

Editor: Irving Kenneth Zola, Ph.D.

Assistant Editor: Joanne Seiden

Dear Readers,

It's hard to believe but with this issue we begin our fifth year of publication. It has been a slow expansion of content (1 issue in each of the first two years, 2 issues each in the third and fourth years, and the quarterly this past year) and a rapid one in readership, edging up to 1600 internationally. At the moment a quarterly seems just about right. Money and resources permitting, we will expand the number of pages per issue rather than the number of issues per year, if necessary. Unfortunately, we are no longer able to send back copies at bulk mail rates in the U.S. so the quarterly will be sent to new readers either at regular printed matter postal rates or new subscriptions will begin with the next issue. This issue of DCDQ will have a heavy emphasis on developmental disabilities and familial response to disability. Spring (deadline March 1) will headline growing older and disability; Summer (deadline June 1) will focus on work and employment; Fall (deadline Sept. 1) will probably emphasize gender and sexuality. As you can see, this is a way to highlight each issue, though each one will still contain much general information. So please keep your comments, suggestions, reviews and monetary donations coming our way. Finally, we would like to thank past, present and future contributors to the DCDQ, with grateful acknowledgement to our regulars, including support people John Seidel (mailing list) and Myron Seiden (computer consultant).

THE EDITORS

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Children, Chronic Illness, and Public Policy
by May Shayne, James Perrin, Henry Ireys, and Linda Moynihan
(Institute for Public Policy Studies, Vanderbilt University)

Children who suffer from severe, chronic illnesses are a neglected group in our society. Conservative estimates are that 10-15% of children in the U.S. have a chronic health condition, and about 10% of them or about 10 million are severely involved. Their suffering, the enormous burdens they and their families bear, are matters largely unknown to the general public. Consequently, families whose children have severe chronic illnesses--such as cystic fibrosis, leukemia, juvenile arthritis, sickle cell anemia, chronic kidney disease, asthma, and hemophilia--have been largely absent from public policy consideration. Chronically ill children have shared in relatively little of the sustained attention given in the last 2 decades to children with other handicapping conditions, such as mental retardation.

Fresh attention to chronically ill children and their families from policymakers and professionals in health, education, and health care financing is timely for at least 2 reasons: 1) dramatic advances in medical technology mean that many of these children, who died young in earlier years, now survive into young adulthood and are an increasing proportion of the population in health care services and schools; and 2) they use a large portion of the resources spent on health care of all children. Chronic conditions account for 1/3 of hospital days used by

all children, and the cost of care of severely chronically ill children is triple the average cost of care of other children. In spite of the heavy burdens these children and their families carry, their increased prevalence, and the high cost of their care, the policies of health care institutions, schools, social service and mental health agencies, insurance companies, and other large organizations have not kept pace with the needs of these children and their families.

A major national review of public policies affecting these children and their families, underway at Vanderbilt University since 1980, has identified issues that merit attention in 4 areas: organization and financing of health services; chronically ill children in schools; training of professionals; and research: 1) Fragmentation of health services pose major obstacles to the complex care these children need. Families have many physicians and other providers to treat their children. This means repeated trips to physicians' offices, to the hospital, to the pharmacy--resulting in a great deal of time lost from work, absence from school, and expenses for transportation and care of other children. The high cost of hospitalization and specialized medical treatment, although covered partly by insurance, erodes families' finances. Private insurance and Medicaid pay for only some of the many services families need, leaving families with out-of-pocket expenses that can mount rapidly and continue for years. For the many uninsured and uninsurable families, the burden is staggering. Insurance is more likely to pay for hospital, medical, and surgical costs than for other services also important--care at home, special diets, rehabilitation, blood products and drugs, appliances and equipment, family and genetic counseling, etc. Often the costs prevent families from obtaining proper care for their children. Federal and state government programs such as Crippled Children's Service and Medicaid provide or insure provision of some needed services. But in many states, these programs serve less than 1/5 of the eligible population and often do not support provision of non-medical services.

2) Most have no learning problems per se and do not qualify for special education. Yet they need "related services" available through P.L.94-142. Many chronically ill children stay out of school 1 or 2 days every few weeks but do not qualify for homebound teachers who see only students who are absent for 2 or more consecutive weeks.

3) Training of professionals has failed to take into account the special needs of these families. Medical training stresses cure, not care. Teacher education, strengthened in dealing with children with developmental problems such as mental retardation, has not incorporated chronically ill children into the curricula.

