be refereed. Abstracts should be sent before 15 November 1989 to: Stephen C. Hey, Department of Sociology, Willamette University, Salem, OR 97301.

C. Research in the Sociology of Health Care, Volume 9, seeks contributions on any area related to medical sociology. Longer papers (30-60 pages) are particularly welcome. Use ASA style. Deadline: September 1, 1989. Send to: Dorothy C. Wertz, School of Public Health, Boston University, 80 East Concord Street, Boston, MA 02118.

D. The Review of Radical Political Economics invites submissions of articles and book reviews for a special is-

sue on Women and Development. The special issue will focus on the relationship between capital accumulation, women's work in the labor market and the household, state policy and ideology. The changing position of Third World women, both in the developing and the advanced capitalist countries, is of particular interest. We strongly encourage submissions that develop a strong theoretical analysis of the interconnections between class, race, ethnicity and gender. The deadline for submissions has been extended to September 1989. Send to RRPE, Janet Spitz, Economics Dept., U Utah, Salt Lake City, UT 84112.

E. Sexuality and Disability publishes original papers concerning normal and abnormal sexual function in the physically and mentally ill. Clinical practice reports, case studies, research and survey data reports, state-of-the-art papers, guidelines for clinical practice, contemporary developments in special programs for sex education and counseling for disabled persons, as well as book and film reviews will be welcomed. All manuscripts and other editorial correspondence should be submitted in triplicate following Index Medicus style, to the editors: Arnold Melman, M.D. and Leonore Tiefer, Ph.D., Sexuality and Disability, Montefiore Medical Center, Department of Urology, 111 East 210th Street, Bronx, New York 10467-2490.

F. Social Problems seeks papers on AIDS and AIDS-related questions, especially papers reporting on AIDS research and/or critically examining in detail the way we think about, study, and act toward AIDS as a social phenomenon. Contact: Joseph W. Schneider, Sociology, Drake Univ., Des Moines, IA 50311-4505; 515/271-3563; BITNET: JSCHNEDR@DRAKE.

G. Women Make a Difference, a reader seeking papers dealing with women in contemporary American culture. This volume will examine the current position of women in various institutional sectors. Issues to be addressed are: actual representation of women in a given field, progress made, hardships in breaking in, prejudice and discrimination, specific type of work, and visibility and success. Deadline for submissions and inquiries should be directed to: Emanuel Levy, Dept. of Sociology, Wellesley College, Wellesley, MA 02181, or 11 Riverside Drive, Apt. 17PW, New York, NY 10023.

SOLICITATIONS

A. The Center for European Survey Analyses and Studies (Zentrum fur Europaische Umfrageanalysen und Studien, ZEUS), Univ. of Mannheim, is trying to set up a network of social scientists who are interested in or already doing research on the socio-political impact of AIDS within the social sciences, especially with respect to cross-nationally comparative research, to exchange information and to organize common projects.

Contact: Dr. Habil. Oskar Niedermayer, Director, Zentrum fur Europaische Umfrageanalysen und Studien (ZEUS), University of Mannheim, Tattersallstr. 2, D - 6800 Mannheim 1, Federal Republic of Germany.

B. Rannveig Traustadottir, a doctoral student at Syracuse University, seeks contact with people who are interested in combining gender and disability issues. Such issues might include (but are not limited to) the following: (1) Women's informal caring work, e.g. in providing care for a family member with a disability or in building and supporting informal social networks around people with disabilities. (2) Women's formal caregiving work within the service system, as professionals and paraprofessionals. (3) How the sex segregation of today's society affects community integration of people with disabilities. (4) Women with disabilities; their lives and experiences. Please contact her at the Center on Human Policy, Syracuse University, 200 Huntington Hall, 2nd Floor, Syracuse, NY 13244-2340. Tel. 315/443-4355.

C. Betty Wolder Levin would like to facilitate communication among people interested in **anthropology and bioethics**. Please send information on your activities (research, teaching, syllabi, consultation, membership on committees, etc). Will circulate lists of addresses and interests with hopes of organizing session and get together at the meeting in November. Please contact Betty Wolder Levin, Dept. of Health and Nutrition Sciences, Brooklyn C, Brooklyn, NY 11210; 718/780-5026, 212/866-4602.

OPPORTUNITIES: AWARDS, FUNDING

A. National Center for Health Services Research and Health Care Technology Assessment (NCHSR) invites submission of grant proposals for studies on home health care with emphasis on services delivered in the home by formal providers for the management and coordination of continuing care and on certain groups of patients, such as acutely ill patients who have been referred for home health services while recuperating from hospitalization. Also to be addressed: patients who have chronic disabilities or require prolonged periods for recovery; the impact of new forms of home health care management on patient care; discharge planning and patient outcomes; home health services for AIDS patients; impact of the growth of technologies; reimbursement for care. Check details in Research Agenda on Home Health Care, available from NCHSR Publications and Information Branch, Parklawn Bldg., Rm. 18-12, Rockville, MD 20857; 301/443-4100.

B. The National Center for Health Services Research and Health Care Technology Assessment invites proposals for a contract to conduct a prospective, longitudinal survey of acquired immuno-deficiency

syndrome (AIDS) patients and their health care providers. The survey is intended to document in detail the impact of the human immunodeficiency virus epidemic on the use of health resources within specific geographic areas and patient groups. The request for proposals (RFP) was advertised in the Commerce Business Daily on April 14, 1989. Contact: Ms. Marianne Mink, 301/443-2475.

C. The Susan B. Anthony Center for Women's Studies at the University of Rochester announces a postdoctoral fellowship for a recipient of the Ph.D. in any discipline. The applicants work should be closely related to women's studies. The fellowship is for one academic year beginning September 1989, with an option for a second year. The fellow will be appointed in an existing academic department and will teach two courses during the year. The course will bridge a standard discipline and women's studies (eg, Anthropology of Women, Philosophy of Feminism). Send vita, three letters of recommendation, a 1-2 page proposal and samples of published or unpublished work to Dir., Susan B. Anthony Ctr., 538 Lattimore Hall, U. Rochester, Rochester, NY 14627; 716/275-8318. Deadline is February 1, 1989 (Past, but worth noting for the future).

FILM CLIPS
By Nora Groce (Harvard University Medical School) and Gary Kiger (Sociology, Utah State University)

AIDS & SOCIETY Color, 60 minutes, 1987.
Distributed by: Worth Publishing, 33 Irving Place, New York, NY 10003.

AIDS & Society is a supplemental teaching aid supplied by Worth Publishing for instructors who adopt Ian Robertson's best selling introductory text, Sociology (3ed.). The videotape could be made available to others upon request from the publisher.

The film is a videotape of Ian Robertson giving a lecture at Portland Community College in early April of 1987. There is good news and there is bad news about this videotape. The good news is that it is informative and, occasionally, it raises provocative issues. The lecture provides a litany of facts about AIDS including epidemiological information as well as theories about etiology. The social aspects of fear of AIDS, transmission of AIDS, disability payments, insurance compensation and government policy are explored in a concise fashion. An example of one of the more interesting social-psychological insights provided was Robertson's reflection. He observed that this generation will likely come to equate sex with death.

The bad news about this videotape is that it is badly filmed. We watch Ian Robertson (the author of an excellent text but not a particularly dynamic lecturer) talk, talk, talk for one hour. The camera shot is straight-on, in the documentary style. Shots shift periodically from

Mr. Robertson to a blackboard. The blackboard has written upon it, "AIDS and Society," the lecture topic, but the board is not being referred to in the talk itself. Perhaps the cameraperson is restless. And when Ian Robertson concludes his talk with "I can take questions," the tape ends. This is disappointing since questions and answers can be as instructive as a talk itself.

So, while the videotape is informative, the information is imparted in a dry, plodding lecture format. This might or might not be a constructive way to get information out to the public in general and to college students in particular. (Gary Kiger)

NO SAD SONGS 24 minutes, 1985.
Producer: Nick Sheehan, AIDS Committee of Toronto.

This film, by the AIDS Committe of Toronto, was produced in 1985 to provide some basic information on AIDS to the general public. The intention was to remove fear of the disease through knowledge, and this short, well-made film does indeed provide some background about the disease. It is a measure of how quickly the field is moving, however, that this obviously well intentioned film is now somewhat outdated. AIDS, for example, is viewed as a "gay" disease in the film, although it is clear that it now affects the heterosexual community as well. There has also been a trend in more recent films to discuss the transmission of AIDS and the affects of the disease in much more direct terms. Oblique references to "sexual transmission" from a few years ago, have been replaced by open discussion of condom usage and how intravenous drug users can avoid infection. A recent public television special of AIDS actually followed an AIDS victim to his death bed. Since it is imperative that the general public receive as much information on AIDS as quickly as possible, a more recent film that provides more detailed discussion about the subject is probably preferable. (Nora Groce)

CURRENT RESEARCH

Disability and Sexuality Research: Suffering from a Case of The Medical Model
A Commentary by Carol Gill, Los Angeles, CA

In my work as a disabled pychologist, I have noticed that my disabled clients' distress about sexual issues is relieved only to a point by psychotherapeutic self-examinination. Ultimately, they need facts for practical solutions. In contrast to the amassed data on nondisabled human sexuality, however, there are no classic studies, no comprehensive surveys yielding well-replicated results on disability and sexuality.

The literature, such as it is, lacks focus and rigor. It offers articles by health care providers arguing for the

legitimacy and benefits of sexuality for "the disabled." Along side these sensitizing lectures on what disabled people should be enjoying sexually is an empirical literature discussing what disabled people can enjoy sexually. These reports primarily concern studies of physical functioning in men with spinal cord injuries. There are also scattered studies of other groups: women with spinal cord injuries, people disabled by accident or illness (e.g., stroke, cancer, arthritis, multiple sclerosis, heart disorders), and people disabled in childhood. Completing the literature are didactic pieces, including articles in professional clinical publications as well as popular disability sources. Both types often take information from general (nondisabled) sexuality research and translate it into advice for disabled people. The untested assumption here is that the sexual needs and experiences of disabled people are continuous with those of everyone else.

While some research studies on disability and sexuality are better designed and executed than others, most are flawed by an outmoded model of disability which overlooks the essential social component. Disability is viewed in medical terms as a measureable deficiency in the individual. In adhering to this medical model, disability/sexuality researchers have missed an important paradigmatic shift made some time ago by much of the disability community, from scholars to activists. According to the new viewpoint, disability is a minority lifestyle or social identity, not a medical condition. It is derived from the interaction between the individual and the social environment, rather than residing in the individual as a static quality (Hahn, 1985).

In addition to its narrow, demeaning view of disability, the old medical model lacks heuristic value in sex/disability research. It fails to generate ideas or advance knowledge because it fails to fit reality. Using an incorrect model, the disability and sexuality literature asks and then answers all of the wrong questions: Q: Should disabled people pursue sexual activity? A: Yes, they should; it is beneficial. Q: Can disabled people enjoy sexuality? A: Yes, they can; sexual desire and response are rarely destroyed in an individual by a disability.

The trouble is, information about individuals' physical potential tells us absolutely nothing about the possibility of sexual fulfillment for disabled people in the real world. People with disabilities need more than medical reassurance that they should or can enjoy sex.

It is of little reassurance to a woman with a new spinal cord injury, for example, to be told, as many are, that she can continue to have sex as she always has. Sexuality in real life is more complex than mere physical positioning and the possibility of intercourse. The woman's disability changes not only her body but many factors in her life via her relationship

with the social environment. She will be reassured only when we can tell her something accurate and helpful about how people are likely to respond to her as a sexual person, what she can do to maximize her chances of success in sexual encounters, and what she can do to cope with the difficulties of her changed status in the world. Unfortunately, sex/disability researchers have no conclusions to report to her about such matters. They have missed the real issues.

The appropriate question for future research is not <u>should</u> or <u>can</u> disabled people have sex but <u>do</u> they? What really happens? Are disabled people enjoying sexuality? Under what conditions? Which behaviors or attributes influence the sexual experience of people with disabilities? What can be done to enhance sexual fulfillment and minimize barriers to intimacy? What works?

Disability/sexuality researchers must adopt a model that accounts for the data, one that reflects the interaction of the individual with the social environment. They must further prove their commitment to uncovering the truth by designing better studies, improved in both rigor and relevance. This requires greater attention to such problems as sampling bias, self-report measurement, and social desirability response set--factors which typically complicate social scientific investigation and which run rampant in disability research. Disability/sexuality researchers must explore some difficult, highly complex, unpleasant territory in their quest for accurate and valuable information. They must be willing at some point to talk about prejudice and deeply-buried primitive fears and aversions.

