

Editor, Irving Kenneth Zola, Ph.D.
Assistant Editor, Joanne Seiden

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THE DISABILITY AND CHRONIC DISEASE QUARTERLY

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As usual, we are trying to develop and adapt to new needs and demands. With the increase in your participation and the growing availability of materials, we became a quarterly in January. To reflect this, with the April issue we change our name to THE DISABILITY AND CHRONIC DISEASE QUARTERLY. We will remain a free periodical for as long as possible. And during the coming year we will continue to explore sources of funding. Given the labor intensive nature of our operation, however, we feel a word processor with a good printer will be a high priority for the future. Currently the cost for printing and postage per issue for U.S. and Canadian subscribers is approximately \$.50, while for foreign readers it rises to \$1.50. Also while back copies are still available, we often cannot take advantage of bulk mailing, so the cost for U.S. and Canadian subscribers is \$.65 per issue. Thus, dear readers, any monetary donations will be greatly appreciated. Checks can be made out to Brandeis University/Disability and Chronic Disease Quarterly and sent to Professor Irving Kenneth Zola, Department of Sociology, Brandeis University, Waltham, Massachusetts 02254, U.S.A. Donations are tax deductible.

Again, please keep your suggestions, criticisms, and contributions coming. And our sincere thanks and appreciation to our regular and new contributors and support people.

The Editors

FOCUS

Pitfalls of Prevention

by Peter Conrad (Soc. Brandeis University)

Prevention is becoming a medical watchword in the 1980s. Government, the health insurance industry, and the medical profession are joined in extolling prevention as at least a partial solution to our health care crisis. The Surgeon General's report Healthy People (1979) proposes specific goals for health promotion and disease prevention into the 1990s. U.S. Secretary of Health and Human Services, Richard S. Schweicker, has declared that prevention is "first and foremost on my agenda for health."

It is easy to cheer for a call for a more prevention oriented approach to health care. The sick care approach that has dominated Western medicine has dwarfed preventive efforts. Sure there has been public health, but its mandate has been limited mostly to pure food and water, sanitation, epidemic control, and to a lesser degree screenings and vaccinations. And in terms of expenditures for health, less than 5 percent has gone into prevention.

These newer approaches to prevention explicitly maintain that the key to prevention is found in lifestyle and social behavior. Social scientists of health can find a certain amount of vindication here. With the increasing emphasis on chronic illness and disability, there is a renewed interest in the complex etiologies of these disorders. And while many of the etiologies remain a mystery, a consensus is growing that changes in health behaviors are the primary prevention that medicine is seeking.

The model is to change people's behavior and prevent the disease. We now see notions about changing diet, stopping smoking, reducing stress, exercising, wearing

seatbelts, limiting substance abuse, and the like as almost a panacea of prevention. Lifestyle and bad habits are seen as the culprits and individual behavioral change toward health habits, the goal. No doubt changes to healthier habits can improve individual health but refocusing prevention in this particular manner raises some thorny issues. There are at least four which are worthy of attention.

First, an emphasis on individual responsibility for changing lifestyle and health habits provides an ideological justification for reducing medical services. At a time when medical inflation continues unabated and medical care takes nearly 10 percent of our GNP, there are repeated calls for controls on health costs. In the wake of ineffective cost controls, preventive action is promoted as a cost-effective strategy. Thus by suggesting that individuals rather than the medical system are responsible for health, we have a convenient rationale to cutback on medical services provided.

Second, by focusing on the individual, behavioral prevention decontextualizes behavior and risk from the social fabric. For example, behavioral prevention does not seriously consider the cultural meaning of cigarettes or disease promotion by the cigarette industry, much less the heavy government subsidies for growing tobacco. Is it sensible to attempt to prevent smoking while ignoring the profitable and well-connected tobacco industry? To take another example, we define "Type A Personality," which seems to raise the risk of coronary heart disease, as a characteristic that inheres in individuals rather than looking at the work, home, and cultural condition which engender Type A behavior.

Third, focus on the individual increases the potential for victim blaming. Holding people responsible is only a precarious half-step away from blaming them, and we often fall into that too easily. We blame smokers for their smoking, the pregnant adolescent for her lack of prenatal care, the obese patient for his/her indulgence and lack of control, workers for their inability to manage stress, and the working class mother for a diet of convenience foods, twinkies and soda pop.

Fourth, when we focus on prevention as changing health habits we begin to be more explicit about our moral judgment. This behavior is good; this one is not. We begin to develop notions akin to "sickness as sin" and "health as salvation." Some behaviors are seen as deviant and bad. In some circles smoking has almost reached that status; perhaps eating sugar and processed foods or drinking coffee is next. Our long experience with alcoholism should sensitize us to the fact that moral condemnation rarely changes behavior and only alienates people from one another.

No one is against prevention. But the pitfalls of behavioral prevention can make preventive work counterproductive for health. If we are serious about prevention, we need to look beyond unhealthy habits to the structures of society that support and sustain them. By reconceptualizing prevention in this way we can begin to reveal the complex connections between society and health that are obscured when we see changing lifestyles and behaviors as the key to a healthier society.

COMING EVENTS

- A. SSCIID (Society for the Study of Chronic Illness, Impairment and Disability), First Annual Meeting, April 25-28, 1984, San Diego, CA

The SSCIID is a new professional society dedicated to promoting the growth of social scientific knowledge (theoretical and practical) about impaired persons in society. It will attempt to pursue this goal through forums where social and behavioral scientists can gather and discuss their research. Previous meetings were held under the auspices of the Western Social Sciences Association (see DCDQ, 1/84 issue, p. 3) under the sponsorship of the Sociology Division. The 1982 and 1983 meetings brought together sociologists, anthropologists, documentary

film makers, nurses, psychologists, and professionals providing services to people with a wide range of impairing and disabling conditions. This year's meeting will again take place during WSSA sessions.. The sessions are organized so that at least 2 different social science disciplines are represented on a panel with no one session focusing on a single impairment/disability. Besides papers, there will be open discussion and documentary films. Contact: John Seidel, Sch of Nursing, Univ. of Colorado, 4200 E. 9th, Denver, CO 80262, 303/394-8661.

- B. Seventh Annual Renal Conference "Maximizing Rehabilitation in Chronic Renal Disease: Innovative Therapies and Programs", April 26-27, 1984, Ritz-Carlton Buckhead, Atlanta, GA
Sponsored by Emory Univ. Sch of Medicine, it will review the contribution of home dialysis, CAPD, CCPD, and transplantation to rehabilitation of chronic renal disease patients. Innovative programs to improve dialysis consumers' physical functioning, psychological and social functioning, and vocational success will be presented. Contact: Ethel B. Warner, Ctr for Rehab Medicine, 1441 Clifton Rd NE, Atlanta, GA 30322, 404/329-4809.
- C. "Physician-Writers: Can One Serve Apollo Two Ways at Once?", April 27-28, 1984, Univ. of Connecticut Health Care Ctr, Farmington, CT, Keller Auditorium
A 2-day conference devoted to the study of the relationships between literature and medicine through the non-scientific works of physician-writers (e.g. Robin Cook, Walter Percy, Samuel Shem, William Carlos Williams) with physician-writer speakers and 3 distinguished literary critics. Contact: Cecile J. Volpi, Continuing Education Coordinator, Univ. of Connecticut Health Center, Farmington, CT 06032, 203/674-3340.
- D. "Human Rights and Mentally Disabled Individuals" Conference , April 28-29, 1984, Framingham State College, Framingham, MA
This Mass. Dept. of Mental Health and the Center for Law and Health Sciences, Boston University School of Law conference will feature nationally known speakers and over 30 presentations on a wide variety of topics related to human, legal, and civil rights of individuals with mental disabilities. Contact: Larry Wheeler, Clients Rights Unit, Mass. Dept. of Mental Health, 160 North Washington St., Boston MA 02114, 617/727-9863.
- E. 9th International Congress of Physical Medicine and Rehabilitation, "Rehabilitation Medicine: The Bridge Between Medical Science & Society", May 13-18, 1984, Jerusalem
Topics include: Cerebro vascular accident, traumatic brain injury, aphasia, degenerative diseases of the central nervous system, spinal cord injury, peripheral neuropathy, myopathic disorders, electrodiagnosis, kinesiology, rheumatology, rehab of the amputee, cardiac rehab, sex rehab, hand rehab, sport & disability functional assessment in rehab, pediatric rehab, basic research in rehab, training & educ. in rehab, ethical aspects of rehab, respiratory disorders, pain, rehab of war injuries, geriatric rehab. Some of the speakers include Paul Bach-y-Rita and Carl V. Granger (USA), John V. Basmajian (Canada), Axel Fugl-Meyer (Sweden), Kurt A. Jochheim (W. Germany). Contact: THE SECRETARIAT, 9th International Congress of Physical Med & Rehab, P.O.B. 50006, Tel Aviv 61500, ISRAEL.
- F. "National Industrial Rehabilitation Institute on Chronic Disease in the Work Place", June 5-7, 1984, Stouffer's Dublin Inn, Columbus, OH 43017
Sponsored by the International Center for Industry, Labor and Rehabilitation, the 3-day conference will be an in-depth forum for the development of skills, concepts, policies and practical strategies to reduce the economic and personal impact of chronic health problems in the workplace. Special attention will be paid to the development of corporate responses to the management & rehab issues related to chronic backache, arthritis and heart disease. Each session (combination of information sessions & small