4) Biomedical research has dominated the research agenda but studies are needed in other areas of comparable importance--to determine how best to organize and deliver the broad range of services these children and families need, how to contain costs and encourage quality of care, how to provide coordination and continuity of services, and how schools and other institutions central to the lives of chronically ill children can enable them to participate fully and productively.

The research team at Vanderbilt proposes policy changes to address the needs common to chronically ill children regardless of their diverse medical diagnoses. The recommendations emphasize strengthening family-centered, community-based services and ensuring provision and coordination of health, education, and family support services. The complete findings, recommendations, and a series of commissioned reports from the Vanderbilt project, The Constant Shadow: Childhood Chronic Illness in America by N. Hobbs, J. Perrin, and H. Ireys will be published this fall by Jossey-Bass, Inc. San Francisco, California.

COMING EVENTS

- A. 5th Annual Sun Belt Social Network Conference, February 14-17, 1985; Palm Beach Hilton, Palm Beach, Florida. Session topics will include networks through time-bounded versus open networks, network measurement, comparison of methods for the analysis of social networks. Contact: H. Russell Bernard, Anthro. Dept., Univ. of Florida, Gainesville, Florida 32661 or Alvin Wolfe, Anthro. Dept., Univ. of South Florida, Tampa, Florida 33620.
- B. Ethics on the Front Lines of Medical Care: Access to Health Care--Rationing Resources, February 20-22, 1985; Denver, Colorado. Sponsored by the Center for Applied Biomedical Ethics at Rose Medical Center in Denver and co-sponsored by the American Society of Law and Medicine and the Univ. of Colorado Schools of Medicine and Nursing, the conference is designed to help health care workers on the front lines to understand and deal with ever-changing attitudes toward and methods for the delivery of health care. Contact immediately: The Center for Applied Biomedical Ethics at Rose Medical Center, 4567 E. Ninth Ave., Denver, Colorado; 303/320-2895.
- C. A Celebration of a Quarter Century of Humanistic Psychologies, March 7-9, 1985; Cathedral Hill Hotel, San Francisco, California. Sponsored by the Assoc. for Humanistic Psychology (American Psychological Assoc., Div. 32, Saybrook Institute) the conference--featuring Carl Rogers, Rollo May and 60 renowned theoreticians, researchers, and practitioners--will examine the past, present, and future of humanistic theories and their applications in psychotherapy, psychological research, education, management, social policy, and world peace. Contact: Assoc. for Humanistic Psychology, 325 Ninth St., San Francisco, California 94103; 415/626-2375.
- D. First International Congress on Ethics in Medicine, March 10-13, 1985; the Sir Immanuel Jakobovitz Center for Jewish Medical Ethics, Ben Gurion University of the Negev, Beersheba, Israel. The international faculty will discuss such topics as Dialysis and Organ Transplant; Life Support Systems; Gene Splicing and Genetic Manipulation; Humanism and Technology in Medical Education; Allocation of Health Services. Contact: Beth Israel Medical Center, Medical Education Office, 10 Nathan D. Perlman Place, New York, New York 10003.
- E. Rehabilitationstage 85, International Exhibition on Technical Aids for Rehabilitation, March 13-16, 1985; Karlsruhe, Federal Republic of Germany. Contact: Interservice Borgmann, Hohe Strasse 39, P.O.B. 748, D-4600 Dortmund 1, Federal Republic of Germany.
- F. Society for Applied Anthropology 1985 Annual Meeting, March 13-17, 1985; Washington Plaza Hotel, Washington, D.C. Theme: Anthropologists at Work: Solving Human Problems. Contact: Gretchen Schafft, SFAA Program Chair, 1222 Noyes Dr., Silver Spring, MD 20901.
- G. 31st Annual Meeting of the Western Gerontological Society, March 16-20, 1985; Denver, Colorado. Theme: Power and Justice in Aging. Contact: Conference Division, WGS, 833 Market St., Suite 516, San Francisco, California 94103.
- H. National Council for International Health Conference, March 18-20,

1985; Salk Institute for Biological Studies, San Diego, California. The conference will examine the major problem areas in the immunization cycle. Contact: Graeme Frelick, NCIH, 2100 Pennsylvania Ave. N.W., Washington, D.C. 20037; 202/466-4740.

