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THE DISABILITY AND CHRONIC DISEASE NEWSLETTER

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The response to the resurrection of this newsletter has been very encouraging. Many of you have passed it on to colleagues. If you think there are other people or organizations who might benefit from receiving it, please tell us and we will add them to our mailing list. Back copies of Vol. 2 are still available. Remember the newsletter remains free, at least through the next issue. Right now we are trying to find ways to continue this subsidization. If you have any ideas, send them along.

As of now we will continue to publish twice a year, though I think the amount of material could merit a quarterly. In any case, please send in more items, requests, reviews, etc. One of our readers suggested that so far there has been insufficient attention paid to development and learning disabilities, so if you have any material... The next issue will come out in July, so we will probably be able to incorporate material through mid-June.

Thank you again.

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FOCUS

(As promised, this will be a space for comments on issues of concern to the readers of this newsletter. Future columns will be written by other colleagues and will deal with such topics as the working situation of a social scientist in a rehab setting and international aspects of rehabilitation.)

Erving Goffman - In Memoriam

On November 19, 1982 Erving Goffman died. America lost one of its premier social observers and the disability rights movement lost one of its early mentors. Born in Canada, he received his Ph.D. from the University of Chicago during the halcyon days of fieldwork when Blumer and Hughes were its guiding lights. At his death he was Benjamin Franklin Professor of Anthropology and Sociology at the University of Pennsylvania and the President of the American Sociological Association. To those who knew him publicly he was an extremely astute, cynical, and often biting and depressing observer of the social scene. To those who knew him privately he was much the same. I write of him in these pages not because of his eminent position as an observer of the American way of life (It is no accident that Time Magazine used his works on the rituals of everyday life to introduce its new section on behavior) but because of the debt we in the disability movement, activists and researchers alike, owe him. For in two books, Asylums (a Doubleday-Anchor paperback), written in 1961, and Stigma (a Prentice-Hall Spectrum paperback), written in 1963, he gave social scientists and the lay alike the tools to begin to analyze and ultimately lift the oppression that weighs so heavily on disenfranchised groups.

He was not himself a political man and often completely disavowed any political aim or even concern. Yet by continually focusing on the underdogs, he gave a new legitimacy to their position. One could, of course, trace this issue in his earlier work but it is seen most evidently in two of his most enduring and popular classics. In Asylums he coined the term "total institutions" to describe closed worlds like prisons, army training camps, boarding schools, nursing homes, sanitariums where the inmates spend their entire life in the company of other inmates and have to rely for their total physical and psychological sustenance on the institution which holds them. He focuses particularly on mental hospitals and systematically questions the primacy of their therapeutic aims. For him the most important factor in forming perhaps permanently who the patient is is not his or her illness but their 'caring institution' and 'its healers.' If you are not crazy when you enter such places, you surely are by the time you get out. Yet despite the overwhelming gloom of his subject matter, his books have an optimistic glow; for whatever they are about, they are about survivors. In Asylums there is a separate section entitled "The Underlife of a Public Institution: A Study of Ways of Making Out in a Mental Hospital." As Ken Kesey does in One Flew Over the Cuckoo's Nest, the mental hospital became also a metaphor for the struggle of the individual against society, of the individual spirit against the forces of conformity. In a chapter which foresees the critiques of the 1970s, he indicts the medical profession and its vagaries with his "notes on the vicissitudes of the tinkering trades." In his later book Stigma, the institution which oppresses those who do not fit is no longer the hospital but the entire society. Whereas in Asylums he notes the inmates continual struggle to find an identity within the institution, in Stigma the subtitle "Notes on the Management of Spoiled Identity" tells it all. Here he describes in agonizing detail how those with a physical disability or chronic disease go about maintaining themselves in a society which prizes the young, the beautiful, and the healthy. Drawing on autobiographies and case studies, he notes the precariousness and marginality of "stigmatized people" and examines the alternatives which face them - to display the disability or mask it, to let on or to deny, to flaunt or to pass - and in each case to whom, how, when, and where. I make no claim that he pointed to any solutions. But he did two things. He gave the problem name and attention. It is clear that women had trouble long before Betty Friedan wrote The Feminine Mystique but that book marked a turning point because it gave their trouble currency and name. So, too, with Goffman. By delineating the full nature of the oppression - of those with physical and mental disabilities - and by describing the way that the very institutions set up to heal and cure, often hurt and perpetuate, he laid the groundwork for demystification and with that came the beginning of empowerment. Thank you and goodbye, Erving Goffman.