work groups) will be directed by a national leader in the field of chronic disease in the work place. Registrations accepted until May 27, 1984. Contact: Kenneth Mitchell, PhD, Conference Director, ICILR, 188 Stonefence Lane, Dublin, OH 43017, 614/889-0781.

- G. 8th Annual Post-Graduate Course on the Rehabilitation of the Brain-Injured Adult and Child, June 7-10, 1984, Medical College of Virginia-Virginia Commonwealth Univ.
The conference will address various aspects of the rehab of the traumatically brain-injured adult and child through plenary sessions, small groups, panel discussions, roundtables, poster & paper presentations. Focus will be on presenting information related to clinical skills in treating the brain-injured adult and child; describing & discussing innovative treatment approaches & techniques; presenting research data; providing a forum for exchange of ideas among professionals. Contact immediately: Sheri Rosner, Office of Continuing Medical Education, Box 48-MCV Station, Richmond, VA 23298, 804/786-0494.
- H. First National Meeting of the Assoc. for Health Services Research & the Foundation for Health Services Research, "Health Services Research & Public Policy", June 11-12, 1984, Hyatt Regency O'Hare, Chicago, IL
Topics include issues in prospective payment, system responses to regulation and competition - the development of alternative delivery systems; health care for the poor in an era of retrenchment; long term care; an assessment of the cost-effectiveness of alternative treatment settings; findings from the Rand National Health Insurance Experience. There will be a series of intensive workshops designed to update participants' research skills as they study these issues. Contact: Foundation for Health Services Research, 2233 Wisconsin Ave. NW, Suite 525, Washington, DC 20007, 202/625-2624.
- I. "Innovations in Special Education", Summer Sessions at Syracuse University, July 9-20, 1984
This is an intensive 2 week, 3 credit course (SPE 600) designed to focus on major new developments in the field that promise major change for how we educate students with disabilities. Some topics include: the new image of disabilities; culture redefined; computers and their promise for special education; disabled people speaking for themselves; lessons for the human services; functional programming and other theories of curricula construction; the revolution in education for autistic students: from medical to educational models; models for transition from high schools to the work place; normalization ten years later: a look into the future; the integration imperative: lessons for how schools integrate students with the most severe disabilities; reforms in classroom organization; process consultation: applications to special education. The course is taught by Prof. Douglas Biklen, Director of the Division of Special Education and Rehabilitation at Syracuse University. Selected consultants will participate in several of the presentations. Cost is \$647 (219 per credit). Audit fee is \$394. Contact: Douglas Biklen, Director, Division of Special Education and Rehabilitation, 805 S. Crouse Ave., Syracuse, NY 13210.
- J. 1984 International Health Conference "International Health and Family Planning" June 11-13, 1984, Washington, DC
Contact Ms. Barbara Kohl, NCIH Conference Coordinator, 2100 Pennsylvania Ave, NW, Suite 740, Washington DC 20037 for information and call for abstracts of papers for presentation (Note: the latter call for paper abstracts may already be past due).

- K. "Institutional Ethics Committees and Health Care Decision Making", June 14-15, 1984, Hyatt Regency, Cambridge, MA

Intended for physicians, administrators, nurses, attorneys and clergy desiring up-to-date, practical guidance on the establishment of ethics committees, the American Society for Law and Medicine will conclude its four-part series of conferences to discuss the roles and functions of ethics committees in all types of health care institutions. Contact: American Society of Law and Medicine, 765 Commonwealth Ave., Boston, MA 02215, 617/262-4990.

- L. "The Social Effects of Computers" June 15-16, 1984, Rochester, NY

Sponsored by the University of Rochester, NY, the conference will look at papers that report research and evidence on the questions: Have computing and computers had any social effects? If so, what have been the effects? Contact: Dean Harper, Dept of Sociology, Univ of Rochester, Rochester, NY 14627.

- M. First Annual Summer Institute on Women, Health and Healing, July 8-21, 1984, Berkeley, CA, Univ. of California

The Institute will bring together specialists in a variety of disciplines related to women's health who will work with participants on issues faced in teaching courses in this area. Sponsored in part by the Dept. of Social & Behavioral Sciences at the Univ. of California, San Francisco's Sch of Nursing, the Institute is part of a larger project on Women, Health and Healing. Contact: Patricia Anderson, Project Coordinator, Women, Health and Healing Project, Dept of Social & Behav Sciences, Sch of Nursing, Univ of California, San Francisco, CA 94143.

- N. "The Dynamics of Health Service Systems: Strategic Planning for Complex Health Organizations", July 23-27, 1984, Massachusetts Institute of Technology, Crambridge, MA

Offered by the faculty of the Sloan School of Management and distinguished visiting faculty, the program is intended for health care administrators, practitioners, and educators interested in pursuing new approaches to health systems problems. Contact: Director of the Summer Session, Room E19-356, MIT, Cambridge, MA 02139.

- O. "Management of Medical Technologies and Health Care Practices: Development, Utilization and Costs", July 30-August 3, 1984, Massachusetts Institute of Technology, Cambridge, MA

Another summer program offered at MIT, this session is geared to health care managers and policy makers faced with resource allocation decisions and the acquisition of medical technologies, biomedical scientists and engineers in academia and industry who are interested in medical applications of their research and medical practitioners who would like to better understand the current use of analytic tools such as cost/benefit analysis and decision analysis applied to health problems. See contact above.

- P. "Biopsychosocial Dimensions of Physical Rehabilitation", May 17-18, 1984, Sheraton-Tara Hotel, Braintree, MA

Sponsored by Braintree Hospital (an intensive phy rehab ctr), the Conference will present and discuss progressive concepts of diagnosis, assessment and treatment that affect the biopsychosocial adjustment of the physically disabled person from the onset of injury through the rehab process to re-entry into the community. Format includes formal lectures by specialists in rehab med and workshops. Regis. by April 15, 1984. Contact: Barbara McKenney, Pub Relations Dept, Braintree Hosp., 250 Pond St., Braintree, MA 02184 or call 617/848-5353 or 848-5363 x300 or x358.