I. Microcomputers in the Rehabilitation of Brain-Damaged Adults: A Theory-Based View, March 21-22, 1985; New York, New York. Presented by the faculty (Rosamund Gianutsos, John Gianutsos, Eugene Piasetsky and Jack Rattok) of the Research and Training Center on Head Trauma and Stroke of New York Univ. Medical Center, who have had extensive experience in remediating a broad range of problems in individuals who are traumatically brain damaged or post stroke, the workshop will aim to share the theory and experience which they integrate into their own work with patients so workshop participants can take these key principles to their own patients and settings. Contact: Margaret Brown, R&T Center on Head Trauma and Stroke, 400 E. 34th St., New York, New York 10016; 212/340-6186.

J. 7th Congress of the International Association for the Scientific Study of Mental Deficiency, March 24-28, 1985; New Delhi, India. Contact: Dr. V.R. Pandurangi, Chief Organizer & Coordinator, 36-A Osberton Place, Sheffield S11 8XL, United Kingdom.

K. 6th Annual Meeting of the Society for Behavioral Medicine-- Behavioral Medicine Across the Life Cycle, March 27-30, 1985; New Orleans Marriott, New Orleans, Louisiana. Contact: Margaret Chesney, Program Chair, Society for Behavioral Medicine, P.O. Box 8530, University Station, Knoxville, Tennessee 37996; 615/974-5164.

L. Learning Difficulties of Children with Multi-Handicaps, March 29-April 4, 1985; Cambridge, United Kingdom. Contact: Anita Loring, Secretary General, ICPS, 5a Netherhall Gardens, London NW3 5RN, United Kingdom.

M. Diagnosis, Remediation and Management of Cognitive and Behavioral Problems in Adults with Severe Head Trauma, April 1-5, 1985; New York, New York. This 5-day workshop by the faculty (headed by Dr. Yehuda Ben-Yishay) of the Research and Training Center on Head Trauma and Stroke of New York Univ. Medical Center is based on clinical and research programs developed with this population. See I above for contact information.

N. Midwest Sociological Society Annual Meeting, April 10-13, 1985; Chase Park Plaza Hotel, St. Louis, Missouri. Of particular interest are the sessions: "Theorizing Ages: Critique and Renewal" and "Health Policy and the Restructuring of Health Care in the '80s: Who Benefits, Who Loses". The latter is on Thursday, April 11 and is organized by Mary Zimmerman, Dept. of Health Services Admin., Univ. of Kansas, 110 Watkins Home, Lawrence, Kansas 66045; 913/864-3212. For more general meeting information contact: Jaber F. Gubrium, Dept. of Soc. and Anthro., Marquette Univ., Milwaukee, Wisconsin 53233.

O. International Conference on Model Programs and New Technologies for People with Mental Retardation and Developmental Disabilities, April 24-26, 1985; New York, New York. Contact: Young Adult Institute, 460 W. 34th St., New York, New York 10001.

P. 6th Conference of the Society for Menstrual Cycle Research-- Menstruation: Clinical Implications, May 2-4, 1985; Galveston, Texas.

Contact: Judith Abplanalp, Dept. of Psychiatry & Behav. Sciences, Univ. of Texas Medical Branch, Galveston, Texas 77550; 409/761-1430.

Q. Biennial Conference of the American Deafness and Rehabilitation Association--Integrating Human Resources, Technology and Systems in Deafness, May 21-25, 1985; Little Rock, Arkansas. Contact: Dr. Sue E. Ouellette, Research and Training Center on Deafness, 4601 W. Markham St., Little Rock, Arkansas 72205; 501/371-1654.

R. Annual Conference of the National Council for International Health--International Health, and Family Planning: Controversy and Consensus, June 11-13, 1985; Washington, D.C. Contact: NCIH Conference Coordinator, 2100 Pennsylvania Ave. N.W., Suite 740, Washington, D.C. 20037; 202/466-4740.

S. Annual Conference on Rehabilitation Engineering Society of North America, June 22-27, 1985; Memphis, Tennessee. Contact: RESNA, Suite 402, 4405 East-West Highway, Bethesda, Maryland 20814.

T. 9th Annual Convention of the Registry of Interpreters for the Deaf, July 4-8, 1985; Town and Country Hotel, San Diego, California. The objective of "Interpreting: The Art of Cross Cultural Mediation" is to introduce or expand the working knowledge of practicing interpreters and students of interpretation on the discipline of intercultural communication through workshops and free paper discussions. Contact: Ken Rust, Chairperson, RID National Convention Program Committee, Madonna College, 36600 Schoolcraft Road, Livonia, Michigan 48150.