People with disabilities are losing faith in the "experts." A few years ago, any seminar or workshop titled, "Disability and Sexuality," would attract a large attendance by disabled people eagerly seeking information. I have noticed a dwindling in their numbers lately. Having attended or participated in many such seminars professionally, I cannot blame them. They keep hearing the same thing over and over. Yes, you can be sexual. Yes, you can probably have orgasms. You should reassess your sexual values and go out there with the right attitude. After all, your problems are really not very different from the sexual difficulties of all people. What's that you say? How do you find partners open to a relationship with a severely disabled person? How do you find privacy for self-exploration in an institution? Do relationships with nondisabled people really work? How do you maintain positive body image in a society that disdains physical imperfection? Well . . . let's see . . . does anyone out there in the audience have any answers to share? Anyone out there?

A recent addition to the disability/sexuality literature offers a ray of hope. Disabled people themselves, mostly women, have been writing about their sexual feel-

ings and experiences in a variety of first person accounts (e.g., Browne, et al, 1985; Duffy, 1981; Matthews, 1983). Like raw gems, these data are scattered and unsystematic but often brilliant. They suggest interesting ideas for research. For example, how does using a wheelchair versus walking affect a person's status in a romantic encounter? Do nondisabled women treat disabled men the way men have traditionally treated women in our society? With any luck at all, such possibilities will generate enough interest to depose the medical model and end its domination of disability/sexuality research. When we begin to investigate the right questions, the answers we have been needing can begin to accumulate. Perhaps before we know it, we will have some conclusions with an impact reaching far beyond the laboratory or the rehab hospital.

REFERENCES

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A. Physically Disabled Women's Perceptions of Social Support and Experiences Affecting the Transition Through Parenthood

By Beverly Kopala, School of Nursing, Loyola University of Chicago.

This exploratory study examined physically disabled women's perceptions of social support and health care experiences when considering pregnancy, anticipating birth and during childrearing. Fifty women over 18 years of age with a neurosensory or neuromuscular disability completed a self-administered questionnaire. Using a Likert scale, they rated support provided by family, friends and healthcare providers and the perceived influence of that support on the parenting decision. Responses of 34 subjects who perceived that they had made a decision to become a parent were included in the analysis of social support. Analysis of variance and a post hoc comparison using the Tukey HSD method revealed that the physically disabled woman does perceive significant differences in the social support provided by family, friends, and health care providers when making a decision to become a parent. Pearson correlation analyses suggested that a relationship existed between emotional support, instrumental assistance, and information received and the influence of that support on the parenting decision. Eleven of the fifty subjects participated in semi-structured, telephone interviews. Content

analysis of the transcriptions revealed that the women had needs, concerns and experiences similar to non-disabled counterparts as well as unique concerns. Support, creativity and initiative enabled these mothers to successfully adapt to parenthood. The research identified the need to: strengthen personal support systems, increase, improve and disseminate information about pregnancy and disability, improve the knowledge base of health care providers toward pregnancy and disability.

B. Living With AIDS: Community Service Needs Among Disabled and Non-Disabled Persons with AIDS and ARC
by Holly Korda, Vince Scardino, Paul Oostenbrug,
The grant writing task force of the AIDS Action Committee of Massachusetts

This paper reports the results of a mail survey conducted by the AIDS Action Committe (AAC) of Massachusetts to assess the needs, supports and use of services among persons diagnosed with AIDS and ARC in its metropolitan Boston service area. Findings are presented to allow comparisions among persons receiving disability benfits; persons who identified themselves as disabled but who are receiving no benefits; and persons who do not consider themselves disabled. The survey does not specify type or source of benefits, and is based on respondents' self-reported health status.

In addition to demographic data, respondents were asked to indicate their need for services and their use of interpersonal and community supports. AAC clients were also asked to indicate their use of, and satisfaction with, services provided by the AAC. This paper presents information on service need reported by persons with AIDS and ARC in Greater Boston. A total of 157 useable surveys were returned, 122 of which were completed by AAC clients.

Results

The 157 respondents who indicated their disability status were categorized as follows: Group 1 included 77 persons who identified themselves as disabled and receiving benefits; Group 2 included 28 persons who reported being disabled but were not receiving benefits, or were awaiting determination of eligibility; Group 3 included 52 persons who described themselves as not disabled.

The majority of respondents, across all groups, were gay white males in their thirties, with one or more years of college. At least half of each group reported a diagnosis of AIDS (84.4% for Group 1, 63.0% for Group 2, and 50.0% for Group 3).

By disability status, the three groups were similar with respect to race, gender, age and education. However, non-gay respondents (primarily intravenous drug users and heterosexual sex partners of persons with HIV) were significantly over-represented among the disabled who were not receiving benefits. A diagnosis of AIDS was positively

related with disability status ($p > .05$), and with whether an individual was likely to receive disability benefits. Persons who were disabled and receiving benefits were significantly more likely to have been living with diagnosed AIDS or ARC for longer periods of time (23.7% had been diagnosed more than two years prior to the survey) than those who were disabled and not receiving benefits (7.4%) or those who were not disabled (11.1%).

Significant differences in living situations were also observed across the groups. Disabled persons, including those who received benefits and those who did not, were more likely to live with others in a variety of arrangements (72.8% and 85.7%), while more of the non-disabled lived alone (42.3%).

Significantly fewer of the respondents who received disability benefits reported their health as excellent or good (1.4% and 35.2%) than of those identified as disabled but not receiving benefits (29.6% and 48.1%) or of those not disable (23.1% and 59.6%). There were also significant differences across groups with respect to the frequency of hospitalization during the previous year. Respondents who were disabled and receiving benefits were more likely to have been hospitalized more than two times (35.1% vs. 19.2% for those disabled and not receiving benefits and 7.8% for the non disabled). More than half (62.7%) of non-disabled respondents had never been hospitalized for HIV-related conditions.

Medical insurance coverage also varied across groups. Non-disabled persons were more likely to be covered by commercial insurance, including Blue Cross and Blue Shield (88.5%) than those who were disabled and not receiving benefits (50.0%) or those who were disabled and receiving benefits (39.0%). Almost half of disabled beneficiaries (49.4%) were covered by Medicaid, compared with 28.6% of the disabled respondents who were not receiving benefits and only 1.9% of those who were not disabled.

Health/information Needs. Disabled respondents who were receiving benefits reported more Set 1 (health/information) needs than disabled respondents not receiving benefits, reporting averages of 6.34 needs for Group 1 and 6.18 needs for Group 2 within this set. Non-disabled respondents reported the fewest needs, with Group 3 averaging 4.69 needs.

Significant differences were noted between both disabled groups and the non-disabled with respect to the need for health care at home (41.6% and 35.7% vs. 9.6%), help applying for Medicaid (66.2% and 71.4% vs. 9.6%), help paying for hospital bills (35.1% and 46.4% vs. 7.7%), and help paying for drugs/medical supplies (41.6% and 57.1% vs. 19.2%).

Each group also identified different needs by frequency of mention and in order of priority. For example, the need to learn specifics about AIDS-related infections and treatments was cited most frequently by persons who were disabled and receiving bene-

fits (77.9%), while the need for help applying for Medicaid was identified most frequently by disabled respondents who did not receive benefits (71.4%), the need to find out how the kinds of problems they were facing were being handled by other patients (support groups) was identified most frequently by non-disabled respondents (63.5%).

Although there is some overlap, some needs appear to be more important than others, even though other needs may have been identified more frequently. For both disabled groups, the need for help applying for Medicaid was identified most frequently as one of respondents' three most important needs. Learning about specific infections and treatments, and the need for support groups were identified as second- and third-most priorities by respondents who were disabled and receiving benefits. Among respondents who were disabled and not receiving benefits, paying for drugs/medical supplies was the second most frequently cited priority need. Three needs were identified with equal frequency as third among their priority needs: help paying for hospital bills, learning about specific infections and treatments, and support groups. Non-disabled respondents, by contrast, identified the need to learn about specific infections and treatments, finding out about AIDS, and support groups as first, second and third priority needs.

Practical Support Needs. Differences between disabled groups and the non-disabled were even greater when their practical supports were examined. Disabled respondents, whether they received benefits or not, reported approximately three times as many needs (mean 6.73 for Group 1 and 6.93 for Group 2) than those who were not disabled (mean 2.35). By frequency of mention, virtually every service was identified as a need by a significantly higher proportion of disabled respondents than by those not disabled.

The practical support needs cited most frequently among respondents' three most important needs were similar for the two disabled groups. Although more respondents noted the need for help preparing a will or power of attorney among the disabled who received benefits (47 of 77, or 61.0%), help in applying for government assistance was mentioned most frequently as a priority, followed by the need for help with transportation for health care and money for rent. Respondents who were disabled and who did not receive benefits identified the need for rent money most frequently as a priority need. The need for help applying for government assistance was cited second most frequently, followed by the need for money for food, and transportation for health care. None of these items was cited frequently as a priority need for the non-disabled group. Non-disabled respondents identified preparing a will or power of attorney as their first priority, followed by the need for help with insurance questions and the need for recreation activities.

For more information on method, findings, and implications write Holly Korda, 84 Prescott St., Cambridge, MA 02138.

C. "Gender and Sexual Development of Women with Mental Retardation"
Michelle Davis, Sociology, Brandeis University

This study involves the lives of 24 women with mental retardation who live in various community residences in the Boston, Massachusetts area. All of these residences are operated by one human service agency. Of the 24 women represented, 12 women were directly interviewed, and 12 were represented through staff interviews or informal conversation. All persons interviewed are their own legal guardian, and signed a consent form giving permission to have their stories written about.

This study focused on the women's gender and sexual development. Of the 12 women directly interviewed, there was a broad range in age (late 20's - early 70's), physical/mental abilities (lower-functioning to very high-functioning), sexual and life experiences (one widowed, one woman has a child, one woman is engaged to be married). 11 of the women were institutionalized for some portion of time, 6 are post-menopausal, 2 are sterilized, and 9 are survivors of rape or sexual assault. I find this group of women to be homogenous, despite their seeming diversity. Most of the women are white, heterosexual, economically privileged, and grew up in the same surrounding area. One woman is Native American, and one woman is Chinese-American.

There were several interesting findings from this group of women. The most obvious finding is that there is a high percentage of rape/sexual assault survivors (9 out of 12 interviewed. Of the other 12 there was an equally high percentage of about 4/5). These women were raped or sexually assaulted in their homes (3 out of 9), or in the institution (6 out of 9). I initially believed that menstruation would be the universal point of sexual and gender development. Though menstruation was in fact an important and special part of their lives, they all cited the moment of development from girl to woman as the time that they were raped/sexually abused for the first time, institutionalized, or both (as the case may be).

One area of discussion that had mixed reactions was on marriage and childbirth. Though the women all had a sense that marriage and childbirth was what was <u>expected</u> of them, very few of the women actually wished to ever participate in it. Often marriage was directly linked to children, and both were frequently seen as annoying, troublesome and difficult to maintain. These women all told stories that revealed how they had few examples of family or marriage structure, and apparently this lack of example has carried over into their present relationships. I found it quite refreshing that these women were so independent and comfortable with

their single-ness, or non-conventional relationships or marriages. Though in ideology these relationships are unconventional, they unfortunately seem to fall into very conventional, sex-stereotyped roles once they develop in reality. Marriage and childbirth, though not desirable to these women, were still seen as ways to be "normal." This was a very important element attached to marriage and children, enough so that I suspect the women engaged in marriage and childbearing simply to achieve this "normal" status.

BOOK NOTES

A. Butler, Robert N., M.D., and Lewis, Myrna I., A.C.S.W., (two books). Midlife Love Life: How to Deal with the Physical and Emotional Changes of Midlife and Their Effect on Your Sex Life, New York, Harper and Row Publishers, 1986, Revised Edition, 204 pp., $6.95 softcover; and Love & Sex After Sixty, New York, Harper and Row Publishers, 1988, Revised Edition, 176 pp., $7.95, softcover.