RETROSPECTIVES

- A. First International Meeting of Medical Sociologists in Hungary, "Polish-Hungarian Medical Sociology Meeting, May 31-June 1, 1983
L. Csaszi of the Dept. of Medical Sociology, Budapest Medical Sch, Hungary, reported in Social Science & Medicine, Vol. 17 of this important meeting. Both Poland and Hungary are communist countries. This means that the problem of their health care systems and the situation of medical sociology are similar. But whereas Poland has a long tradition in medical sociology, Hungary has not. The first medical sociology unit was established at the Budapest Medical Sch only in 1980. During the meeting, the following lectures were given: C. Labanowska (Warsaw) on "The attitudes of medical students towards educational system at medical school seen against a background of their life values"; J. Halik (Warsaw) on "Medical care as social behavior" (He distinguished Warsaw inhabitants according to their use of the medical system.); B. Uramowska-Zyto (Warsaw) on "Sociological aspects of medical diagnosis"; L. Molnar (Budapest) spoke on "Life-events and cardiovascular diseases"; L. Honti (Budapest) on "Suicide in Hungary"; L. Csaszi (Budapest) on "Control and self-limitation in medical school, the Hungarian Case."
- B. Eighth International Conference of Social Science & Medicine, August 22-26, 1983
Stirling, Scotland
During the 8th International Conference, a group of people expressed their interest in establishing a network of persons working in the broad area of social science applications to primary health care (PHC) activities in developing countries. They welcome suggestions of names of people and institutions in developing countries which are active in training or research in PHC. It is suggested that members of the network take the initiative to exchange papers of interest and to ask advice from others whose experience is relevant to their particular area of interest. The following can be contacted: Carol Barker, Nuffield Center for Health Services Studies, 71-75 Clarendon Rd, Leeds LS2 9PL, Great Britain; Hermione Lovel, Tropical Child Health Unit, Institute of Child Health, 30 Guilford St., London WC1N 1EH, Great Britain; Alanagh Raikes, Center for Development Research, 9, Ny Kongensgade, DK 1472 Copenhagen K, Denmark; Corlien Varkevisser, Dept of Social Research, Royal Tropical Institute, Mauritskade 63, 1092 AD Amsterdam, Netherlands. Hermione Lovel is especially interested in identifying and making available simple/practical sociological and anthropological techniques or perhaps "appropriate social science technology" that can be used by a range of health practitioners and others engaged in PHC program development, implementation and evaluation.

SOLICITATIONS: CALL FOR PAPERS

- A. The Association for the Social Sciences in Health seeks contributing papers for its sessions at the Annual Meeting of the American Public Health Association, Nov. 11-14, 1984 in Anaheim, CA. Deadline for 6 copies of abstract due April 6, 1984 so check first if you can get in under the wire. Papers should present a significant social science perspective on issues and topics of public health, broadly defined; may be a report on completed or continuing research, developments in methodology, policy analysis, or other subjects of interest to an audience of social scientists and other health professionals. Contact: Richard Kasius, Room 723, 1 East 75th Street, New York, NY 10021.
- B. The Program Committees of the American Academy of Physical Medicine & Rehab and the American Congress of Rehabilitation Medicine invites submission of scientific papers describing original work in the field of Rehab Med. for the Annual Scientific Mtg., Boston, MA, Oct. 21-26, 1984. Deadline is May 14, 1984 for submitting papers c/o AAPM&R/ACRM Central Office, 30 North Michigan Ave., Chicago, IL 60602. To submit a paper, type an abstract of less than 200 words. 3 peer evaluators will independently study each abstract and notify authors by July 1, 1984. Authors whose papers are

accepted will be allotted a maximum of 13 minutes for presentation, inclusive of slides and/or films. 7 minutes allotted for discussion to be led by the Session Chairperson. Those papers accepted for Poster Presentation will follow a separate protocol.

- C. The Wisconsin Sociologist will publish a special Fall 1984 issue on "Sociology of Moral Inquiry" and welcomes submission of papers on such issues as the ethics of research, practice, writing, and teaching; the relationship between knowledge and power; who does and who should benefit from research; and how sociology might be used to better help people lead the morally good life. Papers should not exceed 25 pages; 4 copies and a return acknowledgement postcard should be submitted by May 1, 1984. Contact: Charles S. Green III, Editor, The Wisconsin Sociologist, Dept of Sociology, Univ. of Wisconsin, Whitewater, WI 53190.
- D. A research conference centered around the general theme of "Social Change and the Deaf Community/Deaf Culture" is being planned for June, 1986 at Gallaudet College as a follow-up of the 1982 "Social Aspects of Deafness" Conference. If you are interested in submitting a paper, send a 3-5 page summary of what you plan to do by May 15, 1984 to John B. Christiansen or Richard Meisegeier, Dept. of Sociology & Social Work, Gallaudet College, 800 Florida Ave. NE, Washington, DC 20002. Authors will be notified by August 15, 1984 and asked to submit formal papers for consideration. Unsuccessful submissions will also be acknowledged. Final papers are due August 15, 1985. A one-volume "working papers" format will be distributed to all participants in March, 1986. A final, revised volume will be published and distributed by Gallaudet College Press that fall.
- E. Proposals are invited for contributed papers, panels, roundtables, and workshops for the Association for the Advancement of Policy, Research and Development 1984 Annual Conference, Nov. 14-16, 1984, Roosevelt Hotel, New York, NY. While thematic presentations are particularly welcome, any worthwhile proposal of research interest to the audience will be considered. Deadline for manuscript submission - August 1, 1984. Contact: Mekki Mtewa, Executive Director, Association for the Advancement of Policy, Research and Development, P.O. Box 24234, Washington, DC 20024, 202/393-5037.
- F. The study of migratory populations has often afforded social scientists unique research opportunities to study the effects of large-scale movements and dislocations on health and health care delivery. Thus the following may be of some interest. International Migration Review invites papers on 6 special issues to be published in 1984-86. Planned themes are: 1) Undocumented Aliens: An International Perspective; 2) Women in Migration; 3) Types of Temporary Worker Programs: Mechanisms, Conditions, Consequences; 4) Theory and Practice of Measurement of International Migration; 5) Refugees; 6) Civil Rights and Socio-Political Participation of Immigrants. Contact: Editor, IMR, 209 Flagg Place, Staten Island, NY 10304, 212/351-8600.
- G. Ray Elling reports that recent contact with the ISA Secretariat has indicated the likelihood that the 1986 Congress of the ISA will be held in New Delhi, India. He invites submission of topic ideas for paper sessions and volunteers to organize paper sessions from the membership. Contact: Ray Elling, Dept. of Community Medicine and Health Care, Univ. of Connecticut Health Center, Farmington, CT 06032.
- H. International Rehabilitation Medicine is the official journal of the International Rehab Medicine Assoc., the goals of which are to educate and encourage government and society to recognize the reality of disablement (its nature as well as its magnitude); to promote provision of rehab services for at-risk persons with impairments, chronically ill persons and the elderly; and to promote research. The journal encourages submissions of papers on all aspects of disablement. It is hoped that authors may be people who themselves have disabilities or any professional or investigator exploring the nature of disablement experiences and the ways in which this may be mollified. Contact: Dr. Philip Wood, Editor - IRM, Arthritis & Rheumatism Council Epidemiology Research Unit, Medical School, Univ of Manchester, Oxford Rd., Manchester M 13 9 PT, Great Britain.

OPPORTUNITIES

- A. In 1981 a unit was established in Hungary at the Budapest Medical School, Dept of Medical Sociology (See also this issue, Retrospectives, p. 5) to teach sociology of health for medical students and to develop different surveys in the field of medicine. The faculty recognizes the many problems they face; there is no tradition in sociology, especially the sociology of health in Hungary. They have no masters, former projects, information/books, journals, etc. But they are young, full of energy to learn and elaborate on special social problems in the field of health in Hungary and feel their work will be of interest to other medical sociologists. For information, exchange of publications, etc., contact: Lagos Csaszi, M.D., Budapest Medical School, Dept. of Medical Sociology, Nagyurdred ter 4.xx. emelet, Budapest, Pf. 370, 1445 Hungary.
- B. A group of health care professionals in Spain would like to get in touch with others from Latin and Central America to discuss, research, and expand information about health and social sciences. Among other things, a bulletin is being edited every 3 months. Contact: G.S.M. Apolo Corveos, 9407 Barcelona, Spain or to Editor, Alicia E. Kaufmann, Departament de Sociologia, Universitat de Barcelona, Barcelona 34, Spain.