U. International Symposium on Youth and Disability, on themes, adolescents with disabilities, impact of disability on family, and youths as volunteers in disability work, July 7-12, 1985; Jerusalem, Israel. Contact: Israel Society for Rehabilitation of the Disabled, 18 David Elazar Street, Hakiryat, Tel Aviv, Israel 61909.

V. International Workshop in Technical Aids, to be held in association with the Congress of International Federation for Medicine and Biological Engineering, July 7-13, 1985, Helsinki, Finland. Contact: International Federation for Medical and Biological Engineering, c/o National Research Council, Ottawa, Ontario, Canada K1A 0R8.

W. Social Science and Medicine Semi-Annual Conference, July 8-12, 1985; Forest Lake Hotel, Korpilampi (near Helsinki); Finland. Contact: Peter J.M. McEwan, Glengarden, Ballater, Aberdeenshire, AB3 5UB, Scotland.

X. 13th International Congress of Gerontology--Aging: The Universal Human Experience, July 12-17, 1985; New York Hilton Hotel, New York, New York. Contact: IAG Cong. Secretariat, c/o The Gerontological Society of America, 1411 K St., N.W. Suite 300, Washington, D.C. 20005.

Y. Congress of the World Federation for Mental Health--Mental Health 2000, July 14-20, 1985; Brighton, England. Contact: National Association for Mental Health (MIND), 22 Harley St., London W1N 2ED, United Kingdom.

Z. International Seminar on Rehabilitation Engineering (followed by XIV International Conference on Medical and Biological Engineering with a theme on technical aids for disabled people), August 11-16, 1985;

Espoo (near Helsinki), Finland. Contact: RI Finnish Committee, Parkaritutvantie 4, 00410 Helsinki 41--Finland.

RETROSPECTIVES

A. At the last World Congress of the International Organization of Consumers Union (IOCU) in The Hague, prominence was given to the needs of people with disabilities. Since good design is crucial in extending the range of people who can use equipment, in 1981 IOCU became one of the joint sponsors of an international symposium on Design for Disabled People. At this symposium it was able to emphasize 1) the importance of comparative testing, and 2) the importance of evaluating ordinary products in the light of the needs of disabled and elderly people. A second such symposium was held in Tel Aviv in November 1984, again organized by the Israel Centre for Industrial Design, with IOCU as one of the joint sponsors. These symposia are particularly imaginative and valuable in that they bring together rehabilitation workers, industrial designers and engineers covering wide field of specialties plus, of course, disabled people. With the emphasis on design, they also bring together aesthetic and functional aspects. IOCU links the activities of consumer organizations in some 50 countries and promotes world-wide cooperation in consumer protection, information and education. Contact: IOCU, Emmastraat 9, 2595 EG The Hague, Netherlands. Tel. (3170) 47 63 31; Telex. 33561. Regional Office for Asia and the Pacific: P.O. Box 1045, Penang, Malaysia. Tel. 04-20391; Telex. MA 40164 APIDCU. (Edited from a report "Consumer Organizations and the Disabled Consumer" by Michael Dunne, Consultant on Disability to the Research Institute for Consumer Affairs, London)

B. In Fall 1983 a group of professors at the University of Siegen in West Germany (Universitat-Gesamthochschule-Siegen, Fachrichtung Sozialwesen, Holderlinstrasse 3, 5900, Siegen 21, Federal Republic of Germany) joined in a collegial seminar to discuss the problems encountered by disabled persons within German communities and the difficulties in bringing about institutional changes which might ameliorate these problems. Eight resident academic professionals were joined by 2 visiting sociologists--Professor M. Sokolowska from Poland and Professor S. Tannenbaum from the U.S. A result of these discussions was the organization of a collaborative seminar presented during Spring 1984 to interested students. Its focus was upon the concept of normalization, its application to the amelioration of the problems of disabled people and to their socialization within society, and its feasibility within the existant German welfare structure. The following papers were presented: "The Principle of Normalization as a Conceptual Guideline for the Structuring of Social Assistance" by N. Schwarte, U. of Siegen; "Possibilities for Normalization of the Mentally Handicapped" by S. Weinmann, U. of Siegen; "The Problems of Professionalization within the Helping Professions" by R. Depner, U. of Siegen; "Normalization and the Differentiated School System" by H. Linden, U. of Siegen; "Medicalization and Normalization in Connection with the Concepts of Disease and Disability" by M. Regus, U. of Siegen; "The Training of Bodily Movements and the Principle of Normalization" by K. Weber, U. of Siegen; "Cooperatives of the Disabled in Poland: Is This a Form of Social Integration?" by M. Sokolowska, U. of Warsaw; and "Theories and Strategies for Integrating Juvenile Delinquents in the U.S. Social and Economic Systems" by S. Tannenbaum, U. of Houston. In the first session the concept of normalization was explored and the need for further discussion voiced. The continued participation of the students was a gratifying component