Irving Kenneth Zola

#### COMING EVENTS

- A. The First European Conference on Research in Rehabilitation (theme: Measurement of Outcome in Rehabilitation), University of Edinburgh, April 6-8

Organized by the Rehabilitation Studies Unit of the University of Edinburgh on behalf of The Society for Research in Rehabilitation, Great Britain, the conference welcomes all professionals concerned with research in the care of disabled persons: doctors, physiotherapists, occupational therapists, rehab engineers, nurses, clinical psychologists, social workers, etc. Full cultural & social

programs and clinical facility visits are available. For information, contact: Mr. W. Campbell, University of Edinburgh, Center for Industrial Consultancy and Liaison, 16 George Square, Edinburgh EH8 9LD Scotland, U.K.  
 Note: The conference language will be English.

- B. 1983 Western Social Science Association Meeting, Albuquerque, New Mexico, April 27-30

Under the aegis of the Sociology Division of the WSSA, several interesting sessions on impairments and disabilities will be held. The tentative listings include: Historical and Cross-Cultural Perspectives on Physical Impairments and Disabilities; Interaction Between Impaired and Non-Impaired Persons; Social Adjustments of Impaired and Disabled People; the Organizational Processing of Impaired and Disabled People in Society; Film Essays: Impaired and Disabled People in Society; and Problems of Disabled and Impaired People in Society: Issues for Further Research. For information, contact: John Seidel, 7700 W. Glasgow 14-D, Littleton, CO 80123 (303/979-2498) OR Gary Kiger, Dept. of Sociology, Univ. of Colorado, Boulder, CO 80309 (303/492-6427)

- C. Annual Meeting of the North Central Sociological Association, Columbus, OH, April 28-30

Of particular interest is the session "Support Systems in Illness Situations", chaired by Professor Rosalie F. Young (Dept. of Community Medicine, Wayne State Univ., Gordon H. Scott Hall of Basic Medical Sciences, 540 E. Canfield Ave., Detroit, MI 48201).

- D. The Sixth World Congress for Sexuality sponsored by the World Association for Sexology will be held in Washington DC, Washington Hilton Hotel, May 22-27

Much of the May 25 meetings will address topics related to sex and disability. Proposals for papers as well as more information should be sent to: Ervin J. Haeberle, Ph.D., United States Consortium for Sexology, 1523 Franklin St., San Francisco, CA 94109.

- E. American Rural Health Association Seventh Annual Institute on the Delivery of Human Services to Rural People, Lake Tahoe, Nevada, June 11-13

The theme of the meetings is "Cooperation in Rural Health: Maximizing the Resources." For further information, contact: Dr. Raymond Coward, Center for Rural Studies, University of Vermont, Burlington, VT 04501.

- F. International Society for Sexually Transmitted Disease, Seattle, WA, August 1-3

Solicited papers include STDs in women, infections in homosexual men, epidemiological aspects of Herpes Simplex Virus and other STDs. Contact: King K. Holmes, MD, PhD, Seattle Public Health Hospital, 1131 14th Avenue, S., Seattle, WA 98114.

- G. The VIIIth International Conference on the Social Sciences and Medicine, University of Stirling, Stirling, Scotland, August 22-26

Some themes include: Assessing recent developments and opportunities in the promotion of health; Communication across cultural and disciplinary boundaries in the sociomedical sciences; Concepts of right and justice and their implication for policy; Effects of material deprivation on neurological functioning; Female/male differences in becoming ill and getting better; Health and unemployment; Health systems as a defense against the consequences of poverty; Implications of comparative hospital organizations and structure for inter-professional behavior and the delivery of care; Issues in the accessibility and confidentiality of patient records; Processes in the formulation and legitimization of professional ethics in a changing world; Relationships of lifestyles to patterns of health; assessment and implementation of health care priorities in developing countries; The family as resource unit in health care; The nature and influence of popular movements in health policy and modern health practice; The relevance of traditional medical cultures to modern primary health care; Values in health care choices; Working conditions and health - social epidemiology, patterns of stress, coping and change. For further details, contact: Dr. P.J.M. McEwan, Glendarden, Ballater, Aberdeenshire AB3 5UB, Scotland.

- H. Society for the Study of Social Problems 33rd Annual Meeting, Detroit, MI, August 28-30

Theme: "The Making and Maintenance of Social Problems." Some topics requested by the Division of Health, Health Policy and Health Services include: public vs. private priorities in health and medicine and shifting patterns of control; emerging issues in medical student socialization; evolving nature of medical sociology and social "problems"; and changing contours of health and disability. For information, contact: Diana B. Dutton, Health Services Research Division, Dept. of Family, Community and Preventive Medicine, Stanford Univ. School of Health, 703 Welch Rd., Suite G-1, Stanford, CA 94305.

#### SOLICITATIONS AND INQUIRIES

1. The American Foundation for the Blind, Inc. in cooperation with the Research Unit for the Blind, Warwick University, is developing a file of researchers in the area of blindness and visual impairment. If you or other researchers are doing any research and/or demonstration projects in this area, please send your name, address, phone # and name of co-workers together with the title(s) and a brief (100 words) description of the project(s) to: Bernice R. Bloom, Technological Development Department, American Foundation for the Blind, 15 West 16th Street, New York, NY 10011. All such information will be included in the continuously updated International Register of Research on Visual Disability (described in BOOK NOTES).