FUNDING/GRANTS

- A. The National Institute on Alcohol Abuse and Alcoholism (NIAAA), in consultation with the National Institute on Aging (NIA) is actively encouraging the submission of grant applications in the alcohol-aging area. Contact: Nathan Rosenberg, PhD, Health Scientist Administrator, NIAAA, Rm 14C-17, 5600 Fishers Lane, Rockville, MD 20857, 201/444-4223. The submission of concept papers to him prior to submission of formal applications may be helpful if you wish to discuss topics or have questions.
- B. An NIMH-Sponsored Training Program on Identity, Self, Role and Mental Health invites applications from new/recent PhDs, including those who will complete doctorates this year for postdoctoral fellowships. Applications are welcomed from those whose work has been in sociology, social psychology, psychology, special education, or related fields. The program will train researchers in contemporary theories of the self and contemporary multivariate methods and to apply these to mental health relevant topics and in mental health settings. Send current vita, letters of reference, published or unpublished papers, & a brief description of research interests & plans to Sheldon Stryker, Director, Social Psychology Training Program, Dept of Sociology, Indiana Univ, Bloomington, IN 47405.
- C. University of Maryland, College Park, Dept of Sociology & Sch of Social Work and Community Planning anticipate several openings for a 1-yr. post-doctoral training program in applied research in Family Mental Health starting Fall 1984. (Application deadline was March 15, 1984 so write to see if you can still apply.) Program will train PhDs in Sociology and/or Social Work to conduct research in health and human service organizations whose programs affect the mental health of families. Stipends begin at \$14,040. Contact: Edward Z. Dager, Dept of Sociology, Univ. of Maryland, College Park, MD 40742 or Paul H. Ephross, Sch of Social Work and Community Planning, Univ of Maryland, Baltimore, MD 21201.
- D. Stanford University, Research Training Program on Organizations and Mental Health, invites applications for postdoctoral traineeships. The program focuses on 3 areas: 1) the examination of organizations as socio-cultural contexts affecting the development and mental health clinically defined, of their participants; 2) the examination of mental health agencies as social instruments that deliver mental health services and affect mental health outcomes; and 3) the study of mental health service systems functioning at local, state and national levels. It is funded by NIMH. Stipends range from \$14,040-\$19,716 for 12-month appointments. Deadline for application is May 1, 1984. Preferred starting date is Sept. 1, 1984. Contact: W. Richard Scott, Program Director, Res Training Program on Organizations & Mental Health, Dept of Soc, Stanford Univ, Stanford, CA 94305.

CURRENT RESEARCH

- A. B. Badura (principal investigator) and G. Kaufhold, H. Lehmann, H. Pfaff, T. Schott, and M. Waltz (Oldenburg Cardiac Rehabilitation Study Group, Univ. of Oldenburg, D-2900 Oldenburg, W. Germany) have begun an examination of the social, psychological, medical and institutional factors that affect recovery among a population of over 600 male patients under 60 years of age who have experienced one type of life-threatening illness - myocardial infarction. The sample also includes the wife and primary physician. Major variables in the study consist of 1) functional impairment level and prognosis; 2) patient and spouse images of illness; 3) social support resources and chronic life problems in family; 4) work-related support and strains; 5) patient self-concept; and 6) social and emotional impact of illness on patient and spouse. Methods used are a mailed paper and pencil questionnaire. The first interview is in the hospital; the second is 6-8 months later; the third is one year after the heart attack. A first English report will appear in the fall of 1984 in Social Science and Medicine. (Millard Waltz)
- B. Sally Power (Research Associate, Henry Murray Research Center, Radcliffe College, 10 Garden St., Cambridge, MA 02138) is directing a 2-yr. project funded by the William T. Grant Foundation on Coping with Stress: A Longitudinal Study of Adolescents and their Families. The project was designed to investigate the stressful events and experiences which seriously ill and healthy adolescents and their families encounter, the ways in which these adolescents and their families cope with stress, and how family members' personality and social-cognitive development is associated with stressful events and family coping abilities. Three samples of adolescents and their families are studied: psychiatrically hospitalized adolescents, diabetic adolescents, and non-patient adolescent high school students. Data from the project include clinical interviews, family interviews, standardized psychological tests and questionnaires given to family members, and direct observation of family interaction collected annually for 4 years. First analyses have been completed and indicate that families with psychiatrically ill adolescents report that they are more passive in response to stress, less confident in their family problem-solving abilities, and use community resources more often than families of non-patient adolescents. Families of diabetic adolescents report that reframing their family problems in a more positive light and use of community resources were more highly valued coping patterns than for families of non-patient adolescents. Also families with diabetic adolescents report more use of their extended family, their church and religious resources and more confidence in family problem solving than families of psychiatrically ill adolescents.
- C. Dr. Attila Bagyoni (Director, National Institute for Health Education, Nepkoztarsasag Utja 82, H-1062, Budapest, Hungary) reports on a pilot research project on risk lifestyles being undertaken by the Institute because of concern for greater effectiveness in primary health care. The study focuses on a sample of 2,000 randomly selected individuals in a Budapest district and was prompted by lack of information on risk lifestyles and also by the fact that people do little exercise and often do not have a balanced diet (Cardiovascular diseases are the main cause of mortality and morbidity in Hungary). Begun in 1980, the research, an integral part of the national research development plan and one that takes into account current WHO policies, is based on a questionnaire of 186 items, divided into 4 sections: physical activity, nutrition, personality, and general information. An all-round picture of the respondents has now been attained: their work and home environments, diet, leisure time activities, socio-economic conditions, qualifications, etc.
- D. The report "Patients in Public Hospitals: Who Pays, How Sick?" HCUP Research Note 2, (PHS) 83-3344 is now available from NCHSR, Publications and Information Branch, 1-46 Park Bldg, 5600 Fishers Lane, Rockville, MD 20857 (Send with request a self-addressed self-adhesive mailing label). In this recently released study researchers found that urban public hospitals do treat more Medicaid and uninsured patients. However, the

patient data, analyzed for seven commonly diagnosed conditions with a four-stage disease severity scale, show no more severity of illness in urban public hospitals than in urban voluntary hospitals. Rural hospitals showed no major difference in payment status or severity of illness between public and voluntary hospitals.. The researchers drew their patient data from a national sample of 314 short-term, general, nonfederal, public and voluntary hospitals.

- E. Child Health and Human Development: An Evaluation and Assessment of the State of the Science and Child Health and Human Development: An Overview and Strategy for a Five-Year Research Plan are now available free in single copies from the Office of Research Reporting, National Institute of Child Health and Human Development, Bldg. 31, Rm. 2A32, 9000 Rockville Pike, Bethesda, MD 20205. An extensive 5-yr. plan developed by the NICHD outlines the direction federally supported health research will take in the areas of maternal and child health, human development and population research. The 51 goals in ten research areas, along with 5-yr. objectives and a strategy for ongoing planning and evaluation are contained in these 2 volumes.
- F. For those contemplating research, the following reports resulting from support by the National Center for Health Services Research (NCHSR) are available from the National Technical Information Service (NTIS), Springfield, VA 22161, 703/487-4650. Payment must accompany orders. Copies in microfiche - \$4.50. Listed prices are for paper copies. Reports are listed with a detailed abstract in the NTIS publication Government Reports Announcements & Index and in their Health Planning and Health Services Research. NCHSR reports may be accessed through the National Library of Medicine's on-line MEDLARS file, Health Planning and Administration.
- Disease Staging: A Clinically Based Approach to Measurement of Disease Severity, Vol. 1, Executive Summary. Daniel Z. Louis, et. al. SysteMetrics, Inc., 25 pp., PB83-254656, \$8.50. Computerized disease staging overview which includes conceptual foundations, methods of development, and a brief description of the software and its applications.
- Disease Staging: A Clinically Based Approach to Measurement of Disease Severity, Vol.2, Medical Staging Criteria. Daniel Z. Louis, et. al. SysteMetrics, Inc. 619 pp., PB83-254631, \$43. A reference volume containing written descriptions of the medical staging criteria for 408 diseases.
- Disease Staging: A Clinically Based Approach to Measurement of Disease Severity, Vol. 3, Coded Staging Criteria. Daniel Z. Louis, et. al., SysteMetrics, Inc., 15 pp. PB-83-254623, \$7. A guide to the development and generic interpretation of the coded staging criteria, which translate medical criteria sets into ICDA coded criteria sets. The coded criteria are listed separately in the appendices.
- Disease Staging: A Clinically Based Approach to Measurement of Disease Severity, Appendix A of Vol. 3, ICDA-8 Coded Criteria for Disease Staging. Daniel Z. Louis, et. al., SysteMetrics, Inc., 487pp., PB83-254615, \$35.50. Translation of the medical staging criteria sets into ICDA-8 codes.
- Disease Staging: A Clinically Based Approach to Measurement of Disease Severity, Appendix B of Vol. 3, H-ICDA-2 Coded Criteria for Disease Staging. Daniel Z. Louis, SysteMetrics, Inc. 487 pp. PB83-254607, \$35.50. Translation of the medical staging criteria sets into H-ICDA-2 codes.
- Disease Staging: A Clinically Based Approach to Measurement of Disease Severity, Appendix C of Vol. 3, ICDA-9-CM Coded Criteria for Disease Staging. Daniel Z. Louis, et. al., SysteMetrics, Inc. 487 pp. PB83-25499, \$35.50. Translation of the medical staging criteria sets into ICDA-9-CM codes.
- Disease Staging: A Clinically Based Approach to Measurement of Disease Severity, Vol. 4, Staging Software User's Manual. Daniel Z. Louis, et. al., SysteMetrics, Inc. 55 pp. PB83-254581, \$10. Describes use of the staging software and installation procedures for IBM 370-type mainframes.
- Disease Staging: A Clinically Based Approach to Measurement of Disease Severity, Vol. 6, Staging Software Magnetic Tape. Daniel Z. Louis, et. al., SysteMetrics, Inc. PB83-254649, \$400. Computer tape providing the algorithm for assigning disease staging categories to computerized patient discharge abstracts, and documentation of vol. 1-4.