These are revisions of earlier books but greatly updated and enhanced. Both these comprehensive, splendid books will be very useful to those who work with the disabled as well as to disabled persons themselves. Actually, the Midlife Love Life book addresses itself to the situation of the old as well as to the middle aged, and the authors had intended to rest with just that one revision. However, older readers requested that, because there was a great need for their age group, Love & Sex After Sixty also be revised, and it was two years later. Love & Sex After Sixty has larger type than the midlife volume and more tables on the medications old people take and their effects on sexuality, but otherwise the two books contain much the same information and certainly the same wisdom, compassion amd frankness. Both give very specific information on how various diseases and surgery, as well as normal aging, can interfere with sexual functioning and what remedies may be sought and how helpful they may be. Both volumes are written clearly enough for the layperson but also have information of value to professionals who work with the old and the disabled. The sections on heart disease and sex may prove very reassuring to doctors and patients that a heart attack need not mean the end of a sex life. Resources and addresses are provided for organizations and services helping in a variety of sexual dysfunctions. Both genders, and both homosexuals and heterosexuals, receive from these volumes good advice and understanding. The issue of the lack of available male partners for women at later ages, because of skewed demographics, is addressed and suggestions made to women. Masturbation or self stimulation is endorsed and institutions exhorted to be more understanding of peoples' needs.

All in all, the husband and wife team of authors have an accepting and facilitating

philosophy of sexual possibilities. (Ruth Harriet Jacobs, Wellesley College Center for Research on Women)

B. Doress, Paula Brown, and Siegal, Diana Larkin, (in conjunction with the Midlife and Older Women's Book Project of the Boston Women's Health Book Collective). Ourselves Growing Older. New York, NY: Simon and Schuster, 1987; 511 pp., $15.95.

Unlike traditional texts which depict the physical and mental limitations experienced by many older people as a given, Ourselves Growing Older is based on a philosophy which stresses the empowerment of midlife and older women in confronting the challenges of growing older. Possibilities for personal growth physically, spiritually and mentally also are a reality for a growing number of older people.

The book builds upon the tradition of selfhelp generated by its predecessor, Our Bodies Ourselves, and focuses on strategies for prevention, changes to create health lifestyles and acceptance of one's self as one ages. In essence it is an informative manual which covers a myriad of topics, including habits worth changing, sexuality in older years, childbearing in midlife, housing and living arrangements work and retirement, economics of aging, caregiving and managing a variety of physical and mental ailments common to middle age and older women.

More than anything else this manual is valuable for promoting self acceptance of older and middle aged women by themselves, countering societal trends to spotlight only youth and physical beauty. The book uses a nonjudgemental approach in advising women to become more actively involved in taking control of their lives from considering cosmetic surgery to planning for financial security in one's old age. Practical tips for dealing with specific physical and mental problems are sprinkled throughout the workbook. More importantly, themes focusing on women's self determination in major areas such as securing better medical care, fighting for nursing home rights and entitlements are featured.

Mutual cooperation and networks are particularly needed for women to overcome the physical and mental decrements that sometimes occur with aging. This is particularly true because of the traditional economic vulnerability of women and their likelihood to live longer than male counterparts. A wonderful resource guide to community services, support groups and articles of interest is included in the back of this tremendously helpful manual. (Janet M. Logan, Assistant Director, Public Policy Alzheimers Association, Chicago, Illinois and Heller School, Brandeis University)

C. Falco, Mathea and Cikins, Warren I. (Eds.). Toward a National Policy on Drug and AIDS Testing. Washington, DC: The Brookings Institution, 1989, 81 pp., $10.95 softcover.

This slim volume contains four essays which present, with varying degrees of balance, the controversy surrounding the use of drug and AIDS (HIV) tests. Falco's "Introduction," which summarizes all the arguments presented, and Osborn's "Medical Considerations" are especially strong essays. These authors point out that AIDS and drug tests are different from other medical tests because they are not initiated to allow treatment beneficial to the individual. Rather, they are performed for societal benefit--safety in the workplace, deterrence of socially proscribed behavior, safety of the blood supply, estimation of prevalence, and to limit the financial exposure of health and life insurers. While some persons may change their behavior following a test result, broad testing of the population poses dangers to the individual. The dangers discussed vary from emotional trauma, social isolation and discrimination which may result from a false positive HIV finding, to loss of a job from the detection of a single use of marijuana. This book makes clear that the central dispute surrounding such tests is whether the benefits to the society outweigh possible personal injury and the invasion of privacy. It also acknowledges the roles that fear and prejudice play in preventing the initiation of helpful policies, such as clean needles, education for safe sex, and attention to drug and alcohol abuse and addiction.

Disability rights issues are also a part of the testing controversy, although they are not discussed as such in this volume. For example, inquiries into chronic impairments and medical conditions are generally prohibited unless they are related to job performance. The use of pre-employment drug tests may nullify this protection since a full disclosure of conditions requiring medication may be necessary to prevent a false accusation of illegal drug use. One of the main purposes of AIDS testing is to enable discriminatory treatment--the exclusion of infected blood from the blood supply, isolation of HIV infected prisoners, or refusal of insurance. While these actions are generally legal, illegal disability-based AIDS discrimination is also enabled by AIDS tests.

This book is useful as a concise summary of the issues for and against drug and AIDS testing. The points of consensus on pages 20-21 provide a start for policy development, although I am concerned that insufficient attention is paid to the protection of individual rights. The title indicates that a single policy on drug and AIDS testing should and can be developed. Yet, the substance of the essays suggests that drug testing and AIDS testing may require separate policies. (Nancy R. Mudrick, School of Social Work, Syracuse University)

D. Elizabeth Fee and Daniel M. Fox Eds. <u>AIDS: The Burden of History</u>. (Berkeley, Cali-

fornia: University of California Press, 1988. ix plus 362 pp.).

We get deep into this book of essays before we learn much about AIDS. In this case, the past is not only prologue but a very long prologue. The editors insist on taking this long view and on not pushing the contemporary relevance of history too hard. Although the essays are frustrating in their refusal to draw easy lessons, we can only applaud their sophistication and appreciate the scholarship on which they rest.

Their book brings together leading practitioners of medical history and the history of public health for a series of essays on the meaning of AIDS. The editors give the contributors considerable latitude. Charles Rosenberg begins with a speculative piece on the nature of disease which, in his view, becomes a sort of mirror on the culture in which it takes place. AIDS, like previous diseases, thus has a social construction whose meaning changes over times, yet Rosenberg emphasizes the tension between a biological and a "social understanding" of the disease.

Instead of moving forward from Rosenberg's speculations to a chronicle of the modern plague years, the editors insist on educating us and thus provide us with solid pieces on previous epidemics. Guenter Risse, for example, finds parallels between past efforts to scapegoat Jews, immigrants, and the poor and modern efforts to blame AIDS on gays.

The next set of essays center on the historical treatment of venereal disease as a controlling metaphor for the treatment of AIDS. As Elizabeth Fee notes in her look at venereal disease control in twentieth century Baltimore, "ways of perceiving and understanding disease are historically constructed," and no disease better illustrates how cultural and other impressions have contributed to the meaning of disease than venereal disease. In a spirited essay, Allan Brandt reminds us, that it is worth the effort to undertake historical research on AIDS because the "social construction of AIDS" has a "powerful impact on the choices made in responding to the disease."

By now we are firmly focused on AIDS, and the final essays in the book look explicitly at this modern disease. First comes a commentary on the importance of epidemiology--which, unlike virology, has a strong social component--in defining the disease. Next, Dennis Altman explores the connection between the response to AIDS and the rise of the gay community as a political actor, arguing that the disease has bolstered the emergence of the gay movement as a recognized pressure group in a standard interest group sense. Finally, Daniel Fox looks at AIDS and American health policy, arguing that resurgent conservative notions, such as the importance of individual responsibility, could not comprehend the reality of AIDS or deal effectively with the disease.

This summary gives you a flavor of the book, written in

the currently fashionable "disease as social construction" mode and disdainful of the quick historical analogy. AIDS, in the end, cannot be dismissed with a facile simile. It is nothing so much as itself. Readers who want to link the AIDS discussion to more general considerations of stigma should look elsewhere. Readers who want to gain a sense of how the best scholars in the history of medicine operate might consider starting here. (Edward D. Berkowitz, Department of History, George Washington Univ.)

This review is adapted from a much longer review to appear in the Journal of Social History.

E. Finger, Anne. Basic Skills. Columbia, MO: University of Missouri Press, 1988, 117 pp., $8.95 softcover.

"And so, dear reader, I leave you with all: a slogan, an image, a moral: and with a plea to reimage our language, to tell and tell our stories again, until we have words to echo our lives." So ends one of the stories in this group of seven, and the life-echo, sounded here, quietly re-echoes in story after story. One might, I suppose, say that disability is a theme that runs throughout the anthology, but, if so, it is a minor, an understated theme. There are no heroics here, no harangues, no annoying tug at the sleeve of one's conscience. There are only the quiet words that echo our lives, with wry humor, with sad wisdom, with mute pity for the human condition. Five of these seven short stories have been published earlier, including the incomparable "Like the Hully-Gully but Not So Slow," which has already established itself as a kind of classic in the field. Anne Finger is cannily "reimagining our language," and it is good to have her work collected in one place, in a low-priced paperback. My best advice: Get out and buy a copy. It is a volume that belongs on all our bookshelves. (Joseph L. Baird, English Department, Kent State University)

F. Grady, Kathleen E., and LemKau, Jeanne Parr (Eds.). Psychology of Women Quarterly. Special Issue, Women's Health: Our Minds, Our Bodies. Vol. 12, No. 4, Cambridge University Press, 1988, 137 pp., $12.95.

This special issue contains eight articles by academic or clinical psychologists--all women--who bring a feminist analysis to bear on such crises as disability, diabetes, AIDS, midlife childbearing, abortion, breast self-examination and menopausal sexuality.

The lead article presents an updated overview of sex differences in mortality and morbidity. Women continue to live longer than men but they are more likely than men to develop a chronic, disabling disease such as arthritis or diabetes. The following seven articles are addressed from either a liberal femininst or socialist-feminist theoretical

perspective.

The majority of the authors are liberal feminists who analyze sexual discrimination against women when they seek traditional health care and appeal to psychologists to provide alternative approaches. Two socialist-feminist authors in their articles on disability and AIDS go beyond sexual discrimination to also analyze economic and political dimensions of women's health-related issues.

The most significant article in terms of disabilities studies was "Defining Disability for Women and the Problem of Unpaid Work." The authors state that much of the scholarly funded research on disability examines paid work disability, principally among male populations. Politically, a greater value is placed on paid work compared with family work and there is a greater concern in the political arena about labor force participation and employment rather than about household production.

Strengths of this special issue are its critical feminist analysis and variety of health issues covered. Weaknesses include not meeting the editors objective of "spanning broadly beyond women's reproductive concerns" as the articles on midlife childbearing and abortion illustrate. Most importantly the editors and authors ignored the Women's Health Movement perspective as an alternative for traditional medical/pyschological views of women. It is ironic that the name given this special issue, Women's Health: Our Minds, Our Bodies, so clearly resembles Our Bodies, Ourselves or Ourselves, Growing Older, yet neither book is used as a reference in the entire issue. (Kathy MacPherson, School of Nursing, University of Southern Maine)

G. Joffe, Carole, The Regulation of Sexuality. Philadelphia, PA: Temple University Press, 1986, 196 pp., cloth $24.95, paper $12.95.

This is a report of an intensive field study of family planning workers. It provides a unique insight into the day-to-day interpersonal dynamics in family planning clinics, intrapersonal conflict and conflict resolution.

It includes an excellent review of the field of family planning as it has grown from the repressive era of Comstock in 1870, to Margaret Sanger's pioneering work in the 20's and 30's, to the present. Various areas are discussed including legal issues, financial issues, social planning issues, religious and moral issues, health developments, and reproductive rights issues.

The crux of the book is an anecdotal-type description of the daily life and career struggles of the family planning/abortion counselor in a clinic setting.

The best audience for this book is probably the health-services delivery planner, and staff at family planning clinics. Excellent descriptions of personal coping mechanisms for dealing with extremely sensitive and controversial issues are present-

ed.

However, for the individual with a disability, there is no discussion of either providers of family planning/abortion services who have disabilities and any particular issues they face, nor is there mention of providing services to persons with disabilities.

I feel the title, "Regulations of Sexuality" without its subtitle, "Experiences of Family Planning Workers" is intriguing, but does not describe the contents of the book.