1. Rosalyn B. Darling (Director, In-Home Services, City-County Clinic, 111 Johns Street, Johnstown, PA 15901) writes: "As a sociologist member of the Professional Advisory Committee of the Spina Bifida Association of America, I would like to hear from fellow sociologists who have done, are doing, or are interested in becoming involved in research on the sociology of birth defects in general and on sociological aspects of neural tube defects in particular. In my capacity as a member of this committee I have been asked to comment on the issues of pre-natal screening, 'selection' for treatment, and effects on the family, among

others. I have, in the past, based most of my comments on my own research and publications in this area and would appreciate input from others involved in similar lines of research. The S.B.A.A. has also recently begun to offer small research grants, and I have suggested that some of these incentives be directed toward sociological research. I believe the case for obtaining this support would be made stronger by the presentation of some concrete research proposals from interested sociologists."

3. Barbara Sosnowitz, M.S.W. (Asst. Prof. of Sociology, Director of Social Work Program, Central Connecticut State College, 1615 Stanley St., New Britain, CT 06050) would appreciate reading lists and suggestions for a course, "Sociology of Persons with Physical Disabilities."

4. The Teaching Committee of the Medical Sociology Section is preparing an anthology of excerpts from literary works which can inform the study of health. It is looking for literature (novels, biography, short stories, drama and poetry) with substantial health content. Send references to: Catherine K. Riessman, Smith College School for Social Work, Northampton, MA 01060.

5. The Wenner-Glen Foundation announces a Working Paper Series on the Anthropology of the Handicapped. The series is devoted to facilitating communication between scholars by making research results, methodological advances, and current orientations more immediately available. Studies that take an anthropological approach to any aspect of the lives of the mentally retarded, the physically disabled, the blind, the deaf, or the chronically ill are encouraged. Manuscripts should be in the American Anthropologist style and under 80 pages in length. Copyright will remain with the author and papers appearing in the Working Paper Series may be submitted for publication elsewhere. Copies will be distributed to a network of interested scholars, and authors will receive 20 free copies to distribute to their own network of colleagues. The Working Papers are currently being distributed to our own network members free of charge and we hope to be able to continue free distribution. Persons wishing to have their names added to the network mailing list or to submit manuscripts should write to Keith T. Kernan, Ph.D., Editor, Working Papers on the Anthropology of the Handicapped, Mental Retardation Research Center, University of Calif., Los Angeles, CA 90024.

6. Rosalie F. Young, Ph.D. (Sch. of Medicine, Gordon H. Scott Hall of Basic Medical Sciences, 540 E. Canfield Ave., Detroit, MI 48201) has formulated for students in nursing, pre-medicine, and allied health fields a course entitled "Illness and the Family: Sociobehavioral Aspects." Should others wish to offer such a course, she would be happy to send her syllabus.

#### ON-GOING RESEARCH

1. Carol Bininger, M.S., R.N., Ph.D. candidate (Center for Nursing Research, Ohio State University, Columbus, OH 43210) is involved in a study entitled: "The Effects on the Self Esteem and Perceived Independence of Physically Handicapped Individuals Who Are Recipients of Support Dogs". She summarizes it thus:

"Self esteem and independence are closely linked to one's ability to function on a daily basis without having to rely on others for assistance. Persons with a positive sense of self esteem and who perceive themselves to be capable of independent functioning are more likely to express satisfaction with their life situation compared with persons whose self esteem is negative and who do not perceive themselves as capable of independent functioning. In this study, 35

physically handicapped persons each will be taught to work with a large-boned dog (support dog). The dogs will have been trained to assist handicapped individuals with activities of daily living. Each subject will be interviewed prior to working with a support dog, at six weeks and again at 12 weeks after the placement of the support dog in the subject's home. During these interviews, data will be collected pertaining to the self esteem and perceived independence of each of the subjects. It is hypothesized that there will be significant changes in the subjects' self esteem and perceived independence after the intervention of a support dog. It also is hypothesized that the social activity level of the subjects will increase and that they will more willingly engage in spontaneous activity.

2. Naomi Breslau (Dept. of Epidemiology and Community Health, Sch of Medicine, Case Western Reserve Univ., Cleveland, OH 44106) has just received a grant from NICHD for a follow-up study of the families she (and associates) interviewed in 1978-1979. One of the questions she will be looking at is the class and race differentials in the effect of childhood disability on the children and their families.