- G. The Baby Doe Controversy - As most readers of this newsletter are aware, there is a growing controversy about the rights of disabled infants and the role of the federal government in guaranteeing these rights. Accent on Living, a magazine about topics of disability, is conducting the following poll and I will try to report the results when they appear in the journal, though you might want to follow it as it appears in the magazine or write them directly. (reproduced from Spring 1984 ACCENT ON LIVING, p. 26)
- ACCENT POLL: Government Intervention in Treatment of Handicapped Babies - Yes OR No? Are newborn handicapped children being denied their civil rights? Are new federal regulations taking the practice of medicine out of the hands of doctors? Are parents being denied the right to decide whether to sustain the life of their child? In the spring of 1982 an Indiana child with Downs syndrome was allowed to starve to death after parents refused surgery to repair a defective esophagus. That led the Dept. of Health and Human Services to impose new rules concerning such cases.
- PROponents OF GOVERNMENT INTERVENTION point to the Rehabilitation Act of 1973 that states it is illegal for institutions to discriminate against anyone on the basis of race, creed, color, religion, ethnic origin, or handicap. Proponents say that intervention on behalf of handicapped children is no different from what happens when state and local authorities step in to protect battered children. They propose instead that physicians be kept more informed of financial aid services for families, and that catastrophic health insurance be made available to help families of handicapped children.
- OPponents OF GOVERNMENT INTERVENTION say that the decision about whether to sustain life is a very personal matter. They argue that the methods proposed by the advocates of government intervention are a serious threat to the privacy and confidentiality of families in agonizing circumstances. Though society has an obligation to be sure the right decision is being made, opponents say, these issues can be dealt with more effectively and compassionately on the local level.
- WHAT DO YOU THINK? ACCENT wants to know. Indicate your opinion, pro or con, on a postcard, along with your comments, and send it to ACCENTS ON LIVING, Disabled Children Poll, P.O. Box 700, Bloomington, IL 61701.

RECENT DISSERTATIONS

- A. Nora J. Krantzler's (Ph.D. University of California, Berkeley, 1982) "Treatment for Cancer: Nurses and the Sociocultural Context of Medical Care" is an anthropological study of a hospital Oncology Unit aimed at understanding and interpreting the meaning of the CA treatment situation for nurses. Using the analytic distinction between illness and disease, she compared the ideologies in cancer care of nurses and physicians and found nurses to be illness-oriented and physicians disease-focused. While formal nursing ideology emphasizes both technical and psychosocial skills, informally nurses focus on social and emotional aspects of care as most critical. These and other discrepancies are examined and a recommendation to reduce nurses' difficulties are offered.
- B. Larry Allen Nuttbrock (Ph.D. Case Western Reserve Univ., 1983) in "The Management of Health Identity Among Physically Impaired Older People: Some Empirical Specifications" examines various social and psychological factors associated with self-identity (inactivity, dependency, incapacity) among those with physical impairments and the extent to which various presentations of health (good health and poor health) can be viewed as attempts to validate this identity. His analysis indicates that self-identity is dictated by both self values and a variety of costs and benefits associated with a given version of the impaired role, often constituting social ambivalence.
- C. Judith J. Carta (Ph.D. Univ. of Kansas, 1983) in "An Investigation of the Object Play Skills of Handicapped and Nonhandicapped Preschoolers" obtained data to support her hypothesis that play of these 2 groups differed significantly with children with handicaps exhibiting notably less object manipulation, constructive play and pretend play; less problem-solving, random construction, self-pretending and object-pretending. Types of toys children were exposed to made a significant difference in average amounts of time that preschoolers spent engaging in constructive and pretend play.

FILM CLIPS by Nora Groce (Anthro, Brown Univ.) and Gary Kiger (Soc. Utah State Univ.)

- A. HI, I'M DAN 1982, color, 9 min.; produced by M. Sottnick, D. Maloney and S. Sachs; distributed by MTI Teleprograms, 3710 Commercial Ave., Northbrook, IL 60062. Sale: 16mm, \$195; video \$180. Rental: 16mm \$35

This film is about Dan, an elementary school-aged boy who is deaf. It begins with Dan walking around the park; he is nearly run over by children riding "Big Wheels." These children do not appreciate that Dan is deaf and could not hear them approaching. Dan joins a football game, but he leaves when the others do not show patience or cooperation with his impaired hearing. At home he reads Aesop's fable of "The Tortoise and the Hare." The story is portrayed to the viewer in choreographed silhouette imagery. Encouraged by the story, Dan heads back to the park to play. It is always a pleasure to encounter films about impairment which are directed toward a younger audience. This film is certainly appropriate for elementary school-aged children. Its particular power is that the sound periodically fades in order to give hearing viewers an opportunity to experience (briefly) what the everyday world sounds like to a hearing impaired person. There are 2 issues raised implicitly in this film which deserve mention. When Dan arrives home from the park in a depressed mood, his father (behind the newspaper) says to the mother, "Ask him what he did today." This notion of nurturing mother who signs and non-involved, non-signing father may be the norm statistically, but it is an issue better left out of this film since it was glossed over. It is not constructively presented. Secondly, the message of this film seems to be that perseverance pays off for handicapped persons, as it did for the tortoise in Aesop's fable. This is an important message, but cooperation and sharing is a two-way street: what about the responsibilities of Dan's playmates? (Gary Kiger)

- B. MAKING FRIENDS series: "Can We Be Friends?", "We're Friends", and "Staying Friends" 1982, color, 28 min., produced by WGBH Educational Foundation; distributed by The Production House, Pond St., Essex, MA 01929. Sale: 16mm \$372; video \$189. Rental: 16mm \$39 (series)

This 3-part series is an excellent instructional tool; the series is directed to an elementary school-age audience. The films address the issue of "mainstreaming," or including handicapped students in the regular classroom. In the first segment of the series, "Can We Be Friends?" the audience is introduced to a number of students with disabilities and to a number of their non-handicapped friends. Fonfon, a boy with spina bifida, gets around well on crutches and befriends a classmate. Jessica, an accomplished flutist, befriends Mia, who is taken by Jessica's flute playing. And Joey, who has cerebral palsy, befriends Jason after they initially fight. In "We're Friends," the message is that we all need friends--someone to be with, someone to trust. The school children tell the audience this in their own words. Disabled and non-disabled students are no different in this important regard. "Staying Friends," deals with friendships as processes. In a variety of scenes, friendships among the children are interrupted by anger or frustration. Then we discover ways that the children are able to put their friendships back together. This film series cannot be recommended highly enough for those who work with elementary school-aged children. Extensive instructional aids are available. (Gary Kiger)

- C. MORE THAN HUGS AND KISSES: AFFECTIVE EDUCATION IN A MAINSTREAMED CLASSROOM color, 23 minutes; produced by Grania Gurievitch, Togg Films; discussion guide available from Filmmakers Library, 133 East 58th St., NY, NY 10022. Sale: 16mm \$425; rental \$45; Videocassette, purchase only \$375.