It has limited application to the field of disability. (Nora J. Baladerian-Andrade, Mental Health Consultants, Culver City, CA)

H. AIDS: The Public Context of an Epidemic, The Milbank Quarterly 64(supplement 1), 1986. $10.00, 182 pp.

This special edition of The Milbank Quarterly contains eight invited essays which analyze how social and economic forces in the United States have affected 1) the spread of AIDS and 2) the health care system's attempts to control that spread and to meet the needs of those already afflicted. Charles Rosenberg puts AIDS into historic perspective by analyzing how AIDS clarifies both the social and the biological aspects of illness and thus feeds into long-standing debates about the meaning of illness. David Musto uses historical data to argue that quarantines have never been effective measures against epidemics and that AIDS will be no exception. Two essays discuss the reasons behind what the authors consider the government's failure to respond effectively to the AIDS crisis, while a third essay discusses the insurance industry's responses to the AIDS crisis. Dorothy Nelkin and Stephen Hilgartner provide a fascinating analysis of how competing ideas about acceptable risk affected the response of one school district to a pupil with AIDS. Finally, the concluding essay by Ronald Bayer describes how AIDS poses a conflict between the values of public health and those of individual liberty, and suggests how to resolve that conflict. Although none of the essays address the experience of illness (the topic with which readers of DSQ are most concerned), all are well-written, informative, and interesting. (Rose Weitz, Sociology, Arizona State University)

I. Neistadt, Maureen and Freda, Maureen. CHOICES: A Guide to Sex Counseling with Physically Disabled Adults. Malabar, Florida: Robert Krieger Publishing Company, 1987, 132 pp., $12.50 hardcover, $8.50 softcover.

At last there is a book that guides the consumer and the professional through the accumulated literature on sexuality and disability. This is not a textbook but rather a reference that summarizes the clinical knowledge as it relates to sexuality and various disabilities. Disabilities

and medical conditions are divided into the classifications of anatomical and endocrine, cardiovascular and neurological, and then further addressed by functional impact in a later chapter. The issues of communication and intimacy, counseling, privacy, dating, marriage and raising families, fertility, pregnancy and contraception are also discussed in general for persons with disabilities, and also specifically for individual disabilities.

This volume is necessarily an over-view of a very vast topic and therefore gives general information even as it addresses specific disabilities. The reader needs to use it as a guide rather than truth for a particular individual with a disability. It is best used as a springboard to further reading--its bibliography and footnotes are quite extensive. To use it without reading more in-depth from the materials it references is to misuse its design and intent. As it is stated in the Preface, "it is not meant to be a comprehensive textbook on sexuality and counseling, but rather a practically oriented manual summarizing the essentials for a supportive, information-providing type of counseling."

Neistadt and Freda have done an important service in compiling a great deal of material in such a useable format. It is unfortunate that their fine work reveals that little has been published in this field since the early 1980's. Hopefully this publication will inspire other clinicians to publish more recent work in this most important field. (Susan E. Knight, Benicia, CA)

J. Pan American Health Organization. AIDS: Profile of an Epidemic. Washington, DC: World Health Organization (Scientific Publication No. 514. Pan American Sanitary Bureau, Regional Office of the World Health Organization, 525 Twenty-third Street, N.W., Washington, DC 20037), 1989, 365 pp.

This book is a collection of a diverse set of papers, comments, and reports about the problems associated with HIV infections in the Americas. As the introduction states, it is an epidemiologic mosaic of the similarities and differences among the different regions in this Hemisphere.

The first part of the book contains 16 papers on the epidemiology of HIV infection in numerous countries and regions. The topics covered include immunopathogenisis, technical aspects of HIV testing, the prevalence of infection in different countries, projectioons of future infection and disease rates, routes of HIV transmission, as well as ethical issues and societal responses. The second part of the book consists of five round table comments about the appropriateness and accuracy of projects of the numbers of AIDS cases.

The third section of the book consists of reports and abstracts from numerous sources on HIV related topics, including regional and global

responses, results of the first Pan American Teleconference on AIDS, guidelines and considerations for prevention activities, and reports of current research.

The papers in this book are somewhat uneven in coverage of both topics and areas. It provides a valuable model, however, of the way information about HIV infection can and should be compiled and disseminated. The period between concept and publication was only six months and this book contains an extraordinarily valuable array of information. It is admirable, that the Pan American Health Organization has been able to compile such a worthwhile compendium and make it available so quickly. (Paul D. Cleary, Dept. of Health Care Policy, Harvard Medical School)

K.. Phillips, Elizabeth. Women and Girls with Disabilities: An Introductory Teaching Packet. Organization for the Equal Education of the Sexes, Inc., 438 4th St., Brooklyn, NY 11215. Copyright, 1986. 44 pp., $12.95.

This information packet provides elementary and secondary teachers with preliminary material about gender and disability, and suggests ways that the subject may be presented in the classroom. Presuming that teachers have little prior knowledge of disability issues, the introduction briefly describes the impact of attitudinal barriers, and offers gender-related statistics on the employment and earnings of disabled women and men. It emphasizes the tremendous need for role models for all young people with disabilities, and the long-standing scarcity of such models for disabled girls.

The material for classroom use includes a questionnaire about architectural barriers in the students' school; a brief biography of the actress Linda Bove, who is deaf, with thought-provoking questions for discussion; and a list of other women with disabilities about whom the students might conduct research. The packet concludes with an extensive bibliography on women with disabilities, and a selected listing of children's books which present positive images of disabled women and girls.

Phillips urges that disability should not be studied as an isolated topic, but should be integrated into the general curriculum. She suggests, for example, that students might interview some people who are disabled if they are talking with people who work in various careers. Harriet Tubman's seizure disorder could be mentioned in a lesson on the Underground Railroad. Additional ideas along these lines would have been helpful. Some teachers might also wish for activities tailored to specific age groups.

As Phillips makes clear, this packet is only a starting-point. Yet, brief though it is, it conveys strong, positive attitudes toward people with disabilities, and toward disabled women in particular. (Deborah Kent, Chicago, Ill. 60630)

L. Rousso, Harilyn. Disabled, Female and Proud!. Exceptional Parent Press, Boston, 1988, 144 pp., $9.95.

Disabled, Female and Proud! is edited by Harilyn Rousso, a woman with a disability, with photographs by Flo Fox, a visually-impaired photographer. The book is a strong contribution to the collections of personal stories by people with disabilities. It grew out of the work of Harilyn Rousso, a social worker and therapist, who created a big-sister project for disabled women and girls in New York City to address the lack of role models in the media and the community for young disabled females. In my experience working with a full age range of disabled women, this book is a much needed resource to counteract the isolation so many of us feel in our struggles with work and life.

Ten women with various disabilities, from diverse age, race, class and language backgrounds offer their perspectives on living with a disability. While the women in this book have "made it" in terms of achieving satisfying work, they don't appear to be "super-crips"; most of them work at ordinary kinds of jobs. But in order to find these jobs they often have had to be extraordinarily creative and persistent.

The book contains concrete suggestions on ways to put non-disabled people at ease, communicate one's strengths, and function in the bureaucracy that serves disabled people. Other key aspects of womanhood are focused on at length, including relationships, pregnancy and parenthood, still controversial issues for this generation of women with disabilities.

Once, on a visit to an undergraduate classroom, a student complained to me that their enlightened professor had invited a seris of articulate, well-integrated, socially and politically active disabled people to speak about what it's like to be disabled. "When do we get to meet disabled people who are having a hard time? People who hate being disabled?" The barriers disabled young women will face in experiencing disability, in overcoming discrimination in getting an education and seeking employment are dealt with squarely in this book: sometimes it is hard to be disabled, and to confront sex-bias in addition to pervasive misconceptions about disabled people's ability to do the job, but it is possible.

In a review in the Disability Rag, this book was criticized for presenting politically unevolved perspectives on disability. When I read the book, that's actually one thing that impressed me about it. Equal time was given to the expression of insecurities, of the pain of loss, the confusion around whether to "pass" or not, the resistence to asking for help, aspects of oursleves as disabled people that we can all admit to if we're honest the idea that we can and should all arrive at some prescribed level of political consciousness and correct attitude is

limiting; it invalidates where any person might be, at a given point. It is not entirely reassuring to newly disabled or young disabled people to hear only of empowered activists, who have it all together as disabled people. For women with disabilities and possibly also for men, one can find an aspect of oneself somewhere in this book, and stimulus to take the next step. (Marsha Saxton, Project on Women and Disability, Boston, MA)

M. Rule, Jane. Memory Board. Tallahassee, FL: The Naiad Press, Inc., 1987, 322 pp., $8.95 softcover.

At first I wondered why I was reviewing this book for an issue on gender but after retelling the story to friends, I realized why. It's a gendered view of one life--twins, one male, one female. David and Diana, born in Canada, father dies, mother remarries, everyone feels alienated. Diana goes off to England during the War, David stays at home. David marries; Diana comes back with a woman lover, Constance.

Ironies abound: this is a story about memory, told in flashback but Constance is in the middle stages of Alzheimer's Disease and isn't constant at all. Jane Rule likes structure to help tell her story and here she uses fine technique in a fine way.

The story revolves around David re-establishing his relationship with his estranged sister of whom his wife never approved. His wife is now dead and his two daughters and their families don't even know about his sister. Through present tense and flashback, the story unfolds and we grow very fond of the characters. David goes ahead and agressively pusues his siter, his daughters come to terms with their own lots in life, Diana grows to love Constance in a new way and new family configurations are formed by the end of the story.

> Diana laughed. There was no one in the world like Constance, and she wasn't . . . ridiculously misnamed; she was constant in will to herself even now against the blanks, the confusions, the terrors.
>
> "I love your honesty," Constance said, "even when I have to go on believing you."
>
> "Keep me in mind," Diana said.
>
> "Yes, and what's his name," Constance said, nodding to Daivd's half-eaten lunch.
>
> "David, my brother."

I was sorry to see this story end. (Diane Hamer, The Arthur and Elizabeth Schlesinger Library on the History of Women in America, Radcliffe College)

N. Shaffer, Patricia. How Babies and Families are Made. Berkeley, CA: Tabor Sarah Books, 1987, 64 pp, $6.95.

Many books for young children explain how babies are "made," even with candid descriptions of reproductive anatomy and physiology, but few depict the variety of ways in which people now create families, nor the great diversity among adults seeking to become parents.

How Babies and Families are Made, by Patricia Shaffer, is such a book. Through both text and numerous excellent illustration it acknowledges racial and physical differences among parents, depicts blended families, and unlike almost all books of its kind, offers positive images of people with disabilities as parents.

The simple and straightforward description of sex and reproduction has just the right amount of detail for the 5-9 year-old-crowd. I especially like the passage on intercourse: "A woman and a man feel like getting very close to on another. They hug and kiss and touch each other's bodies because it feels good. The decide to get extra close by putting the man's penis into the woman's vagina."

Although intercourse is the "most common way to start a baby," Shaffer mentions in vitro fertilization. The text notes that "very few babies are made this way," but passes no judgment on this alternative mode of procreation. Nor is there any allusion to IVF's controversial status. Even though this is an issue quite complex for young children to understand, IVF could and should have been presented with more cautious commentary.

Refreshingly, this book recognizes the home and hospital as appropriate birth settings, although one sentence does suggest that home birth, in general, is less safe than hospital birth ("Many women prefer to go to the hospital to have their babies in case 0they or their baby need emergency help.") No good data show that planned screened out-of-hospital birth is less safe than hospital birth. Mention of birth centers would have been a nice addition as well.

Shaffer's book also introduces miscarriage, Cesarean birth, prematurity, and multiple births, though there is no mention of gay and lesbian parents or donor insemination. Overall, it is an affirming book for young children that will help prepare them for what lies ahead in their own and in others' families. (Judy Norsigian, Boston Women's Health Book Collective)

0. Taub, Nadine, and Cohen, Sherrill, editors. Reproductive Laws for the 1990's - A Briefing Handbook. Newark, New Jersey: Women's Rights Litigation Clinic, Rutgers University School of Law, 1988, 312 pp., Softcover. $34.50.

This collection of policy papers focuses on six major reproductive issues: time limits on abortion, prenatal screening, the fetus as patient, reproductive hazards in the workplace, interference with reproductive choice, and alternative modes of reproduction. Produced by the Project on Reproductive Laws for the 1990's, a collaborative effort

coordinated by the Women's Rights Litigation Clinic and the Institute for Research on Women of Rutgers University, the Handbook includes articles by activists and scholars who are committed to making the principle of gender equity central to the development of reproductive laws and policies.

In the "Social Context" section at the beginning of the book, Kathryn Kolbert provides a visionary manifesto of sorts, which unites the other articles. Kolbert presents nine underlying principles for a Reproductive Rights Agenda for the 1990's: freedom and legal right to make voluntary, informed decisions; comprehensive, quality, and affordable health care and human services; sexuality, reproductive and life skill education, freedom to express one's sexuality, reproductive and life skill education, freedom to express one's sexuality, and adopt varied family arrangements or life styles; economic equity; freedom from violence; freedom from reproductive hazards; fair and equitable family law and services; and political participation. These are fine goals, yet, as the other selections in the book demonstrate, the issues are complicated ones, and when specific reproductive policies are addressed, it is not always easy to determine the single, principled response.