3. Nancy Books and Ronald Matson (Dept. of Sociology, Wichita State Univ., Wichita, KS 67208) are interested in knowing of others doing similar work or with related interests on "Social Psychological Adjustments to Multiple Sclerosis: A Longitudinal Study." Their study employs a longitudinal design to analyze the adjustment process of 103 people diagnosed with multiple sclerosis and in the middle and later stages of their illness careers. The mean age of the second sample is 52 years, and mean duration since diagnosis is 17 years. Four sets of variables are analyzed in their relationship to adjustment: 1) socio-demographic, 2) disease-related, 3) medical, and 4) social-psychological. Results indicate that the majority make satisfactory adjustment as indicated by maintenance of positive self concepts over the 7 year period, although the disease is chronic and progressive. For patients in the middle and later stages of illness careers, the data suggest comprehensive rehabilitation efforts that enhance autonomy and development the social-psychological resources of the patient lifestyle.

4. Julia S. Brown and her colleagues (Community Health Care Systems School of Nursing, The Oregon Health Sciences University, 3181 S.W. Sam Jackson Rd., Portland, OR 97201) are engaged in a series of studies on the quality of life of individuals or families with a chronic disease or disability. Three papers which have already appeared are:

a. Brown, Julia S., Perman, Bette S. and Dobbs, Jeri L. "The Will-to-Live: Dependence on a Prosthesis for Survival." Research on Aging, June 1981, 3, 182-201. The researchers found that generally the 100 chronically ill elderly who must rely on a pacemaker for survival "cherished their lives and expressed a strong will-to-live; they perceived their health to be as good as that of their age-peers; they took a middle position concerning the extent to which their own behavior affected their health; and they led quite active social lives" (p. 198).

b. Brown, Julia S., Rawlinson, May E. and Hardin, Donald M. "Family Functioning and Health Status." Journal of Family Issues, March 1982, 3, 91-110. Using the Family Functioning Index (FFI) of Pless and Sutterwhite (1973), the researchers looked at 100 cardiac subjects and their families in an attempt to correlate health and illness on family life. They were unable to support their proposition that the more severe the illness, the less adequately the family functioned. They speculate that the impact of illness on a family differs in intensity, depending on the disease, age and stage of family life cycle at which the disease strikes, and the status and position of the ill person within the family.

c. Brown, Julia S., Rawlinson, May E. and Hilles, Nancy C. "Life Satisfaction and Chronic Disease: Exploration of a Theoretical Model." Medical Care, Nov 1981, 19, 1136-1146.

Undertaken to demonstrate the usefulness of a theoretical model for explaining differences in the life satisfaction of persons with different chronic diseases, the research project concluded that predictors of life satisfaction vary with the disease, as does the manner in which social activity, perceived health, health locus of control and degree of disability interact to mitigate or compound the impact of a disease.

5. Patricia S. Graves' M.S., R.N. (Center for Nursing Research, Ohio State University, Columbus, OH 43210) study, "The Impact of a Child With a Visible Disfigurement on a School-Aged Sibling", focused on an examination of the school-aged siblings' perceptions and reactions to the child with a disfigurement. The sample consisted of 11 siblings from 7 families. The siblings and their parents were interviewed separately. The major foci of the sibling interviews were: relationships with the child who had been burned; relationships with peers; perceptions of parental time spent with themselves as compared to the burned sibling; and worries or concerns they have relative to their burned sibling, their parents, other family members and/or themselves. The parents were asked similar questions to compare their answers to their children's responses. The majority of the siblings expressed protective concerns and worried that the burned child might get hurt. They also expressed anger towards people who made unkind remarks or stared at the burned child. Results of the study indicated that the majority of the siblings of burned children are emotionally affected by the child's disfigurement, but the extent to which the sibling is affected is not dependent on the severity of the child's disfigurement.

6. The Seva Foundation, the U.S. and Nepalese governments, and the University of Michigan, assisted by the Institute for Social Research, conducted a survey recently on the prevalence and distribution of blindness in Nepal. The study was carried out as the first step in an international campaign to eradicate blindness in Nepal by the year 1985. Preliminary findings indicate that: 1) the rate of blindness in Nepal exceeds that in the U.S. by 20% with more than 117,000 Nepalese permanently blind; 2) more than 2/3 of these cases arise because of cataracts, an easily curable condition requiring an operation costing less than \$15 in Nepal; 3) of the some 900,000 cases of trachoma, 13% might result in permanent blindness unless surgical programs and chemotherapy are instituted.

7. Jerome Siller and his colleagues and students (Department of Educational Psychology, New York University, Washington Square, New York, NY 10003), in a series of studies (available from Siller) found seven stable factors which describe the attitudes of nondisabled people toward those with amputations, blindness, cosmetic conditions, deafness, obesity, and disability in general. These include: 1) interaction strain - uneasiness in the presence of people with disabilities and uncertainty as to how to deal with them; 2) rejection of intimacy - a rejection of close, especially intimate relationships; 3) generalized rejection - unpleasant personal reactions and advocacy of segregation; 4) authoritarian virtuousness - people seemingly 'pro-disabled' but having an attitude rooted in an authoritarian context and advocating 'special' treatment; 5) inferred emotional consequences - an assumption that disability impairs the character and emotions of its 'victims'; 6) distressed identification - personal reactions to disability arising from anxiety about one's own vulnerability; 7) imputed functional limitations - restricted evaluations of the ability of people with disabilities to function in the environment.