This film focuses on the preschool classroom of Alice Brogan at the Jowonio School in Syracuse, NY. One-third of the children in this class are developmentally delayed. Ms. Brogan, who herself uses a wheelchair because of spina bifida, advocates "affective education", a wholistic teaching technique which stresses the importance of the social and emotional development of children, in addition to their intellectual growth. This reviewer is not familiar enough with the current philosophies in education to specifically address the 'affective education' approach advocated by Ms. Brogan, but it does strike me as being very reasonable. Be that as it may, this film does not

contribute very much to our knowledge of mainstreaming. While we watch children and teachers interact, and while we are shown Ms. Brogan working with an autistic child, most of the problems that might be anticipated with a mainstreamed child are not shown or discussed. Although possibly of interest for undergraduate classes on education, this film is not particularly relevant for those interested in disabled children in the classroom. This is not a bad film - it is simply not very informative. One additional note: the catalog suggests that Ms. Brogan's own disability is relevant in this film. I disagree. Ms. Brogan's obviously outstanding abilities as a teacher are what is important here. That she uses a wheelchair should be beside the point. (Nora Groce)

BOOK ETC. NOTES

- A. Proceedings on a workshop on the Nature and Extent of Alcohol Problems among the Elderly, held at Washington University in St. Louis, Missouri, on Nov. 3-4, 1984 and sponsored by NIAAA (National Institute on Alcohol Abuse and Alcoholism) and the National Institute of Mental Health will be available on a first-come, first-served basis in December 1984. Contact: Nathan Rosenberg, Ph.D. NIAAA, Rm. 14C-17, 5600 Fishers Lane, Rockville, MD 20857, 201/443-4223.
- B. Proceedings from a congressional seminar, "Health and Human Behavior," sponsored by the Medical Sociology Section and the Consortium of Social Science Associations (COSSA) May 26, 1982, have been published in the COSSA Occasional Papers series and may be obtained from COSSA, 1755 Massachusetts Ave., NW, Suite 300, Washington, DC 20036. The seminar was designed to acquaint congressional staff with recent social & behavioral science research on the causes and treatment of poor health and illness in the USA today. Edited by Sol Levine of Boston University and Roberta Miller of COSSA, the proceedings includes 4 papers: "Social and Behavioral Factors in Cardiovascular Disease" by C. David Jenkins; "The Individual's Role in Health Care" by Marshall Becker; "Social Science and the Response to Alcohol Abuse" by Ralph Hingson; and "Social Science, Health and Behavior" by Frederick Robbins. (reported by Linda Aiken, Robert Wood Johnson Foundation)
- C. "Being Blind and Being a Woman", a special issue of the Journal of Visual Impairment and Blindness (Publications and Information Services Dept., American Foundation for the Blind, 15 W. 16th St., New York, NY 10011)
The topics for this issue were derived from an informal survey of blind and visually-impaired women. In fact, with just four exceptions the authors themselves are blind or visually-impaired women. While no single issue can cover all the topics equally well, Mary Ellen Mulholland is well justified in her claim that the articles clearly argue that "the problems blind and visually-impaired women have are much more sex-related than they are disability related." We need more such thematic forays.
- D. Current Gerontology: Long Term Care, \$8.45 from The Gerontological Society of America, 1835 K Street, NW, Suite 305, Washington, DC 20006, 202/466-6750.
This is a new 160-page reader assembled by the Gerontological Society composed of 19 articles from GSA publications; the reader's 3 sections cover general issues, treatment perspectives, and policy considerations, including such topics as the controversy regarding relocation efforts, impact of institutionalization on families, sexual expression, reminiscence group therapy, and linkages between nursing homes, acute care hospitals, and community services.
- E. All About Home Care: A Consumer's Guide is a new booklet put out by the National Homecaring Council and the Better Business Bureau of New York. It describes basic home care services, lists agencies, and offers advice on how to judge agencies and their employees. The Council address is 235 Park Ave. South, New York, NY 10010.
- F. O'Brien, Mary Elizabeth, The Courage to Survive: The Life Career of the Chronic Dialysis Patient. New York: Grune & Stratton, 1983, \$24.50.
This is the result of a 9-yr. research effort in which the author sought to identify and describe the attitudes and behavior patterns adopted by long-term hemodialysis

patients in coping with their illness and its therapeutic regimen. The book describes and analyzes the dialysis experience from the perspectives of the patients, their families, and their professional care-givers. The hemodialysis unit is evaluated separately from a social system perspective and correlates of both early and long-term adaptation are discussed.

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There is a growing interest in the daily living experiences of people with disabilities and chronic diseases. In recognition of this, we will in this and upcoming issues devote several of our book notes to such accounts. The first will be for first-person patient narratives told by lay people; the second will be narrated by professionals; a third will be "fictional" accounts; a fourth is parents writing about their children; and a fifth about aging and disability. We will continue the series as long as there is interest.

- G. Brightman, Alan J. (Editor). Ordinary Moments: The Disabled Experience. Baltimore: University Park Press, 1984, paperback \$14.95.

For the past two years an exhibit of photographs by Alan Brightman entitled Ordinary Moments has been touring the country. The original exhibition, produced in recognition of the United Nations International Year of Disabled Persons (1981), was designed to bring people closer to images of disability that were neither didactic nor sensational. In the author's words, "The photographs of Ordinary Moments were much like those one might take of a friend; less a display of art than an expression of familiarity and affection." As it turns out, many of the people here are friends of mine. But even to someone like me who thought he "knew" them, the stories are revealing. These are not tales of high drama in the "disease" or "crip of the week" style of television. They write as in the title - of ordinary moments that they share with everyone: their highs and lows, their successes and frustrations, their loves and hates. And while all detail the many dozens of unique concerns they need to deal with as they go through each day, they are at the same time describing a common experience - how it is to be perceived as "different" and "invalid" in a country which values youth, beauty, and bodily perfection. How they tell their stories varies - some through a series of anecdotes, others through a detailed experience. One gets the sense that Alan was no passive editor in this process. He is, after all, no stranger to writing about disability. He has co-authored at least 3 other books, one of which Hollis has been used in the educational experiences of elementary-aged children. His guiding hand thus shows in the flow and easy narrative, with padding at a minimum. But that is not all, for each story is accompanied by photographs of the writers at work and play and the book is introduced by a commentary of his involvement in the project and concludes with his own final thoughts of what he and his authors have been trying to tell us as well as an annotated list of his own personal favorite "accounts of disability." Ordinary Moments is no ordinary book. It is to be read, savored and read again. (IK Zola)

- H. Cousins, Norman. The Healing Heart: Antidotes to Panic and Helplessness. New York: W.W. Norton, 1983.

In 1979 Norman Cousins wrote Anatomy of an Illness as Perceived by the Patient. It was his account of his battle against a supposed terminal illness - of how through systematic attention to his emotions, particularly the positive ones, he not only stopped his downhill slide but actually cured himself. Now several years later, he recounts his similar battle with a major heart attack. The book is really 3 separate sets of documents. The heart of it (both figuratively and substantively) is his debacle with the best available medical advice. In essence he felt he knew himself better than the doctors did and so eschewed their advice, questioned their tests, and refused their surgery. And ultimately (two years post myocardial infarct) his course of treatment - more psychological, more holistic, though with medical supports - proved correct. The other 2 pieces, the last half of his book and the series of forewords and afterwords written by physicians, are both support and an extension of his thesis.