The fact that there are no easy answers is best acknowledged in the two "background papers" included in the Handbook. These comprehensive articles, "Reproductive Laws, Women of Color, and Low-Income Women," by Laurie Nsiah-Jefferson, and "Reproductive Technology and Disability" by Adrienne Asch are the most valuable selections in the collection. Both authors address the complexity of the issues, implicitly acknowledging the potentially competing interests among women, which must be addressed in the process of building a feminist reproductive rights agenda. For example, Nsiah-Jefferson raises the issue of the social allocation of health resources. Women of color and poor women need access to basic health services. How can these needs by balanced against the demand for the development and use of "high tech" and high-cost reproductive technologies currently used primarily by more privileged women? Nsiah-Jefferson wants poor women and women of color to have access to the high-tech procedures as well; she is also clear about the ways in which some health technologies (e.g. sterilization) have been abused, with devastating consequences for individuals and eugenic implications for minority communities.

Asch raises important questions about the use of prenatal diagnosis, describing the consequences of such "disability-preventing" activities as abortion following a positive prenatal diagnosis indicating that the fetus has an impairment. Asch is adamant in her support for a woman's right to choose. She also acknowledges the eugenic implications of prenatal diagnosis and examines the relationship between this "quality

control" and attitudes about disability. Can a case be made for abortion following a positive diagnosis of a fetal condition that does not devalue people with disabilities? Asch calls for a synthesis of feminist and disability perspectives on human autonomy, just as Nsiah-Jefferson calls for the incorporation into the feminist agenda of the needs and perspectives of poor women and women of color.

Other slections in the book offer concrete policy proposals. Nancy Gertner presents an intuitively appealing but politically difficult reproductive rights statute. In addition to the difficulty of creating the kind of coalition she suggests, a rights-based strategy runs the risk of pitting one set of rights against another (e.g. maternal or women's rights versus fetal rights. This struggle is addressed by Janet Gallagher's selection on fetal medicine.)

A shortcoming of the volume is that policy implementation issues are not directly addressed, and the activist/strategist component of the academic and activist coalition responsible for the project is under-emphasized. While principled visions and comprehensive programs are crucial to the success of efforts to make and implement equitable reproductive policy, it is difficult to move from visions or policy proclamations (and even more cncrete suggestions such as the model legislation, jury protocols, proposals for health and safety regulatory reform, included in this volume--to the hard political work needed to transform these visions into reality.

The book could have been strengthened by a more comprehensive and detailed discussion of alliances and constituencies, change strategies and methods. The collection also would have been enhanced by the inclusion of a resources section, including a centralized bibliography (in addition to the references contained in footnotes in the individual articles) and a list of organizations involved in research, organizing, advocacy, lobbying, and education around these issues. Reflexive comments by the authors (themselves principal actors in the efforts for gender equity and reproductive justice) about their own work would also add a human dimension.

Despite these shortcomings, its presentation of broad policy guidelines and concrete recommendations, its attention to the complicated nature of the issues and its acknowledgement of the diversity of views on selected issues (e.g. surrogacy)make the volume an important one. For readers interested in the difficult questions associated with the development and use of new reproductive and neonatal technologies, the articles in this volume provide provocative food for thought and the book is an useful resource for teachers, students, activists, and policy makers. (Note: The Asch selection also includes a bibliography and a course outline.) The Rutgers project and all of its collaborators deserve thanks for

coordinating the efforts which led to this volume. (Robin Gregg, Heller School, Brandeis University)

P. Thompson, Karen and Julie Andrzejewski. Why Can't Sharon Kowalski Come Home? San Francisco: Spinsters/Aunt Lute, 1988, 227 pp., $10.95 paperback.

Forget Stephen King. For a real horror story, read Why Can't Sharon Kowalski Come Home? This chronicle of the aftermath of a Minnesota car crash, written by the victim's lover and a lesbian feminist educator, should shock not only lesbians and people with disabilities but anyone with a healthy fear of legal and medical tyranny.

As the authors report, a drunken motorist left Sharon Kowalski, then 27, with a severe brain stem injury in November 1983. News of the crash stunned Karen Thompson. Kowalski was "the person I loved more than anyone in the world," the woman who had "taught me how to laugh." Soon after the accident, on their fourth anniversary as a couple, Thompson wrote to her, "I pledge you my love for a lifetime."

During long hours of painstaking rehabilitation, Thompson helped her make considerable progress. While these session lasted, Kowalski "consistently indicated that she wanted to live me." Convinced that Kowalski remained a "vitally alive human being with potential--not a 'vegetable'," Thompson wanted to try caring for her at their home.

These hopes ended in a bitter battle between Thompson and Kowalski's parents, Donald and Della, over the issues of guardianship, access to Sharon and the extent of her disabilities. Sharon's father--her guardian--forbade visits by his daughter's lover, her attorney, many friends and disability rights groups. Thompson managed to see her once more in August 1985, when Kowalski typed a message: "Help me. Get me out of here. Please take me home with you." The women were not permitted to see one another until February 1989. At this writing, Kowalski is to receive 60 days of belated rehabilitation and evaluation, but her father remains her guardian.

Thompson and Julie Andrzejewski, both of whom teach at St. Cloud State, believe that prejudice and conflict of interest have fueled the legal fight. The parents and their attorney have denied that Sharon and Karen were ever lovers. The father's lawyer, acting on Donald Kowalski's behalf, argued that his other client--Sharon--ought not choose her own attorney, be tested for competency as state law required, or attend crucial court proceedings. Due process has apprently been flouted. For almost a year, Sharon lacked any attorney at all.

Fighting back, Thompson met insults. She has been portrayed by the parents and their allies as a predator. According to Publishers Weekly, Donald Kowalski called Thompson "an animal. As far as I'm concerned, they should

have locker her up long ago." He reportedly told The New York Times, "Karen Thompson has lied about everything."

Unlike gay and other alternative media, which grasped the story's significane early, major news organizations have shied away from coverage until recently. Some have adopted the pitying tone that disability activists loathe, writing, as the St. Paul Pioneer Press did in 1987, that the Kowalskis' "eerily silent daughter lies trapped in her twisted body."

Why Can't Sharon Kowalski Come Home? describes Thompson's transformation from fearfulness to activism. When she and Kowalski first met, Thompson was by her own account not just closeted but timorous. She had shunned activists such as Andrzejewski "like the plague," even remaining aloof from a sex discrimination suit affecting their own university. Now she began, under Andrzejewski's tutelage, to see lesbians and feminists as kindred spirits whose strength could revitalize hers and to emerge as a grassroots leader who recognizes that bigotry's victims must unite.

Often Thompson's speeches emphasized the legal measures that can lessen our vulnerability, whether we are lovers, spouses, or adult daughters with aged mothers. An appendix to the book addresses the granting of durable power of attorney and the choice of a medical decision-maker to act on our behalf in a crisis. "The convicted criminal loses only is or her liberty; Sharon Kowalski has lost the right to choose who she may see, who she may like, and who she may love." The MCLU has also warned that the case raises "fundamental questions concerning nursing home residents' and visitors' rights to free speech and association as guaranteed by the First Amendment . . ."

Why Can't Sharon Kowalski Come Home? is chilling. A loving couple has been riven, as if illegitimate. Years of precious rehabilitation time have been stolen from Kowalski, with the aid of smug meddlers from the legal and medical frat houses. In every intimate particular, two women have been relentlessly judged by strangers.

Yet the book is heartening, too. Thompson has come to see the merit in Andrzejewski's words:

> "Sexism, sexual harrassment, racism, ageism, handicapism, all the issues related." This system oppresses Sharon and me because we're women, we're lesbians, and Sharon is disabled. Anyone, in one split second, could become a Sharon Kowalski through accident or illness. The precedents being set in this case are establishing very bad case law . . . I tell you what has happened to Sharon and me not to depress you but to empower you. (p. 214)

Why Can't Sharon Kowalski Come Home? shows that history is made by passionate and inconvenient people.

The unabridged version of this review first appeared in The Women's Review of Books. To obtain the complete review, together with a column about the Kowalski case and a column about disability rights called "No More 'Supercrip,'" send $4.00 plus a long, stamped, self-addressed envelope to the author: Marie Shear, 282 East 35 Street, Brooklyn, NY 11203.

AUTHOR's I.D.

Marie Shear is a Brooklyn-based writer and editor whose work has appeared in more than 40 publications. She welcomes syndication inquiries about her column, "Media Watch." She has been writing about disability rights since the 1970s.

Q. Ungerson, Clare. Policy is Personal: Sex, Gender, and Informal Care. London: Tavistock Publications, 1987. 166 pp., $49.95.

Recent years have witnessed a flurry of activites that fall under the rubric of community care for various populations of persons deemed dependent. This trend stems from a preference for home and community settings over institutional ones from a humanitarian regard for life quality, as well as economic considerations of cost. Despite this enthusiastic reception among aging and disability advocates, others--those representing carers' concerns--criticize community care on the basis of its exploitation of unpaid labor of family members, especially women. Community care, they conted, has become a euphemism for care by female kin, and its provision imposes tremendous burdens--financial, social, physical, and emotional. This situation has attracted considerable attention in the academic literature and popular press.

In Policy is Personal: Sex, Gender, and Informal Care, British feminist scholar Clare Ungerson goes beyond the who aspects of caring to explore its why dimensions, the social processes behind decisions to care and how carers interpret and (re)construct their roles. Reporting on the findings of her study of nineteen carers--fifteen women and four men--in Canterbury, England, she illustrates the gendered and ranked nature of kinship obligations, within which carers emerge through a negotiation process, and elucidates the social, psychological, material, and historical processes that produced these particular caring relationships.

Ungerson stresses the material (i.e., employment situation, life cycle position, household resources) and the ideological (i.e., dominant view of women as nurturers) determinants in the decision to care. As for the material basis, she notes the important influences of life cycle position and, for women, the compatibility of caring with other parts of their lives, particulary paid work and unpaid

child care. On an ideological level, men and women differ in their descriptions of their motivations, with men using the language of love and women that of duty.

In what is perhaps her most interesting chapter, Ungerson examines the process of caring--how the different men and women in her sample make sense out of their caring situations. The male carers, all of whom cared for their wives, discussed techniques of caring in occupational terms. For them, the protective model of caring remained compatible with marriage. For women, the situation was far more complicated. Ungerson discusses issues surrounding various caring arrangements: spouse versus parent, same versus opposite sex. Power relationships became problematic when daughters care for their mothers; whereas the certian incest taboos may come into play when caring for blood relatives of the opposite sex. Ungerson raises issues about potential problems associated with the intimate care of close kin with a long history under different circumstances.

Thus, Ungerson contributes to the caring literature by describing, at material and ideological levels, the reasons for which the men and women in her study came to be carers and how they attempted to make sense of the situation. Acknowledging the limitations of her small sample, which comprised only carers, she laments the absence of information on non-carers--those who opted not to care--as a basis for comparison. Also, she attempts to address the relational aspects of caring; however, she focuses on only one party to the interaction, providers of care. Additional insight could have been gained through efforts to ascertain the perspectives of the recipients of this care. Nevertheless, Ungerson does broaden our understanding of the complexity of caring arrangements. Her important work highlights the need for considerable sensitivity in formulation of policies that are both adequate and acceptable to all involved. (Kim Smith, Heller School, Brandeis University)

R. Witt, Michael D. (ed.), <u>AIDS and Patient Management: Legal, Ethical, and Social Issues</u>. Owings Mills, MD: National Health Publishing, 1986. 263 pp. $36.00.

This book consists of brief summaries of papers presented at a conference on AIDS sponsored by Tufts New England Medial Center and Public Responsibility in Medicine and Research. The papers were originally presented on April 24-25, 1985 and have been revised to reflect more recent information. In addition, the book includes an introductory overview by Larry Gostin of the Harvard School of Public Health of the dangers of health policy measures currently under consideration or in use. A final section augments the conference materials with several sets of guidelines regarding precautions needed to avoid transmitting the AIDS virus to health care workers.

The book's sections discuss the response of public health authorities to AIDS; the ethical, legal, and pratical difficulties of doing research on AIDS; the legal dilemmas faced by individuals with AIDS; the impact of AIDS on patient, family, friends, and communtiy; the difficulties of protecting both the blood supply and the mental health and legal rights of persons who test positive for exposure to the AIDS virus; historical parallels to the AIDS crisis; and the cross-cultural manifestations of AIDS. As one might suspect from this list, the major (and overwhelming) problem with this book is its attempt to cover too much ground. As a result, the essays average only about two or three pages each. Anyone who is already familiar with the subject will find these essays redundant while those new to the field will find them unenlightening. (Rose Weitz, Sociology, Arizona State University).