8. The United Nations Assembly on Aging took place in Vienna, July 26-August 6, 1982. The conference emphasized that while it is well recognized that industrialized countries have seen increasing proportions of their people survive to the age of 65 and older - with consequences in terms of chronic disease, needed health care and rising costs (not attributable exclusively to the aging of the population) - it is less well recognized that so-called "developing countries" are also beginning to experience the aging of their populations. While in 1950 the "developing countries" had just 56% of those over 60 in the world, by 2025 it will rise to 72%. For future information about the conference, contact: The Secretary-General, World Assembly on Aging, United Nations, New York, NY 10017.

#### FUNDING, GRANTS & AWARDS

1. The American Foundation for the Blind, Inc. announces Awards to support Doctoral Research in the social sciences on issues related to blindness and severe visual impairment. The total to be awarded, \$2500, will be given for each of the 2 deadlines, January 3 and April 4, 1983. Topical priorities include: problems of visual impairment as related to Aging; problems of visual impairment as related to Ethnic Minority Status; improving Education or Employment of blind & visually impaired persons; provision of Low Vision services, and others. Contact: Corrine Kirchner, Director, or Jacki Packer, Research Associate, Social Research Department, American Foundation for the Blind, 15 West 16th St., New York, NY 10011 or phone 212/620-2140 or 2142.

2. Harvard Law School offers fellowships to college and university teachers in the social sciences and humanities to enable them to study fundamental techniques, concepts, and aims of law, so that in their teaching and research, they will be better able to use legal materials and legal insights which are relevant to their own disciplines. Because of the increasing effect of legislation on matters relating to chronic disease and disability, this seems an especially important opportunity. Further information can be obtained from: Chairperson, Committee on Liberal Arts Fellowships in Law, Harvard Law School, Cambridge, MA 02138.

3. The University of Michigan Survey Research Center, in cooperation with the Depts. of Sociology, Psychology, and Epidemiology, announces an NIMH-funded pre and post-doctoral research training program in Psychosocial Factors in Mental Health and Illness. Both substantive and methodological training are offered in the development and course of mental health problems, including their relation to other health problems in both treated and untreated populations. Training will occur through involvement in research projects connected to the training program, participation in a training seminar, and formal coursework in epidemiology, psychology, sociology, and biostatistics. Traineeships cover full tuition and fees, limited travel, and annual stipends for living expenses (\$5,040 for pre-doctorals; \$13,380-\$18,780 for post-doctorals, depending on experience). Traineeship applications accepted anytime during 1983. Contact: James S. House, Survey Research Center, University of Michigan, Box 1248, Ann Arbor, MI 48106.

4. The purpose of the Radcliffe Research Scholars Program is to encourage scholars to revise and enrich their study of women and social change by drawing upon the resources of the Schlesinger Library on the History of Women in America or of the Henry A. Murray Research Center. Radcliffe is particularly interested in research projects that develop new perspectives intended to be incorporated into college and university curricula. The program will award stipends to as many as 4 scholars each year. Appointments will be full time for the academic year or for 1 term

or a summer, and will require residence in the Cambridge area for the length of the appointment. The stipend for the full academic year is \$16,000. Some funds for research assistants and other research costs will also be available. Eligible projects must make effective use of materials in the Schlesinger Library or the Murray Center, or both. Applicants must have received their doctorates, or the equivalent, at least 1 yr. prior to the submission of an application. The application deadline for stipends for the summer of 1984 or for the 1984-85 academic year is Nov. 4, 1983. In each case, appointments will be announced in early April. Contact: Radcliffe Research Scholars Program, The Henry A. Murray Research Center, Radcliffe College, 10 Garden St., Cambridge, MA 02138.

6. Rutgers-Princeton Mental Health Training Program, directed by David Mechanic, Allan Horwitz, and Julian Wolpert, has post-doctoral traineeships for 1983-84, funded by NIMH, in 5 areas: epidemiology of psychiatric disorders and help-seeking; the integration of medical and psychaitric care; deinstitutionalization of the mentally ill; the evaluation of mental health programs; and mental health policy analysis. Trainees receive between \$13,380 and \$18,780 per year, depending on prior experience. Contact: Allan Horwitz, Dept. of Sociology, Lucy Stone Hall, Rutgers University, New Brunswick, NJ 08903.

7. The U.S.-Japan Cooperative Program, administered by the National Science Foundation, currently supports Cooperative Research, Joint Seminars, and 6-12 month Long-Term Visits to Japan. The program covers costs of travel, per diem, and logistics to make possible the cooperative activity. Proposals may be submitted by individual scientists at universities, research institutions and other organizations, after consultation between the scientists concerned in the 2 countries. Contact: National Science Foundation, Div. of International Programs, 1800 G St., NW, Washington, DC 20550.