Cousins tells how he met others who sought similarly to ameliorate the a- or anti-psychological stance of modern medicine. He cites many case studies and the workings of other patient groups. And through it all one gets a sense of how one can cope, avoid panic, and gain control over oneself, one's own life, and one's illness, after it has occurred. It is this 'after' emphasis which is for me the basic disappointment. It is clear he did not learn his lesson as fully as we were led to believe the first time (his earlier book). This is to me wherein we, the large society, could have learned some especially valuable lessons. By his own admission, he let himself go in the intervening years between his two major illnesses, but we get little sense of why and why 'it' will not happen again. Thus he gives us excellent clues to good rehabilitation and for that we are grateful but when it comes to the real 'bummer' - prevention - then he fails himself as well as us. (IK Zola)

- I. Perry, Elizabeth C. and F. Hampton Roy, M.D. Light in the Shadows - Feelings About Blindness. Little Rock, Arkansas: World Eye Foundation, 1982. This "book of feelings" is authored by two sighted individuals after a series of interviews with a partially-sighted and sightless population. She is a social worker and he an ophthalmologist. From the 100 people they interviewed, 7 were chosen as representatives of various aspects of blindness: Edward has retrolental fibroplasia, a gradually progressive blindness; he illustrates an individual's adjustment and preparation for blindness. Fatós has optic atrophy, a deterioration of the optic nerves. First noticeable in high school, she describes in detail the actual experience of losing her sight. Steve is a boy born blind and without eyes to sighted parents. His mother tells of the agonizing struggle first to give him up to foster parents and then to reclaim him. Barbara was selected to define how a disease - diabetes - influences the blindness that occurs. Ira was an 82-year-old Rabbi when he lost his sight. To him it's part of the very adjustment of growing old. Jerry has congenital cataracts and speaks mostly of the lack of difference between sighted and blind individuals. Helen, going blind since early childhood because of retinitis pigmentosa, describes a lifetime of adjustment, making it, and community service. The cases were admittedly chosen to illustrate the positive aspects of blindness but they are not stories of unremitting optimism. Quite the contrary, they are filled with sadness and mistakes - parents give up their children, people desert their friends, some contemplate suicide. It is not so much that these are stories with happy endings. Their lives are still in process. They are coping and the message is that blindness can be dealt with, not so much overcome but integrated. The authors, really editors or compilers, at one point question whether sighted people can really write about blindness. Actually, this book is no answer to that question; for except for a brief chapter on stages of adaptation, they have let the people speak for themselves - and that is as it should be. (IK Zola)
- J. Walsh, Richard with Wanda Layton. The Chase. Wheaton, Illinois: Living Books, Tyndale House Publishers, Inc., 1981. This book is written in the inspirational tradition. It follows Richard Walsh backwards and then forwards from the night of his accident (resulting in his quadriplegia) to his continuing efforts to find himself and God. Successful entrepreneur, family man, and hell-raiser, we see - though in my opinion, do not fully understand - how he "throws it all away." By inference it seems to be because he did not have "enough faith." Thus the story follows his quest. The way he tells it, he does not come off an especially nice guy; thus it is somewhat puzzling how and why his wife and four children, friends and family stood by him, undiminished in their lives. When the book ends, he and his family are running a Christian Book Store in Seattle. When I met him in August of 1983, he was also doing counseling with disabled people. All in all, he seems to be leading a fulfilling and filling life. (IK Zola)

CLASSICS REVISITED (This column is a reexamination of articles, monographs, and books written at least a decade ago but reknown today. We invite suggestions and actual written pieces from our readers.)

"Studies in Adjustment to Visible Injuries: Social Acceptance of the Injured" by Gloria Ladeau-Leviton, Donald L. Adler, and Tamara Dembo, Journal of Social Issues, 1948, 4, pp. 55-61.

by Arthur E. Dell Orto, Ph.D. (Dept of Rehab Counseling, Boston University)

A guideline I used in selecting a classic was that it must capture the past and have a bearing on the present. This article does both. What impressed me about this "classic" of 36 years ago was the powerful concepts which were reflected in its title. It clearly captured the energy, issues, and dynamics of an enormously complex problem that has not been solved but has become more focused. However, embodied in the article are several futuristic statements which have been the key to a greater understanding for both disabled people and the remainder who may become so. Statements such as "disabled people demand acceptance" are the beginning of an awareness that people with disabilities have rights. However, the demanding of rights in 1948 must be placed in the context of post World War II America which responded to many disabled veterans as injured veterans who were entitled to certain benefits.

While recognizing the needs of this population was important, it also may have created a phenomenon of understanding veteran issues while neglecting the needs of the civilian, especially those with non-visible injuries. Even the use of the term 'injured' is very intriguing. In a sense it is more constructive than 'ill' or 'disabled' person since it focuses on a physical reality, accounts for some limitations, but also has the flexibility for improvement.

In contrasting the terms 'acceptance' versus 'participation,' we can see the advances created by technology and the increased awareness of the potential of all people regardless of their physical inconveniences. This is a very important point since in 1948 there were few options and fewer role models. For example, an injured person may be unable to play in a baseball game, not because of lack of ability, but because of a lack of awareness and creativity. There were no or very few teams consisting of all or some players with various physical injuries. There were also no wheelchair marathons, computer competitions or a variety of other advances made in the past 36 years which have created options and opportunities for all people to interact with each other and share their unique physical and emotional resources.

A particular line which had an impact on me was a statement in the article made by an injured person in 1948, "I don't feel bad about not being a fisherman; I get a kick out of going along and watching." My response to this person today would be, "Why do you have to watch? Even for the most severely disabled person the technology of electric reels and one-handed reels makes fishing accessible to almost everyone."

Therefore, this article is one of the first which can be considered a building block for the "new era" for all people. In reading it I was impressed at the insight and awareness of the authors. I was also pleased to be able to find things that were no longer as true or as accurate. My reasoning is that over the past 36 years there have been changes and progress. However, as with all changes there is some degree of loss.

Back in 1948 the problems were great, but in a sense it was easier because there was so much to be done. In 1984 there is the challenge and responsibility of progress which creates an obligation to maintain the gains that have been made. If this is to be done, we must bridge the gap between what the authors label as "apparent versus genuine acceptance." For me, this means not the acceptance of those who are

injured or disabled; it means the acceptance of ourselves. If this could be done, we could more readily maximize the potential of life and living by creating a "mutual experience" that focuses on what there is to do, not what has been lost.

TEACHING ABOUT DISABILITY AND CHRONIC DISEASE by Sandra Bertman (Humanities in Medicine, Univ. of Massachusetts Medical School, Worcester, MA 01605)

MOVE OVER "WHOSE LIFE IS IT ANYWAY" AND MAKE ROOM FOR THE NEW KID IN TOWN --

"TELL THEM I'M A MERMAID"

1983, color, approx. 30 minutes; a Center Theater Group/Mark Taper Forum Production in association with Metromedia and Embassy Television; distributed by Embassy Telecommunications, 1901 Avenue of the Stars, Los Angeles, CA 90067. Sale: 3/4" tape \$250; 1/2" VHS \$175; 16mm film \$450. Rental: \$100/week.

"Cross-clutteral" life and death decisions are getting harder to make. Those real-life people with disabilities keep messing up a rational approach! Attempts to quantify the "quality of life" available to "vegetables" and other "doomed" infants are being attacked by grown-up kids who escaped from the cabbage patch! Formerly comfortable frameworks of theory which allowed us as medical and rehabilitation professionals to operate efficiently and expedite for the general good of our patients and their families are being rattled like the rusty bars of an antique prison. New fangled attempts to maintain the time-honored perogatives are being held up for public scrutiny. The seven "mermaids" in this film are inviting you to shed your preconceptions about life as a severely disabled person and get into the swim. So relax, laugh and shake-off some of the stereotypes and join these gutsy audacious young women.

Jane Fonda introduces this production with a twist that warns us of what's to come! She tells us what we are about to see of these disabled women will forever change our view----of ourselves. These women, first presented on the Metromedia Television Network, tapped on the inside of TV screens in thousands of living rooms, demanding to be let out of the box. Now they move off the screen in classrooms, seminars and conferences to challenge us to re-think what "vitality" and "sexy" and a "full life" mean. With an honesty that cuts to the core of our prejudices, combined with humor, guts, love and charm, they sing away the old bug-a-boos. Briefly each candidly tells us about their personal trip toward awareness of their own disability, what it has meant in their lives, and then they burst out with another outrageous attack on the concept of "pitiful"! Their musical review does not glamorize: they sing and execute their routines up and down Rita Hayworth ramps with all their "flaws" showing. They are dressed casually, as if you discovered them in their daily routine and they had agreed to share a half hour with you. They tell you right out loud, and in harmony, that being disabled for a short while might be the very best experience you could have! But then they acknowledge it could be a real grind if you couldn't lapse back into your temporary able-bodied status. Attitudinal and structural barriers impose limitations on these disabled people--who are "women" first. And you end up not wanting those barriers to be there - like the bars on the windows of old institutions which separate us from each other.

Medical and rehabilitation professionals and students who have too much "care-taker" in their self-image should probably be protected from large doses of "Tell Them I'm A Mermaid." Perhaps five minutes at a time to start will help eliminate their symptoms. Those with healthy egos can proceed to the full half hour show. These outrageously vital and normally sexy young women can knock your socks off if you let them. But that's really all they are asking to do.