of the seminar. Given the German tradition of "academic freedom", their repeated expressions of interest met a very stringent criterion of involvement. An important by-product of the participation of the 2 visiting sociologists was that they provided the first concrete instance at the U. of Siegen of collaboration between the traditionally academic and the more practical professions of the school. (Edited report by Magdalena Sokolowska).

C. "American Healing Systems: An Introduction and Exploration," A Public Conference funded by the National Endowment for the Humanities, Philadelphia, Pennsylvania, June 8-10, 1984. Twenty folklorists, anthropologists and healers (ranging from M.D.s to folk healers) presented lectures and workshops focused on illustrative examples of the various healing systems currently found in the North-eastern U.S. Those attending ranged from the general public to scholars of the healing arts to proponents and practitioners of the various systems under discussion. This mix allowed for both descriptive presentations and debate concerning the risks and benefits of the various systems under discussion, including medicine. The goal was to understand the sources and nature of conflicts among systems and to seek bases for rational discussion among the divergent points of view. (The actual scientific evaluation of systems was explicitly excluded from the primary goals of the conference.) The sessions were audio and videotaped, yielding very useful ethnographic documentation of the interaction at the conference. The tapes and papers will be used to produce both a video package for educational purposes and a book composed of formal papers by the scholar participants and transcriptions of discussion among all participants. A small illustrated loose-leaf book (92 pp.) was written for the conference by the conference organizer, David J. Hufford, of Pennsylvania State University's College of Medicine. The book is a presentation of the primary issues: a systems approach to understanding healing, conflict and negotiation among systems, "natural" versus "supernatural" beliefs, the mechanics of clinical decision-making in situations of intersystem conflict, responsibility, suffering and death in healing systems; two descriptive studies of illustrative systems: health foods (a "natural system") and Roman Catholic pilgrimages for healing in North America (a "supernatural system"); and an annotated bibliography. It is published by The Medical Ethnography Collection of The M.S. Hershey Medical Center, Hershey, Pennsylvania and is available for \$6.50. (Edited report by David J. Hufford, Director, The M.S. Hershey Medical Center, Hershey, Pennsylvania)

SOLICITATIONS

A. The Texas Planning Council for Developmental Disabilities seeks studies and other information on computer applications by people with developmental disabilities for their study "A 'State of the Art' Survey of How Clients with Developmental Disabilities are Using Computers." The project will attempt to survey programs and services currently using computer technology, the characteristics of the computer applications and how the applications were developed, among others. The information collected will be compiled into a computerized data base of services, programs, applications and experts using computers in Texas. An action plan with recommendations for future activities and a written report will also be compiled. Contact: Dick Schoech or Ken Bastin-Martin, Univ. of Texas at Arlington, Graduate Sch. of Social Work, P.O. Box 19129, Arlington, Texas 76019.

B. Robert Mauro is seeking comments from those interested in an electronic newsletter that he would like to produce called "Sex, Attitudes and the Disabled" by and for disabled people. Accessible monthly worldwide via any computer with communication capability with the SOURCE, it would be geared to all people: disabled, nondisabled, professional and nonprofessional, for the purpose of sharing ideas, the breaking down of barriers, and the dissemination of information. "For, being disabled myself" (& editor of two print news digests for the disabled of New York City), "I know how important this is.... before I am permitted to start an electronic newsletter on the SOURCE, I must demonstrate to their editors that there is an interest in it. Therefore, please send me your comments today (on your organization's stationery if possible). I can be reached at SOURCE MAIL BOG138 or at 257 Center Lane, Levittown, New York 11756; 516/579-4043."

CALL FOR PAPERS

A. SPSSI Program Proposals (Poster/Individual Papers; Symposia) are sought for the 93rd Annual Convention of the American Psychological Association, Los Angeles, California; August 23-27, 1985. The theme, "How to Make a Difference--Individually and Collectively," encompasses topics ranging from individual accomplishment to interpersonal effectiveness to community, political and social change. It will address what it takes to have an impact in the various parts of our lives and how to encourage action that leads to such impact. Proposals representing all areas of psychology and a wide range of theoretical perspectives, topics and methods are appropriate. A limited number of individual proposals will be accepted for poster sessions both on the theme and on other social issues. No individual papers will be accepted, however, and authors are encouraged to collaborate and submit a symposium, the major format of the program. Contact: Dr. Susan K. Green, SPSSI Program Chair for 1985, Dept. of Psychology, George Washington Univ., Washington DC 20052; 202/676-7486. Deadline is January 20, 1985.