#### RECENT DISSERTATIONS

Carol Ann Anderson (Dept. of Sociology, Univ. of Colorado at Boulder, 1977; available for loan or purchase from University Microfilms International, 300 N. Zeeb Road, Ann Arbor, MI 48106) "All the Worries and All That They're Worth: Accounts of Physically Disabled Persons Attempting the Ordinary Life". In this quite evocative account, Carol Anderson has attempted to analyze as well as convey the everyday life issues of people with a disability. She examines the creation of Atlantic Community Inc., an alternative to institutional life, by a group of physically disabled people and their able-bodied supporters. According to the author, the major point of the study is that "relationships with a group that is accepting, helpful, tolerant, and supportive are imperative if the severely physically disabled person is going to live successfully among the able-bodied. Without membership in this type of a group, a disabled person is in danger of slipping into social isolation which might prove to be more profound than the social isolation of institutionalization." The story is told in the words of the co-directors of Atlantis and several current and former residents. More so than in many such documents, the interviewer fades into the background, skillfully arranging and editing, and keeping her own observations as a final summing up.

Frances Buck (Department of Psychology, Univ. of Arizona, 1980) "The Influence of Parental Disability on Children: An Exploratory Investigation of the Children of Spinal-Cord Injured Fathers". More than 50 families with disabled fathers were studied along with matched controls. 82% of the disabled fathers were paraplegic and 18% quadriplegic.

Whereas 97.7% of the control fathers were employed full-time while the child was growing up, this was true for only 40% of the disabled fathers. While there are limitations to the findings because the disability was 'service-connected' and thus ensured both a certain honor as well as income, her findings are optimistic for parents who become disabled or disabled people who become parents. Not only were there no differences between the 2 sets of children on a number of different scales testing their adjustment (e.g. MMPI, Body-Cathexis, Rorschach, etc.) but 97.9% of the children of disabled fathers reported they had benefited from having such a father. The study also delineates many of the implications for public policy (e.g. adoption) as well as for issues in rehabilitation counseling.

#### BOOK NOTES

Caplan, Arthur L., Engelhardt, H. Tristram, and James J. McCartney (Eds.), Concepts of Health and Disease: Interdisciplinary Perspectives. Reading, Mass: Addison-Wesley, 1981 (756 pp \$29.50) is a very wide ranging anthology of interest to most health-care researchers and educators. The editors have gathered together some 48 selections of past and contemporary writings on the underlying issues of the nature of disease and health, their moral connections and the scope of medicine. The pieces are of such breadth that they represent a wide range of alternative positions and thus provoke considerable debate.

Darling, Rosalyn Benjamin, Families Against Society: A Study of Reactions to Children with Birth Defects. Beverly Hills: Sage Publications, 1979. This book is based on a study of the parents of children with permanently disabling birth defects and of a small sample of pediatricians. The study revealed vast differences in "definition of the situation" between families and the professionals who treat them. The career paths followed by families in overcoming social and professional resistance are explored.

Darling, Rosalyn Benjamin and Jon Darling, Children Who Are Different: Meeting the Challenges of Birth Defects in Society. St. Louis: C.V. Mosby, 1982. This textbook for medical and other professionals is intended to acquaint physicians with the parents' perspective. As a work of "applied medical sociology", it brings a previously unfamiliar way of understanding their patients to the nonsociological professionals practicing in this area. The material is based on the authors' direct experience with families as well as on other research in the field and points to a need for social rather than individual change. Extensive resource lists are also included.

Dartington, Tim, Miller, Eric, and Geraldine Gwynne, A Life Together - The Distribution of Attitudes Around the Disabled. Tavistock, London & New York, 1981 (147pp \$12.95 hardcover, \$7.95 paper)

Ten years ago Miller and Gwynne wrote a brilliant analysis of the role of institutions in the socializing of patients with chronic physical disabilities (A Life Apart, Tavistock 1972). They claimed that it was simplistic to think that there were conservative versus liberal ways of perceiving and thus handling patients. Both models had their own way of entrapping both the patients and their caretakers. Now with the help of Tim Dartington they carry their perspective into the outside world and attempt to analyze current efforts to integrate the physically disabled into the community. Their analyses of two different housing schemes which place people with disabilities in the midst of a larger able-bodied community is dense in description and insight. Their book is not only a treatise in the complexity of changing attitudes but a step toward unravelling that complexity.

Dressler, William W., Hypertension and Culture Change: Acculturation and Disease in the West Indies. South Salem, New York: Redgrave Publishing, 1982 (158pp paperback).

This is both a field study and a quantitative survey of 100 people, aged 40-44, in Soufriere, St. Lucia. He finds that mating patterns are an adaptive strategy with married subjects having lower blood pressures. "Without adequate social and psychological supports in the face of high-stress life styles, the outcome is life-threatening hypertension."