(written by Mary Jane Owen, The President's Committee on Employment of the Handicapped)

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Please continue to send your ideas, materials, and comments to Sandra Bertman, approximating the following format as closely as possible: Name; Affiliation; Topic; Population; Objectives; Materials used; Methods or Procedures; Discussion. Enclose

any visuals, course syllabi, text or source materials, responses or evaluations. Do indicate if you would like materials returned. Perhaps eventually the DCDQ will compile and distribute a workbook: Teaching About Disability--Resources and Techniques. If you'd like some suggestions on how to use certain texts or visuals, send the material to us and we'll brainstorm along with you.

RESOURCES: NEWSLETTERS, DIRECTORIES, ORGANIZATIONS, DATA BASES, ETC. (This issue will focus on recorded material, newsletters, and directories.)

ON CASSETTE

- A. Journal of Rehabilitation is now available on cassette tape. A request should be accompanied by a blank cassette to replace the one used in filling the order. For a list of regional and subregional libraries cooperating in this plan, write National Library Service for the Blind and Physically Handicapped, Library of Congress, 1291 Taylor St., NW, Washington, DC 20542. And when writing them, why not inquire whether the journal of your profession or one you frequently use is similarly available and what it would take to make it so.
- B. Recorded Psychological Journals (R. Michelle Sheridan, Executive Secretary, 5196 Benito Terrace, Suite 9, Montclair, CA 91763; 714/621-0772) provides visually impaired psychologists and doctoral students tape recordings of 14 professional journals (American Psychologist, monthly; APA Monitor, monthly; Clinical Psychologist, quarterly; Professional Psychology, bi-monthly; Psychotherapy, quarterly; Psyc-Scan--Applied, quarterly; Psyc-Scan--Clinical; Psy-Scan--Developmental, quarterly; Psyc-Scan--LD/MR, quarterly; Voices, quarterly, American Journal of Clinical Hypnosis, quarterly; Journal of Personality and Social Psychology, monthly; International Journal of Clinical and Experimental Hypnosis, qtrly. It will soon begin recording the DISABILITY AND CHRONIC DISEASE QUARTERLY at \$17.00/year. Volunteer readers record on special equipment that allows slow playback speeds and beep-tone audio indexing. RPJ makes the necessary number of duplicates on fast-copying machines and distributes them quickly to subscribers at slightly more than the price of the printed journals. Write for more information.

NEWSLETTERS

- C. Handicapped Americans Reports (Capitol Publications, Inc., 1300 N. 17th St., Arlington, VA 22209) is an expensive (\$140 a year), bi-weekly news report and analysis on funding, regulations, and legislation dealing with disability. It is perhaps better purchased by your institution but does seem a handy compendium of useful information.
- D. Health Education Newsletter (Box 609, Hunter College, Sch of Health Sciences, 425 East 25th St., New York, NY 10010) is a quarterly available for \$5.00/year. It usually consists of several short articles/reviews on a select topic. Vol. III, No. 1, July 1983 dealt with "health education for the chronically ill and the handicapped."
- E. The Independent Living Forum, a newsletter of the Research and Training Center on Independent Living (348 Haworth, The University of Kansas, Lawrence, KS 66045), contains brief articles, editorials, book reviews, and information about the Independent Living Movement. Bibliography of research and documents are available upon request (e.g., E.C. Ross, Participating in the Political Process; P. Jamero, Vocational Rehabilitation's Role in Independent Living; N.A. Brooks, Independent Living and Women with Disabilities).
- F. People to People, a newsletter of the Tucson Public Library Special Needs Service (P.O. Box 27470, Tucson, AZ 85726-7470, Judyth Lessee, Developmental Disabilities Specialist and Editor) is a local and even national resource. A recent issue was entirely devoted to the media - an annotated listing of films, videos, film strips, and resources. Moreover, according to Judyth Lessee, anyone receiving the newsletter is entitled to request any information and/or to borrow from their special collection. She herself is available on a consultant basis to do research for anyone.

- G. Programs for the Handicapped (Clearinghouse on the Handicapped, Office of Information and Resources for the Handicapped, Room 3119 Switzer Bldg., Washington, DC 20202, 202/245-0080) is an excellent, free, comprehensive resource put out by the U.S. Dept. of Education/Ofc. of Special Education and Rehabilitation Services. It cites news of past and upcoming conferences, legislation, research, new publications, organizations, and new programs. Some of the articles in the May/June 1983 issue include "Projects with Industry: A Partnership with Promise"; "Unique Volunteer Program Aids Stroke Victims"; and "The Cost of Community Residential Care for Mentally Retarded Persons."
- H. Woman Wise, The New Hampshire Health Center Quarterly (38 S. Main St., Concord, NH 03301) with an annual subscription rate of \$7.00 is not a local newsletter as its subtitle may imply. It is, in fact, national in scope and deals in full-length articles with many of the chronic health problems facing women. A recent issue focused on AIDS; Aloe-Vera, ancient healer; ovarian cysts, teen sexuality, alternative insemination, the Supreme Court and abortion. All well written and informative.
- I. A newsletter of The National Information Center for Handicapped Children and Youth is inaugurating a two-way flow of information with concerned people in communities across America. It would like to know about the projects you are developing, the progress you are making, and the good things that are happening in services for disabled persons where you live. It will then share the information with many others. Reply to Toni Haas, Director, The National Information Center for Handicapped Children and Youth, 1555 N. Wilson Blvd. Suite 508, Rosslyn, VA 22209.
- J. A very informative newsletter dealing with international social science research in health is that sponsored by the International Sociological Association. The Steering Board has determined that membership dues will be \$20 (USA) for 2 years for members in "hard currency" countries and \$4 (USA) for 2 years for members in other countries, payable to the Secretary-Treasurer. Checks should be made out and sent to Dr. Rance Lee, Director, Institute of Social Studies, The Chinese University of Hong Kong, Shatin, N.T. HONG KONG. The current editor is Dr. Jerome Stromberg, formerly of WHO and now of the Dept. of Preventive Medicine, Univ. of Colorado Health Sciences Center, 4200 E. 9th Ave., Box C-245, Denver, CO 80262.
- K. The Numbers News (American Demographics, P.O. Box 68, Ithaca, NY 14850, 800/828-1133, in NY call 800/828-8686) has been expanded recently to become a 12-page monthly newsletter that covers the full range of demographic information in addition to the Census Bureau. The newsletter follows shifts in statistical agencies in Washington and reports developments in the growing field of private data companies. Information on conferences, data products, recent survey and statistical publications in the field, and other news may be submitted by interested readers to Martha Farnsworth Rice, P.O. Box 5103, Arlington, VA 22205, 703/534-0450.

DIRECTORIES

- L. The Annotated Bibliography of Papers Using the General Social Survey, 4th edition, has been released by the National Data Program for the Social Sciences at the National Opinion Research Center. This 200+ page bibliography abstracts over 750 scholarly papers, articles, and other publications that employ the General Social Surveys. It includes an index by variable so one can quickly identify the literature on specific items and topics. \$6.00 includes postage. Contact: Library, National Opinion Research Center, 6030 S. Ellis Ave., Chicago, IL 60637.
- M. The State and Metropolitan Area Data Book, 1982, provides 700 pages of up-to-date statistical information at the metropolitan, state, regional, or national level. Featured are new data from the 1980 Census of Population and Housing. An outline of table headings showing data included in this volume can be obtained at no charge. Also, computer tapes containing the data for States and metropolitan areas will be available for purchase. To purchase, send \$15 for #S/N 003-024-04932-5 to Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402. For an outline

or information on computer tapes, contact: Chief, Data User Services Division,
U.S. Bureau of the Census, Washington, DC 20233, 301/763-1034.

FINAL WORDS

Waiting in the wings, as it were, are many more books, newsletters (especially those of special interest - i.e., written by and for persons with a particular chronic illness or impairment), organizations, etc. that we will be bringing to your attention in upcoming issues. If you have been one of our contributors and have not yet seen your piece in the DCDQ, do not despair, but keep the information coming. We will do our editorial best!

Brandeis University
Department of Sociology
Waltham, Massachusetts 02254
USA

DISABILITY AND CHRONIC DISEASE QUARTERLY
Irving Kenneth Zola, Editor

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