B. The International Congress on Special Education invites papers from all professionals concerned with the growth, development, care and education of children and young people with special needs for its symposia and poster sessions, Nottingham, England; July 16-19, 1985 (Check if deadline is past). Contact: Dr. Brian Stratford, Secretary, Program Committee, Sch of Education, Univ. of Nottingham, University Park, Nottingham NG7 2RD, England.

C. The Association for the Social Sciences in Health seeks papers for its sessions of the Annual Meeting of the American Public Health Association, Washington D.C.; November 10-14, 1985. Papers should present a significant social science perspective on issues and topics of public health broadly defined and may be a report of completed or continuing research, developments in methodology, policy analysis or other appropriate subjects. Submit 6 copies--1 camera ready & 5 photocopies--of abstract on standard abstract form for the 113th APHA annual meeting, accompanied by stamped, self-addressed envelope by April 1, 1985 to: John F. Newman, Director Research & Development, Blue Cross and Blue Shield Assoc., 676 N St. Claire St., Chicago, Illinois 60611.

D. Dorothy C. Wertz seeks original papers for Research in Health Care, Vol. 7, a research annual designed to include long papers (50-75 typewritten pages or up to 100 pages). The series is designed to repre-

sent a wide variety of perspectives on health and is open to contributions that are interdisciplinary or that consider broad sociological, ethical, or socio-historical issues, as well as those that use more traditional approaches in the sociology of medicine. Although the editor would prefer to receive a draft of the entire paper, a prospectus or abstract is acceptable for initial contact, provided it is sufficiently detailed. Contact editor by April 1, 1985. Notification of acceptance will be sent by July 1, 1985 with final paper due November 1, 1985. Contact: Dr. Dorothy C. Wertz, Editor, Social and Behavioral Sciences Section, Sch of Public Health, Boston Univ., 80 E. Concord St., Boston, Massachusetts 02118.

E. The Hospice Journal, a new refereed multidisciplinary forum for clinical and research aspects of care for the dying, edited by Dr. David Bush, Hospice of Central Iowa, invites articles that focus on applied research or evaluation of care of the dying; pertinent reviews of research, theory, or improved methods of clinical care; or case studies with broad clinical or research implications. For format and other information contact: Lenora Finn Paradise, C201 East Fee Hall, Michigan State Univ., East Lansing, Michigan 48824.

F. Reference Library of Sociology Series solicits a wide variety of types of manuscripts/proposals in sociology and related disciplines for annotated bibliographies, handbooks and sourcebooks in specific branches of sociology and on issues of contemporary interest. Contact: Series Editor Professor Dan A. Chekki, Univ. of Winnipeg, Winnipeg R3B 2E9, Canada.

G. Journal of Applied Social Sciences invites papers in the sociology of social welfare, applications of the social sciences to human services, etc. 3 copies of the paper, APA style, and a 150 word abstract should be sent to: Pranab Chatterjee, Editor, Journal of Applied Social Sciences, Case Western Reserve Univ., Cleveland, Ohio 44106.

H. Beginning in January 1985, Saunders Press announces publication of Medical Heritage, a new juried bimonthly journal devoted to medical history and medicine and the humanities. Submit manuscripts and illustrations (color or black & white) in triplicate to Sharon Romm, M.D., Div. of Plastic Surgery, Univ. of Kentucky Medical Center, Rm. MN275, 800 Rose St., Lexington, Kentucky 40536. Honoraria will be awarded for articles accepted for publication.

I. Parenting Studies, an international quarterly journal designed as a forum for professionals and scholars, is concerned with the study of parents, understanding their role in society, improving skills of coping and family management, understanding the elements of parental success and failure, and fostering interests in the improvement of family life in a variety of cultural, geophysical and socioeconomic environments. It also will address parenting chronically ill and disabled children. Contact: Senior Editor, Dr. Sedahlia Jasper Crase, Dept. of Child Development, Iowa State Univ., Ames, Iowa 50011. Subscriptions: Indiv. \$25/year, \$45/2 years; Institutional \$40/year, \$75/2 years; Student \$15/year, \$25/2 years. Payable to Parenting Studies, P.O. Box 1344, Oak Brook, Illinois 60521.