BOOK AWARDS

A. 1988 Basker Award

The winner of the 1988 Basker Award is Emily Martin. Author of The Woman in the Body: A Cultural Analysis of Reproduction, published by Beacon Press, Martin is Mary Garret Professor of Anthropology at the Johns Hopkins University. The award and the $1000 prize were given to Martin at the Society for Medical Anthropology meeting in Phoenix.

The Basker Award, initiated to promote innovative work in the area of gender and health, is named in honor of Eileen Basker, who died in 1986.

B. 1989 Book Awards of President's Committee on Employment of People with Disabilities

Three books have been selected for the 1989 Book Award by the President's Committee on Employment of People with Disabilities. These books, selected from many titles, are outstanding resources for mainstream employment of qualified people with disabilities.

TOWARD SUPPORTED EMPLOYMENT: A Process Guide for Planned Change, by James F. Gardner, Michael S. Chapman, Gary Donaldson and Solomon G. Jacobson. Paul H. Brooks Publishing Co., Baltimore, Maryland.

In the past 20 years a trend toward community-based employment for persons with severe disabilities has grown. Toward Support Employment examines this concept and the dynamics of change that vocational rehabilitation programs face in the conversion to supported employment programs for persons with severe disabilities.

VOCATIONAL REHABILITATION AND SUPPORTED EMPLOYMENT, by Paul Wehman and M. Sherril Moon. Paul H. Brooks Publishing Co., Baltimore, MD.

Service delivery issues,

models, and philosophies in the concept of supported employment are assembled in this overview of the work history and status of persons with severe disabilities. Relationships are described which suggest that supported employment and other community-based vocational rehabilitation programs are similar to civil rights issues for persons with severe disabilities.

ECONOMICS, INDUSTRY AND DISABILITY, by William Kiernan and Robert Schalock. Paul H. Brooks Publishing Co., Baltimore, MD.

The complexities of contemporary economics, the demands of the labor market, the diminishing labor supply, and the changing employment patterns are variables which signal the employment expansion of persons with disabilities. By focusing on economics, industry, and people with disabilities, this book addresses key issues in the employment picture for adults with severe disabilities.

CLASSICS TO COME?

A. WOMEN WITH DISABILITIES: ESSAYS IN PSYCHOLOGY, CULTURE AND POLITICS, Michelle Fine and Adrienne Asch (Eds), Philadelphia, PA: Temple, 1988, 347 pp., $34.95 hard cover, $16.95 paperback.

WOMEN WITH DISABILITIES is a landmark book, signifying the development of a significant body of data and theory on women and disability. It is an excellent collection of essays. While not all contributors proceed from the same theoretical starting point, the editors have thoughtfully developed this collection out of their advanced and complex theories of both feminism and the disability rights movement, theories which also encompass the role of social class, race and sexual preference. They provide this understanding in a clear introduction and epilogue. A basic and underlying premise is the idea that both gender and disability are social constructions.

Divided into several sections, the book covers major areas of concern. From the first section, Bodies and Images, many readers will gain greater understanding of the bodily experience of disability, for example, from Gayla Frank's account of how a woman like Diane DeVries, born without legs and with arms developed only above the elbow, considered her body complete in itself--clearly a view in direct contrast to society's definition of her. Other papers in this section are of great value, and some are unexpected, for example, Deborah Kent's on images of women with disabilities in fiction and drama.

The section of Disabled Women in Relationships is rich and complex, ranging from a paper on The Construction of Gender and Disability in Early Attachment to one on Never Married Old Women and Disability. It also includes very interesting papers on such topics as disability and ethnicity and disability and

friendships between women. In this section, we see that women with disabilities are less likely than non-disabled women and disabled men to engage in the usual relationships society offers, such as a traditional dating and marriage. We see, too, an incisive commentary on these relationships.

Papers in the third section, Policy and Politics, include data documenting the extent to which disabled women are more disadvantaged than disabled men and non-disabled women in both the work world and by public policies. Here, as throughout the book, authors recognize (and include relevant information when available on) further disadvantage brought about by race and lower social class. The papers which conclude this section offer important ideas on policy and examine the possible tensions between some of the policies advocated by the women's movement and the disability rights movement, such as support for women's choice about abortion and the rights of disabled newborns to treatment.

This book is certainly essential for all women concerned with disabilities. It is also essential for all other women and men, disabled or not, because its depth of understanding of disabled women illustrates the experience of all women and men. (Jean Baker Miller, Stone Center for Development Services and Studies, Wellesley College)

B. Shilts, Randy. AND THE BAND PLAYED ON. New York: St. Martin's, 1987, XXIII + 630 pp. (paperback Penguin $12.95).

What Shilts does best, and what this book should be read for, is to lay out a damning indictment of US society's and government's non-response to AIDS. He explores the medical institutions--the Centers for Disease Control, National Cancer Institute, and National Institutes of Health, which most people rarely see, and details this superstructure of high level medical-scientific-epidemiological organizations which are supposed to deal with epidemic diseases. He traces the politics that kept them from functioning: pervasive homophobia, internal competition, and the fanatical budget cutting and callousness about human life of the Reagan administration. There was little in here that I did not already know about how the government ignored and mishandled AIDS, but I was enraged at each point in the book where it was further summed up. These sections make clear what I, like so many people, have to distance myself from on a day to day level in order to keep from going mad: our lives are considered meaningless by our own society, and our deaths do not matter.

Those of us in the AIDS activist community are, by now, used to make comparisons between the government's lack of response to AIDS and its response to other diseases such as Legionaires. Shilts presents this comparison bluntly, showing again and again how AIDS was left to spread because it hit gay men

first. He also details how the media ignored the epidemic, how the failure to report on it left people ignorant about the risks they could avoid and left the governmental agencies free to ignore AIDS.

SHILTS' STRAIGHTSPEAK

Shilts lays out the context of governmental, societal, and media non-response to AIDS which should set the stage for an understanding and explanation of the gay community's political response to the epidemic. It does not. Instead, the book is filled with constant references to "gay leaders," an unnamed, faceless bunch of people who the author criticizes constantly. "Gay leaders," by which Shilts seems to mean virtually all gay activists, cannot win in this book: they (we) are damned for everything they do and for everything they don't do, and they are damned, most ironically, for recognizing the politics of the epidemic, that is for refusing to ignore or deny that homophobia was shaping America's [non]-response to AIDS. This is the fundamental flaw of the book, the author's inability to accept that the gay community is justified in responding to homophobia and in saying that without dealing with homophobia we cannot deal with AIDS.

Shilts says again and again that the "gay leaders" and the gay community sidetracked society's response to AIDS, even as he describes how homophobia was the issue and how gay people created AIDS organizing. Because he is openly gay and has been reporting on AIDS for the San Francisco Chronicle for years, he is given a great deal of unquestioned credibility in the mainstream world as a gay spokesperson, a gay man who isn't afraid to buck those "gay leaders" and tell straight people exactly what they want to hear about the gay community. He shows no real understanding of the complex ways in which our society's longstanding homophobia and its more recent AIDS phobia quickly coalesced to create an ever more frightening scenario for gay people, from the perspective of discrimination and civil rights violations. He denigrates the very real issues of AIDS discrimination by creating a concept he mockingly calls "AIDS speak," ways of talking about AIDS which, he claims, only "confuse" the issues. (One example is the demand from the national People With AIDS coalition, who prefer the designation PWA to "AIDS victims," with its connotations of powerlessness.) Shades of 1984, only in Shilts' view it is the "gay leader" to whom he ascribes this great power to redefine language.

Although it should not bear repeating here, AIDS is not and never was a "gay disease." People have sexual orientations, diseases do not. This is not to say, however, that diseases do not have social contexts. The context of AIDS in the United States is that it hit the gay male community first and hardest and that, as Shilts has described, the homophobia of the media,

the government and the medical establishment enabled it to spread virtually unchecked. He does not examine, nor seem to take seriously, the details of that context, the backdrop of sodomy laws, lack of civil rights protection in employment and housing, immigration prohibitions, and custody problems that create a context in which gay lives are not taken seriously. This is the context in which thousands of gay men have to die before anyone outside the gay community bothers to notice.

Moreover, Shilts accepts the false dichotomy between civil rights and public health that has become a tenet of conservative and anti-gay AIDS efforts. "Some people might argue that there were civil liberties issues involved," says one of his favorite characters in an early discussion of the bathhouses, yet the author apparently never talked to anyone who could explain what those issues were. The same thing happens in the antibody testing debate later in book: it is called a "classic confrontation between public health and civil liberties." Civil liberties issues are never explored, nor is the public health argument ever put to the test, it is merely asserted.

What gay and AIDS activists have argued for years is that civil rights protections are a necessary part of any public health program. Anti-gay and AIDS related discrimination interferes with public health measures: people will not come forward for education, testing, or in some cases medical treatment, if they fear that as a result they could lose their job or home, be deported or lose visitation rights with their children. Public health concerns are not furthered by dismissing or trivializing people's very real fears.

PUBLIC HEALTH AND CIVIL LIBERTIES: THE TESTING DEBATE

The debate about education, public health and civil rights continues to escalate, especially in regard to antibody testing. Testing is the other area where Shilts believes there is a public health-civil liberties dichotomy. The risks of civil rights violation around testing are both greater and clearer, the public health arguments are both weaker and potentially more damaging. Once test results are in someone's medical file or are circulated in a workplace or neighborhood the information is never secret again. These issues need to be better explored than they are in the book because we will continue to face hard decisions about testing in the coming years.

The book criticizes and discounts any discussion of the civil rights issues raised in the gay community when the HIV antibody test was developed, despite Shilts' documentation of the years of governmental inaction and unwillingness to create confidentiality protections in order to guard against AIDS-related discrimination. The discrimination that gay activists were concerned about does not fall only on those who have been diagnosed with AIDS or ARC,

but also affects those who are antibody positive, those who have a record of having simply taken the test, and those who are, or are presumed to be, in high risk groups for AIDS. And by the time of the testing debate, such discrimination was not theoretical; there was already plenty of evidence showing that AIDS-related discrimination was common and on the rise.

The question of how to use the test is inextricably tied to the question of what the test reveals. It is easy to say, as is said in the book, that testing will stop the spread of infection; asserting this as a conclusion doesn't make it true. Nor does questioning that assertion mean, as Shilts believes it does, that control of the infection was "low on the list of gay concerns." No group experienced more intensively than the gay community what the epidemic meant; no group saw it as a higher concern.

In fact, Shilts describes areas where his "gay leaders" felt the test would be misused--insurance, the military, employment--and all of these scenarios have come to pass. The antibody test is now used to keep people out of the military, the Job Corps and the Foreign Service, and some states require antibody testing in order to get marriage licenses. Test results are pressed for in criminal trials, custody and divorce hearings, and in medical care settings where they may be the basis for decisions about whether or not or what kind of care will be provided. None of this is hysterical fantasy. It is real now, and was predictable three years ago when the test was first licensed.

Shilts comes back, periodically, to the notion of quarantine, using the concept to show, in his view, how foolish and "hysterical" gay activists were to think such a thing was possible. Yet the questions that remains open and is a topic for discussion by conservative and not so conservative politicians, including presidential candidates. Since the test was licensed we have seen a call on the op-ed page of the New York Times for tattooing all who are antibody positive, and we have seen quarantine proposals introduced in state legislatures. Civil rights concerns about the use of the test were not, and are not, overstated.

The HIV antibody test was developed and licensed to keep the blood bank system from unknowingly transfusing blood containing the HIV virus. For this purpose, and in combination with donor deferral requirements for at-risk people, the test works well. The risk of transfusion-related exposure has dropped dramatically in the US since testing blood donations went into effect.

This does not mean, however, as many people wish to believe it does, that the test can thus be useful in a wide variety of settings. American society is looking for an easy answer, an easy way out of this epidemic--one that separates "good" people from "bad" people, one that allows us to avoid talking about sex, to avoid dealing with drug treat-

ment programs which are needed on a massive scale, to avoid dealing with drug treatment about sex, to avoid dealing with drug treatment programs which are needed on a massive scale, to avoid dealing with the causes of widespread i.v. drug usage, to avoid making changes in sexual practices. Our faith in science, which is often overblown, and our reticence about sex, which cannot be overstated, join to make testing look like the perfect answer.