Field, David (Ed.), Medical Sociology in Britain, Fourth Edition. British Sociological Association Medical Sociology Group.

This is a very valuable register of research and teaching in medical sociology in Britain and contains a section on research practices in the area of disability. Available from Nigel Goldie, South Bank Polytechnic, Borough Road, London SE1 1AA (£ 6.75, includes postage and handling).

International Register of Research on Visual Disability (formerly International Register of Research on Blindness and Visual Impairment)

This continuously updated volume describes current research and demonstration projects in the social sciences, educational and technological aspects of blindness and visual impairment. Available from Dr. John M. Gill, Research Unit for the Blind, University of Warwick, Coventry CV4 7AL England (\$10 U.S.; £5 U.K.)

Roth, William, The Handicapped Speak. McFarland & Company, Inc. Publishers, Box 611, Jefferson, NC 28640, 1981 (211 pp).

William Roth, who with John Gliedman wrote perhaps the decade's most incisive analysis of disability, The Unexpected Minority: Handicapped Children in America (Harcourt, Brace & Jovanovich, 1979), has now written a personal account of the 'handicapped experience.' Guided by the gentle probing of William Roth, thirteen people speak out. His introduction aptly summarizes his purposes: "A social science of handicap or public policy of disability, or a reconstituted social construction of handicap must begin with the handicapped person's assessment of his or her situation. The interviews in this book form a real-world basis from which to launch an interdisciplinary study of handicap, appropriate public policy, and that looked-for social reconstitution." He introduces each interview with the public policy issue that is highlighted--be it transportation, work, school, housing, marriage, accessibility. And he ends the book with a brief but pithy discussion of the same issues. To each he brings wit and wisdom - dramatizing their words, heightening their actions, articulating their demands.

#### BOOK UP-DATE:

In the previous issue of this newsletter, I mentioned a monograph that might be coming out of Gallaudet College's Conference on the Sociology of Deafness. It is now out under the general title Social Aspects of Deafness. In all there are over 2000 pages (57 articles) in six separate volumes: 1) Deaf Children and the Socialization Process, 2) Social Aspects of Educating Deaf Persons, 3) The Deaf Community and the Deaf Population, 4) Socioeconomic Status of the Deaf Population, 5) Interpersonal Communication and Deaf People, and 6) Deaf People and Social Change. For a limited time it is possible to purchase the volumes separately at \$10 each. But by early 1983 it will only be possible to buy it by the set for \$50.00. Should this be out of your price range, urge your library to purchase it. In a set of conference papers like this, there is some inevitable unevenness. Yet nothing so wide-ranging about the social aspects of deafness even exist. To order write: Dept. of Sociology & Social Work, Gallaudet College, 800 Florida Ave. NE, Washington D.C. 20002.

NEWSLETTERS, DIRECTORIES, AND CENTERS

A. The Boston Women's Health Book Collective (Box 192, West Somerville, MA 02144, Phone # 617/924-0271) is probably best known as the authors of Our Bodies, Ourselves - A Book By and For Women, the most popular and widely used health resource book for women in the world. As a result of the book, however, it has also become a world-wide information center - lecturing, organizing, consulting, disseminating with its own library and open files. The next edition of Our Bodies, Ourselves (Simon & Schuster, 1983), which has always included some information about chronic disease, will have considerably more, particularly disability, scattered throughout the book.

B. CNR Voices is the publication of the Center for Nursing Research (Ohio State University, 034 Newton Hall, 1585 Neil Avenue, Columbus, OH 43210). This nursing research newsletter reports many of its on-going projects, issues forcing nursing and often has material dealing with disabilities.

C. Comparative Health Systems Newsletter (The University of Connecticut Health Center, Department of Community Medicine, 263 Farmington Ave., Farmington, CT 06032). This newsletter is now entering its fourth year of publication. It is one of the best sources of information about cross-cultural issues in health. At the moment it is free, though they welcome donations. The current editor is Ray Elling.

D. For those of you at universities and colleges or who meet with people who have disabilities interested in higher education, a very good resource is: Higher Education and the Handicapped - Resource Directory 1982-83, available through Health Resource Center, American Council on Education, One DuPont Circle, Washington, D.C. 20036, Phone # 202/833-4707).

E. The International Network for Social Network Analysis (Structural Analysis Programme, Department of Sociology, University of Toronto, 563 Spadina Ave., Toronto M5S 1A1, Canada).