OPPORTUNITIES: FUNDING/PROGRAMS/RESOURCES

A. The Social Research Dept. of the American Foundation for the Blind

announces \$2500 (dispersed between 2 award deadlines--January 2 and April 1, 1985) to be awarded for doctoral dissertation research in areas of its concern. The Jan. proposal deadline is for awards intended to help support research that is proposed to be undertaken or underway during the year April 1, 1985 to March 31, 1986; winners will be announced March 15, 1985. Preference will be given to outstanding proposals whose results may have national policy significance within AFB's priorities: problems of visual impairment as related to Aging; problems of visual impairment as related to Ethnic Minority Status; improving Education or Employment of blind or visually impaired persons; provision of Low Vision services. It is advised that potential applicants contact AFB by mail or phone in advance of submitting a full proposal, especially given the immediacy of the deadline. Contact: Corinne Kirchner, Director, Social Research Dept., American Foundation for the Blind, 15 West 16th St., New York, New York 10011; 212/620-2140.

B. John E. Fogarty International Center for Advanced Study in the Health Sciences announces that senior postdoctoral fellowships are available for outstanding U.S. health scientists who wish to conduct collaborative research abroad--e.g. collaboration in health studies, basic or clinical research, familiarization with or use of special techniques and equipment not otherwise available to the applicant. Applicant must be a U.S. citizen or permanent resident; hold a Ph.D. in one of the biomedical, behavioral or health sciences; have 5 or more years of postdoctoral experience; have professional experience in one of the health, biomedical or behavioral sciences for at least 2 of the last 4 years; hold a fulltime appointment on the staff of a U.S. non-profit institution; be nominated by the dean or appropriate U.S. institutional official; be invited by a non-profit foreign institution; and not be a previous recipient of a Senior International Fellowship. Deadline is January 15, 1985. Fellowship awards are for 3-12 months.

C. The Spina Bifida Association of America awards grants up to \$5000 each for research related to the care and treatment of spina bifida. Sociological proposals are encouraged. Application deadline is March 1, 1985 with winners to be announced in May. Contact: Rosalyn Benjamin Darling, Director, In-Home Services, City-County Clinic, 111 Johns Street, Johnstown, Pennsylvania 15901.

D. The National Institute on Aging invites grant applications for research and research training which focus on the remarkable and unexpected increases in longevity at the later ages and the future explosive growth of that segment of the population. Research here will include ongoing studies of such questions as: What will the old of the future be like--in health, functioning, values and attitudes? What changes will be made in social structures to accommodate their needs and utilize their potential contributions? What is the quality of existing data and how can this be improved? Deadlines are March 1, July 1, November 1. Contact: Ms. Mildred D. Mader, National Institute on Aging (The Oldest Old), Bldg. 31C, Room 4C32, 9000 Rockville Pike, Bethesda, Maryland 20205.

E. The National Cancer Institute (NCI) is accepting applications for paid (about \$8000) 6-month full-time internships at the NCI in Bethesda, Maryland for graduate students interested in health communications. Applications for the July to December 1985 program are due March 31, 1985. Contact: Joan Chamberlin, Internship Director, National Cancer Institute, Office of Cancer Communications, Bldg. 31, Room 10A1B, 9000

Rockville Pike, Bethesda, Maryland 20205; 301/496-5583.

F. William T. Grant Foundation awards 5 young research workers annually in the field of children's mental health. Institutions where scholars work receive \$150,000 plus indirect costs for partial support of the scholars for 5 years. The purpose of the awards is to protect the research time of the scholars during the critical early years of their careers. Preference is given to applicants working in the field of the Foundation's principal interest--understanding how school-age children cope with stress which may lead to failure to fulfill their potential. Deadline is July 1. Contact: William T. Grant Foundation, 919 Third Ave., New York, New York 10022; 212/752-0071.

G. The Carnegie Corporation has announced a grant and project program related to 4 goals, two of which might be appropriate to people working in the area of disability and chronic disease. The program on the prevention of damage to children will concentrate on preventing school failure and school-age pregnancy, and explore problems of childhood injury and substance abuse. The program on developing countries "will try to stimulate U.S. interest in developing countries, especially the need to strengthen the human resources that are so central to the task of upgrading development opportunities in the future. This means good health and adequate nutrition, basic education, and families of workable size." Special attention will be given to countries in particular regions of Africa and the Caribbean. Contact: Carnegie Corporation of New York, 437 Madison Ave., New York, New York 10022; 212/371-3200.