By Kevin Cathcart. Cathcart is a civil rights attorney. He is Executive Director of Boston's Gay and Lesbian Advocates and Defenders (GLAD) where he also coordinates the AIDS Law Project.

This review is excerpted from a much longer one appearing in Radical America, 1988, Vol 21, Nos. 2-3, pp. 48-57.

RESOURCES

E.D.G.E. (Education in a Disabled Gay Environment, Inc.)

By Cook Friedman
A commentary

Alex is a twenty-three year old man who has had cerebral palsy his entire life. While not totaly dependent, he lived at home with his parents and benefitted from their assistance, both financial and physical. Last summer Alex told his parents he was gay. They told him that he had one week within which to find a new place to live.

Susan has a multitude of birth injuries. She is non-amubulatory and has little upper body strength. She has no use of her left arm. A very beautiful woman, Susan has lived at home for the twenty-eight years of her life. Susan is lesbian and her parents and herself have never discussed the matter as she knows it would anger and confuse her strict Catholic family. The hostility and anger to her that underlies almost all of her family's interaction is, Susan believes, a result of their not being able to accept who their beautiful daughter is.

Many of the lesbians and gay men who attend the meetings of Education in a Disabled Gay Environment (EDGE) have compared being both gay and disabled to being in a double closet. On one front, they often endanger the conventional support systems provided by our society (family, church, mainstream support organizations for the disabled) if they let their sexuality become known and on another, they find, particularly if their disabilities are not readily evident, that they encounter fear and ostracism from the social networks that traditionally have supported them if they reveal that they are disabled. Able-bodied people, gay and straight alike, seem to have a combination of fear and pity--with a dollop of repugnance--for the people who look different, act differently and may not be physically attractive to their eyes.

The search for support is

resultingly difficult. The mainstream support organizations may offer groups for the people they service but it is a safe assumption the majority, if not all, of its members will be heterosexual.

Martin was diagnosed with multiple sclerosis when he was thirty-two years old. Like many who become disabled in mid-life he was in a state of crisis and panic. He found the support groups offered by the Multiple Sclerosis Society unacceptable to him; "I didn't want to enter a room where I would first have to explain and possibly defend who I am to the people I was looking to for support!! While there may not have been great differences in what we did. I didn't feel I could receive empathy from another 32 year old who could no longer care for their family because I could no longer participate in political demonstrations of go dancing!" Many of the lesbian and gay disabled find they have nowhere to look for support and assistance with the most fundamental aspects of their not being understood.

The gay and lesbian disabled find themselves facing physical barriers if they attempt to attend the limited socialization sites available to them. Clubs, bars and discos are ususally not accessible to the disabled and the activites therein are often ones in which they cannot participate. Even if the person on crutches or in a wheelchair or with a malformed body do decide to participate, the stares and curiosity they provide is, at best, unsettling and disturbing. If their limitations are not readily apparent it is almost certain that a long detailed explanation of them will be required by any new acquaintance. That rarely makes for light social chit chat and a comfortable atmosphere.

EDGE (P.O. Box 305, Village Station, New York, NY 10014) was founded in 1986 to address the needs and concerns of this special population. Its monthly scheduled meetings provide a comfortable and safe space where disabled lesbians and gay men can meet, socialize and discuss the concerns they have in common. Although the disabilities vary greatly, the concerns do not. Family relations, the perception of the greater community, sexual relations, feelings of self-worth and dependency on other are common to most. The anger that often accompanies these feelings is also openly spoken about. To be sure, many of these issues are common to every physically disabled human being but the comfort and freedom provided by a group of "your own," without explanations being required--or asked for--without fear of condemnation or homophobia is a strongly needed support for the disabled.

A. The AIDS and Anthropology Research Group (AARG) continues to hold regional round-table meetings around the country. These forums give anthropologists working in AIDS an opportunity to meet colleagues to discuss AIDS-related research and activities. If you are an AARG member and would like to organize

an AARG regional roundtable in your area, contact eithe Douglas Feldman at (305) 547-5710 or Norris Lang at (713) 749-3921.

Information about AARG is available by writing to AARG,c/o Moses Pounds, 1303 Northview Rd., Baltimore, MD 21218; (301) 328-7004.

B. AASECT, American Association of Sex Educators, Counselors and Therapists, 435 N. Michigan Avenue, Suite 1717, Chicago, IL 60611-4067, 312/644-0828. AASECT, founded in 1967 is a nonprofit educational association dedicated to the highest standards of education, training, ethics, and patient care in the diverse aspects of human sexuality. The membership includes physicians, psychologists, ministers, counselors, family planning specialists, nurses, social workers, educators, and others engaged in research, law, and the corrections professions.

The objectives of AASECT are to provide training and education in human sexuality and standards for sex education, counseling, and therapy programs.

C. AIDS Action is a new newsletter produced by the Appropriate Health Resources and Technologies Action Group, attempts to promote dialogue on how people are dealing with the AIDS crisis. Contact: AHRTAG, 85 Marlebone High St., London, W1M 3DE, U.K.

D. AIDS Alert, a new montly newsletter, aims to disseminate rapidly new information and development in AIDS research, diagnosis, treatmnet, prevention, legal issues and policy. Contact: AIDS Alert, Dept. 1301, 67 Peachtree Park Dr., NE, Atlanta, GA 30309.

E. "AIDS Bibliography" is a quarterly listing of new references on AIDS organized by subtopic. Contact the Superintendent of Documents, US Govt Printing Office, Washington, DC 20402.

F. AIDS HEALTH PROMOTION EXCHANGE is a quarterly Newsletter published by the Global Programme on AIDS of the World Health Organization. It is intended for those planning, implementing and evaluating AIDS health promotion programmes. The EXCHANGE provides an opporuntiy to learn about innovative approaches and evluation results from around the world. Health educators, communication specialists, social scientists and public health professionals working with AIDS health promotion programmes are invited to request their individual or organizational subscription free of charge from the Global Programmes on AIDS, WHO, 1211 Geneva 27, Switzerland.

G. "AIDS Knowledge and Attitudes for December 1987, Provision Data from the National Health Interview Survey" is available from NCHS, Science and Technical Information Branch, 3700 East-West Hwy, Rm I-57, Hyattsville, MD 20782.

H. AIDSLINE is a new database of 13,000 references to

scientific articles (dated 1980 to the present) about AIDS. Developed by the National Library of Medicine (NLM) and the NIH Office of AIDS Research, AIDSLINE adds to the list of health databases availabe through the NLM online network. Also worth noting, the NLM network offers GRATEFUL MED, a user-friendly microcomputer software program that makes online searches easy to peform. For information, contact NLM's MEDLARS Management Section at (800) 638-8480.

I. AIDS Newsletter publishes news briefs from the media and technical press on all aspects of AIDS 17 times a year. Contact: Bureau of Hygiene and Tropical Medicine, London WC1E 7HT, U.K.

J. AMERICAL JOURNAL OF PUBLIC HEALTH, January 1989, Volume 79, Number 1, Special Issue: Women's Health, including several articles on Breast Cancer.

K. Adrienne Asch has recently written an excellent chapter "Disability: Its Place in the Psycholgy Curriculum," rich in insights and bibliography which appears in Phyllis Bronstein and Kathryn Quina, Editors, Teaching a Psychology of People: Resources for Gender and Sociocultural Awareness, 1988, American Psychological Association, P.O. Box 2710, Hyattsville, MD 20784.

L. ASSOCIATION OF BIRTH DEFECT CHILDREN, INC. is part of the National Network to Prevent Birth Defects (NNPBD). This is a coalition of organizations which are dedicated to preventing environmentally caused birth defects. The Network shares information with members through periodic newsletters and bulletins.

M. "CDC AIDS WEEKLY INFOLINE" is a new free computerized AIDS information service and bulletin board. The service will contain detailed information on upcoming AIDS meetings internationally and a complete listing with addresses of all AIDS periodicals internationally. Information will be updated weekly. Contact Charles W. Henderson, Editor and Publisher, CDC AIDS Weekly/NCI Cancer Weekly, Editorial Office, P.O. Box 5528, Atlanta, GA 30307, (404) 377-8895.

N. THE COALITION ON SEXUALITY AND DISABILITY, 380 Second Avenue, 4th Floor, New York, NY 10010, (212) 242-3900, is committed to advancing the full social integration of people with disabilities. To accomplish this goal, we work to increase the availability of accessible, client-responsive sexual health information and services, and to change those public opinions and policies that hinder integration. As a network of people, both disabled and nondisabled, professionals and members of the community, we act as educators and as advocates for the right of people with disabilities to a full social and sexual life.

O. The Committe to Promote Writing in Disability Studies is pleased to announce the 3rd

edition of A Readers'/Writers' Guide to Periodicals in the Disability Field. An exhaustive listing of the magazines in the field, this latest edition, like the preceding, is aimed primarily at the writer, since it furnishes information on topics of current interest to the magazines, length of time for response, amount paid per article, etc. But, clearly, it will also be of interest to those who wish simply to become acquainted with the journals in the field. The Guide is also provided with a bibliography which lists articles of high quality in various areas of the discipline. Over the years, the Guide has become the standard referecne work on the outlets for publication of work on disability. Copies of the booklet are available from the Committee--at cost of $10 individual, $15 organization--by addressing your request to Professor J.L. Baird, Chairman, CPWDS, English Department, Kent State University, Kent, OH 44242.

P. **THE COMMITTEE ON THE SEXUALITY OF THE DEVELOPMENTALLY DISABLED** is a non-profit organization founded in 1974, governed by a volunteer Board of Directors of parents, consumers and professionals who are concerned about the sexual rights and needs of persons with developmental disabilities. Contact:

The Committee
58 Diablo Creek Place
Danville, CA 94526

Q. DateABLE is a dating service and social club for people with and without physical disabilities. It was founded because existing dating services in the Washington area refused to include people with disabilities. In addition, to matchmaking, there are large parties and small gatherings such as book club meetings and theatre outings. DateABLE began in Washington, DC two years ago. Subsequently, chapters evolved in Cleveland, Ohio and San Antonio, Texas. For people in other communities who are interested in starting a DateABLE chapter, information and assistance are available by writing to: DateABLE, Two Wisconsin Circle, Suite 530, Chevy Chase, Maryland, 20185.

R. DYKES, DISABILITY & STUFF
'cause we always have stuff to share
P.O. Box 6194, Boston, MA 02114

Subscriptions to Dykes, Disability & Stuff quarterly are available in both print and braille editions for $8-$20+/-year/individual, $25-$50/year-/institutional-organizational (U.S. funds, please). Our aim is to make DD&S available free to women in institutions by our second year and we acknowledge the fixed-income limitations of many women with disabilities. We have, therefore, priced DD&S with a wide, inclusive sliding scale. All monies above the subscription price will be accepted as donations. Thank you!

S. NATIONAL TASK FORCE ON SEXUALITY AND DISABILITY, an

ad hoc committee of the American Congress of Rehabilitation Medicine and a publisher of Sexuality Update, a digest of recent research and information. Its editor is

Nathan D. Zasler, M.D.
Department of Rehabilitation Medicine
PO Box 677, MCV Station
Richmond, VA 23298]

The task force's key objective is to provide a forum for the exchange of ideas and information among health care workers and the lay populace regarding sexuality issues in physically challenged persons.

T. The Population Crisis Committee has issued a new Population Briefing Paper, "Country Rankings of the Status of Women: Poor, Powerless and Pregnant." The 10-page report and an accompanying four-color wall chart illustrating 20-scaled indicators of health and well-being among women in 99 countries (92% of the world's female population) is available from the Committee at 1120 19th St NW, Washington, DC 20036. Specify ISSN 0197-2235 BP-20.

U. SIECUS The Sex Information and Education Council of the U.S. Siecus is a private, non-profit, educational organization established in 1964 to promote healthy sexuality as an integral part of human life.

- SIECUS Information Services and Library responds to thousands of requests--in person, by telephone and by mail--for information each year. Its resource facility, the Mary S. Calderone Library, was established in 1978 in affiliation with New York University's Department of Health Education and contains 3,500 books, 50 periodicals, 500 pamphlets, and 200 curricula. A computerized database service is now being established to augment the work being done by the SIECUS Information Service.

  The SIECUS Report, its bimonthly journal, contains articles on the latest programs, research, and political issues related to sexuality. It also provides the reader with resource, workshop, and conference listings; book and audiovisual reviews; and bibliographies in specialty areas. All members of SIECUS receive the SIECUS Report as one of their membership benefits.