INSNA is a clearing house, linking together network analysts and disseminating current information. Formed in 1977, it now has over 300 members from all continents and all social science disciplines, mathematics, and statistics. To link members with each other, INSNA publishes 3 issues of Connections annually. The 70 or so pages of each issue contain research reports, surveys of the field, lots of abstracts, new book announcements, thesis summaries, computer programmes, conference information, teaching aids, research grant announcements, and news items. Already published are such important new information as William Ratcliff's review of network/health research, Joel Levine and Nicholas Mullins' critique of blockmodelling, Harriet Friedmann asking Max Weber if "distributions are really structures?", John Sonquist (and associates) 'do-it-yourself' guide to computerized network analysis, and Ron Rice's review on longitudinal network studies. To keep connected, INSNA's Directory gives addresses, telephone nos., disciplines and descriptions of research interests, all cross-referenced. It updates it bi-annually from information provided on membership forms. INSNA also serves as a framework for organizing conferences: it has met in Toronto, and in Uppsala, Sweden and is discussing conferences to be held in Europe, Mexico, the U.S. and Canada. INSNA members can also subscribe to the affiliated journal, Social Networks, at a special discount. This "International Journal of Structural Analysis" publishes theoretical, methodological and substantive papers on social structure.

F. The Medical Anthropology Newsletter, now in its 15th year, is an extraordinarily informative document. Often running to as long as 40 pages, it comes out several times a year and includes long commentary articles, book reviews, reports and general information for people in the field. It frequently contains review material about chronic disease and disability. It is available to members of the Society for Applied Anthropology. Annual dues are \$12. To obtain more information write: Circulation Department, Society for Medical Anthropology, 1703 New Hampshire, N.W., Washington, D.C. 20009.

G. Murray Research Center News (The Henry A. Murray Research Center of Radcliffe College - A Center for the Study of Lives, 10 Garden Street, Cambridge, MA 02138, Phone # 617/495-8140, Ann Colby, Director, Nancy Bower, Editor).

One of the primary functions of the Henry A. Murray Research Center is to acquire data sets that can be used for secondary analysis, replication and longitudinal follow-up by researchers. The staff continually reviews data acquisition policies in order to be sensitive to new research areas and to provide access to a wide range of data. Suggestions for possible new acquisitions are encouraged. The newsletter provides descriptions of new data sets and describes activities of the Radcliffe Research Scholars Program (some of which deal with health).

Guide to the Data Resources of the Henry A. Murray Research Center provides information about each of the more than 90 existing data sets. In addition, the Guide includes information about the methods of data collection used and the content area covered in the data sets. To receive a guide, send your name, address and a check for \$5.00 (payable to Radcliffe College) to the Center.

H. One of the fastest growing areas of rehabilitation and thus also potentially in research opportunities is in regard to head or brain injuries. I know that chapters to create support and services for the families exist in at least 30 states, some states having more than one. They are more or less federated under the National Head Injury Foundation, Inc., a private non-profit organization. For more information or for their national newsletter, write: The NHIF Newsletter, 18A Vernon Street, Framingham, MA 01701, Phone # 617/879-7473.

I. The University of Michigan regularly publishes a digest of research at their university. The November/December 1981, Vol. 32, No. 11-12 issue of The Research News is called "Toward a Barrier-Free Society: Breaking the Isolation of Handicap." Amongst its dozen or so short articles and reports are ones on "Changing the Research Model of Special Education", "Rehabilitation Medicine", and "Interdisciplinary Research in Mental Retardation". It is available free by writing to the Editorial Office, The Research News, Division of Research Development and Administration, University of Michigan, Ann Arbor, MI 48109 or call Doris Dunger, circulation manager, Phone # 313/764-4277.

#### EDITOR QUERY

As I have mentioned before, nothing in this format is fixed. Our aim is to make this material as useful and as accessible as possible. A new column, perhaps to commence with the next issue, will be entitled, CLASSICS REVISITED. Here I would like to see re-reviewed material at least a decade old, to reevaluate and comment on the work's impact. If you have any suggestions for inclusion or would even volunteer to do such a piece, please let me know.

#### NEWS NOTICE (on last page)

Special from the Massachusetts Coalition of Citizens with Disabilities,  
18 Williston Rd., Brookline, MA 02146

# Game Tested in Capital

WASHINGTON, D.C. — A new video game is being test marketed in Washington D.C. video arcades. Called "Attack the Handicapped," the game features small figures representing persons with disabilities who are trying to advance. A game player shoots holes in the 504 "defense shield," a law protecting the rights of disabled persons, and scores points by injuring the figures. The maximum score possible is 35 million, —the approximate number of American citizens with disabilities.

Games installed in the White House and the Dept. of Justice are proving to be popular. One official called the game "fast-paced and intense. It's exciting to zap the little creatures out of public places, schools, and employment. It's fun to see them scurrying back behind closed doors, into nursing homes, or to institutions."

Anticipating successful test marketing at the federal level, a home video version is being prepared so that the game may be played in local communities.

DISABILITY AND CHRONIC DISEASE NEWSLETTER  
 Irving Kenneth Zola, Editor  
 Department of Sociology  
 Brandeis University  
 Waltham, MA 02254

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