SIECUS also publishes bibliographies of current human sexuality materials in over 80 special categories. Two of special interest are a March 1986 "Sexuality and Disability (6 pages nearly 100 items) and "Sexuality and the Developmentally Disabled" (Nov-Dec 1988 3 pages 25 items).

SIECUS, New York University, 32 Washington Place, New York, NY 10003

V. THE SOCIETY FOR THE SCIENTIFIC STUDY OF SEX (P.O. Box 208, Mount Vernon, IA 52314, (319) 895-8407)

The Society for the Scientific Study of Sex is dedicated to advancing knowledge of sexuality. To acquire that knowledge the Society requires freedom of inquiry, support for research, and an interdisciplinary network of collaborating scholars. The Society believes in the importance of both the production of quality research and the application of sexual knowledge in educational, clinical, and other settings. The Society also sees as essential the communication of accurate information about sexuality to professionals, policy makers, and the general public.

More specifically, with regard to the Society's approach to the issue of disability, Richard Friend, Chair of its Annual Meetings Policy Committee, has stated that his committee is discussing the issue of including disability in its policy of non-discrimination. Under current discussion is the policy statement which assures "that the hotel, or other conference site, does not discriminate based on race, color, national origin, creed, religion, sex, age, gender, sexual orientation or marital status." It has been suggested that "disability" be incorporated in the statement of non-discrimination. There is strong support for this recommendation among the members of the Annual Meeting Policy Committee, and that addition will most likely be approved by the Society's Board of Directors at their next meeting in November, 1989.

W. Critical Reviews of Gender and Anthropology: Implications for Research and Training will be out in late summer 1989. Reflecting diverse theoretical positions on gender studies, the guide contains 18 chapters, each consisting of a comprehensive theoretical essay, ideas for curriculum use, and annotated bibliographies of published literature and audiovisual suggestions.

Sandra Morgen (Massachusetts-Amherst) is director of the Gender and Anthropology Curriculum Project, sponsored by the AAA, which coordinated and produced the Critical Reviews. Copies may be reserved now by writing to her c/o Gender and Anth Curriculum Project, 208 Bartlett Hall, U Massachusetts, Amherst, MA 01003.

X. WOMEN'S AGE PAGE COLLECTION AVAILABLE

The National Institute on Aging (NIA) has assembled a collection of Age Pages of particular interest to women. These fact sheets provide information and resources related to self-care and prevention practices. The titles included are:

Skin Care and Aging
Urinary Incontinence
Arthritis Advice
Osteoporosis: The Bone Thinner

Preventing Falls and Fractures
Should You Take Estrogen?

The information contained in each Age Page will assist women in making educated choices about their health care. For example, "Should You Take Estrogen?" discusses the pros and cons of using hormone replacement therapy for symptoms of menopause and preventing osteoporosis. Another Age Page, "Skin Care and Aging" advises women on how to keep their skin healthy in later years and on avoiding such common problems as dryness and itching and possibly skin cancer.

To obtain this free collection of Age Pages, write to the NIA Information Center/Women's AP, 2209 Distribution Circle, Silver Spring, MD 20910; or call (301) 495-3455.

Y. THE PROJECT ON WOMEN AND DISABILITY, One Ashburton Place, Room 1305, Boston, MA 02108

Project on Women and Disability members have been busy providing training information and referral and publicity on women and disability issues this past year. It is now over a year since we received our first funding. We are proud to announce that our First Year Report 1988 is complete and available to those who request it. j We are especially proud that we did it ourselves; text, graphics, typesetting and artwork were all by PWD members Catherine Lohr, Cindy Kunz and Marsha Saxton. MRC kindly agreed to publish it for us.

If you want to take leadership on a project about women and disability, PWD can help in the following ways:

- a 500 name mailing list to advertize activities and events.
- training and supervision to women starting up or leading an on-going group, and
- technical assistance for women's organizations or agencies on accessibility and attitudinal issues.
- training for disability organizations about identifying and combatting sex-bias.

We can match you up with resource people or "mentors" for your project.

END NOTES

THE SITUATION OF WOMEN WITH DISABILITIES: IS THERE AN ISRAELI PERSPECTIVE?

Nira Dangoor, Kubbutz Ein Hashojet, Israel

This article is an initial attempt to assess the situation of disabled women in Israel, a state which was established 41 years ago and today numbers 4.5 million citizens. During the first fifteen years of statehood the basic legislation pertaining to the disabled (due to all causes) was passed. In accordance with the laws of the

country, this legislation does not discriminate on the basis of race, sex, religion or age.

The Disability Law (Benefit and Rehabilitation) (1959) delineates the responsibility of the state towards those disabled while serving in the military. This law assures medical treatment, permanent monthly stipends and comprehensive rehabilitation services to any person injured while a member of the Israel Defense Forces or any other security forces. The implementation of this law is in the hands of the Veterans Administration of the Ministry of Defense.

The National Insurance Institute (NII), under the auspices of the Ministry of Labor and Social Affairs, is responsible for a number of disability insurance plans which are designed for the general public. The great majority of Israelis pay these insurance premiums through their place of work.

The Employment Injury Benefit Law was passed in 1954. In 1974 the General Disability Benefit Act was passed and at the same time, programs for treating the victims of hostile action were developed. The NII also pays benefits to disabled children and in 1987 became responsible for the implementation of the Long Term Care Insurance Law, which insures treatment and services to the disabled aged.

In the various bodies which are involved in rehabilitation services, the professional work force is composed mainly of social workers, 80% of whom are women (the profession of Rehabilitation Counsellor does not exist in Israel).

The Veterans Administration serves approximately 8,600 disabled veterans whose medical disabilities range from 30% upwards. Of this number, 190, or about 2.21%, are women. Although women as well as men are drafted into the armed forces, they rarely participate in combat and therefore the V.A.'s services are designed mainly for a male population.

Of the women who receive General Disability Insurance, about 7,000 are included in the Plan for the Disabled Housewife, which provides a monthly payment and special attendance allowance in accordance with the degree of medical disability and impairment of ability to fulfill basic housekeeping tasks. (Achdut, 1988) Full disability, according to the General Disability Plan, (including housekeeping services to the disabled housewife) entitled the recipient to a sum equivalent to 25% of the average monthly wage in the public sector of the economy, which today is the income which defines the poverty line in Israel.

In general, the state rehabilitation services are well acquainted with this population which comprises tens of thousands of women. Unfortunately, however, there is virtually no professional literature or research in Israel concerning the characteristics, experiences and special needs of these women. Perhaps the paucity or absence of rehabilitation research regarding disabled women in Israel,

as in other countries, reflects among other things the fact that most rehabilitation programs were developed for men (although all the services offer equal coverage to women). It is not surprising, therefore, that the research that is conducted in Israel is mostly male-oriented, or lacking any specific orientation for disabled women. There are several studies, however, which did not specifically investigate the characteristics of disabled women as part of their target sample, but cited a number of demographic findings which yielded information concerning the marital status and employment of the women in the sample.

Florian & Kening (1981) showed the low percentage of women (17.9%) as opposed to men (82%) in a national survey of applicants to Vocational Rehabilitation Centers of the Ministry of Labor and Welfare (although the number of disabled women is approximately equal to that of disabled men). In a sample of 762 people receiving General Disability Benefits (not including the Disabled Housewife Benefits), Taler (1986) found that more women (73%) than men (64%) were unemployed. In 1985, Gordon found, in a study of 5,106 people who received treatment in the rehabilitation facilities of the NII, that 75% of those treated were men as opposed to 25% women. In contrast to the men (7%), many of the women (33%) were separated, divorced or widowed. She also found significant differences in the rate of employment upon completion of the rehabilitation program: 29% of the women as opposed to 41% of the men.

The author of this survey notes, after a considerable number of meetings with other professionals in the field, that in Israel there are no programs which specialize in guidance and counselling to disabled women or the subjects of family planning, pregnancy and birth, sexual functioning and preparation for parenthood. This may be a reflection of an attitude of non-acceptance of disabled people as partners for an intimate, sexual or marital relationship which is prevalent in the general public. This negative attitude is even more prevalent towards the disabled woman than the disabled man. (Weisel & Florian, unpublished manuscript, 1988)

These findings acquire added relevance in light of findings by Yisraeli and Tavori (1987) in which participants were asked to rank fifteen subjects as to their importance as social problems. Although economic and security subjects were not listed, the participants perceived subjects like crime, unemployment and traffic accidents as the major problems of life in Israel today, and the subject of the status of women was not ranked at all. An example that supports these findings is that in Israel's newly elected government there is not even one woman and in the Knesset, out of 120 members, only 5% are women. It follows that the subject of the status of women in Israel is not the concern of any significant political or social body (and even less so in regard to the

status of the disabled woman).

In Israel, the Independent Living Movement has not yet developed and most of the organizations for the disabled focus mainly on gaining benefits and cultural activities but not on the political/social level.

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DISABILITY AND MASCULINITY

by Harlan Hahn
Department of Political Science, University of Southern California

As a man who has both studied and lived with visible physical difference for most of my life, I could hardly decline an invitation to write about masculinity and disability for this issue on "gender." After all, there are few issues of greater personal or professional concern.

Although these comments are more of a personal statement than an academic study, I cannot begin without referring to the pathbreaking examination by Adrienne Asch and Michelle Fine of "sexism without the pedestal." Their analysis revealed that since both of the characteristics defining women with disabilities have been conventionally associated with weakness, they are doubly marginalized. Hence their oppression is also obviously greater than the disadvantages experienced by men with disabilities.

But if women with disabilities are subjected to twice as many burdens, disabled males must be at least conflicted. They combine one trait (maleness) which is considered strong in this culture with another attribute (disability) which is usually regarded as weak. Understandably, in an effort to cope with this stress, many disabled men

have tended to identify personally and politically with the supposed strength of prevalent concepts of masculinity rather than with their disability. As a result, they have not only failed to ally themselves closely with the interest of disabled women or of women in general, but they have also frequently been compelled to pretend that their disability is only a minor or secondary factor in the major problems that they confront.

Much as they would prefer to deny it, the unavoidable reality is that men with disabilities are significantly devalued in modern society. This devaluation occurs not only in the labor force, where disabled men are often prevented from fulfilling the traditional role of "breadwinner," but also in the social marketplace, where they frequently are deprived of romantic partners and lasting companionship. Both forms of exclusion may result as much from aesthetic aversion to a different physical appearance as from limitations on functional capabilities.

The tendency to identify solely with a conventional notion of maculinity and to deny their devaluation has created both personal and political difficulties for men with disabilities. The impact has probably been most devastating in the latter respect. While numerous disabled females have understandably identified with policy aspirations endorsed by the women's movement, many of their male counterparts have not found a genuine basis for political mobilization. If they attempt to vote or to lobby government officials at all, their proclivity to form electoral preferences on occupational interests, inherited loyalties, charismatic candidates, or other relatively irrelevant considerations has fragmented this segment of the electorate and impeded the formation of a cohesive constituency capable of exerting effective influence on disability policy in the same way that other disadvantaged minorities have voiced their position on issues that affect them directly.

But many disabled men have been no more successful at a personal level. Some have alienated women by their excessive reliance on a precarious manliness. Others have attempted to substitute vocational goals for personal satisfaction or fulfillment. And perhaps most have persevered in a vain--and possibly futile--search for an attachment founded on false premises with a partner who is willing to collude with them in the flimsy denial that their disability has any significant effect on the formation of such relationships.

To escape from these untenable predicaments, disabled men need to redefine their identity. I personally believe this aim might be achieved most effectively by an intensive effort to create alternative processes of socialization encouraging others to interpret conspicuous signs of physical difference or disability as an aethetically pleasing characteristic, which would both enhance personal attractiveness and establish a political identity based on

dignity and pride comparable to the "black-is-beautiful" movement of the nineteen-sixties. But, since I realize that this may be a controversial and seemingly distant goal, let me propose a relatively modest and immediate objective.

I think, ironically, that men with disabilities can acquire strength by acknowledging weakness. Instead of attempting to construct a fragile and ultimately phony identity only as males, they might have more to gain--and little to lose--both individually and collectively by forging a self-concept about the concept of disability. Certainly this approach requires the exposure of a vulnerability that has been a primary reason for the elaborate defense mechanisms that disabled men have commonly employed to protect themselves from the pain of repeated rejection, but the risk seems justified. Enduring personal and political relations might be most appropriately pursued with persons who respect emotional sensitivity rather than muscular strength, unswerving purpose rather than unrestrained power, internal values rather than external appearances, and intellectual integrity rather than idealized images. Fundamentally, there is a "moral strength" in corporeal weakness that appears to be the most important asset which disabled men can present to the rest of society.

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