H. Scientists in health research who are interested in an administrative career with federal programs supporting research, training, and services in health-related fields may be interested in the Grants Associates Program of the U.S. Public Health Service (PHS) which prepares each grants associate for a responsible position in health science administration in the federal government. Admission to the program is highly competitive. Motivation, good interpersonal skills and evidence of executive potential are important qualities. U.S. citizens with a Ph.D. or equivalent degree in a discipline related to biomedical or behavioral sciences, who have significant independent postdoctoral research experience, and are interested in health science administration as a profession should contact: Director, Grants Associates Program, Office of Extramural Research and Training, Building 31, Room 1B-552, NIH, Bethesda, Maryland 20205.

I. A subcommittee was formed by the Social Science Research Council's Committee on Life-Course Perspectives on Human Development (1977-to date) to examine the current and potential theoretical and methodological interactions of child developmental and life-span human developmental research. The program consists of conferences to consider conceptual and methodological developments in specific topics and workshops to design and assist the initiation of research on particular areas. Also it will co-sponsor a Summer Institute on Human Development and Social Change, prepare a catalogue-type inventory of more than 100 longitudinal studies of childhood from the U.S. and abroad, and assemble a bibliography of research reports and publications of relevance to the study of child development in life-span perspectives. Though participation is by invitation, interested scholars should offer papers for the bibliography and inform the Council of their longitudinal studies of relevance to the inventory. Contact: Lonnie R. Sherrod, Social Science Research Council, 605 Third Ave., New York, New York 10158.

J. The 1984-85 Handicapped Funding Directory features over 600 corporations, foundations, government agencies and associations which fund institutions and agencies providing programs and services for individuals experiencing handicaps. It also includes guidelines on how to obtain a grant, addresses of state agencies and their directors, and a bibliography of grant funding publications. Cost is \$18.95. Contact: Research Grant Guides, P.O.Box 357, Oceanside, New York 11572.

K. Guide for Researchers in Search of Funding, an updated guide to research funding in the behavioral sciences will be published by the American Psychological Association in mid-June. The second edition of Guide to Research Support updates information on federal government sources of funding for behavioral science research and also provides a new section on nonfederal sources of research support, mostly foundations. The Guide is the only sourcebook of its kind designed to assist researchers in the psychological, cognitive, and behavioral sciences. It is available through the APA Order Dept., 1200 Seventeenth St. N.W., Washington DC 20036. Price for APA members is \$20; non-members \$25. Add \$1.50 for postage and handling.

CURRENT RESEARCH

A. Marc L. Berk, PhD, Gail R. Wilensky, PhD, and Steven B. Cohen, PhD in "Methodological Issues in Health Surveys: An Evaluation of Procedures Used in the National Medical Care Expenditure Survey" reported on the unique methodological problems encountered in the National Center for Health Services Research (NCHSR) survey--the largest survey ever done of medical care costs and use--as well as a variety of issues common to large-scale survey research. The survey obtained information from 14,000 households in 1977 and from household members' doctors, employers and insurers. An analysis of some of the problems shows that proxy reporting, which permits a household member to provide information about other household members, is cost effective and may be useful in collecting certain types of data when the respondent is not directly available. Further, the use of proxies does not increase bias in reporting of stigmatizing conditions, such as cancer, and has only a moderate negative effect on the equality of data obtained from physicians. Fears of invasion of privacy do reduce survey response, but other factors--including lack of time, little interest in participation, and unspecified reasons--apparently are more important causes of nonresponse. Results indicate that the key to obtaining high response rates lie in convincing respondents that the survey merits an expenditure of their time. This means that increased attention should be focused on sensitizing interviewers to the perceived burden of survey participation. Their report is available from NCHSR, Publications and Information Branch, 1-46 Park Building, 5600 Fishers Lane, Rockville, Maryland 20857.

B. Freddie W. Litton, Ph.D., and James H. Miller (Dept. of Spec. Educ., Univ. of New Orleans) in their study, "Death Perception of Educators," examined the problems faced by educators in dealing with children with chronic illnesses, multiple impairments, and severe disabilities who are considered high risk for early death. It was hypothesized that the variables age, locus of control, religious preference, and position held within the educational community would be related to expressed death anxiety; and that death anxiety would be related to prior experiences with death. The hypotheses were tested and rejected. An ancillary

analysis, however, indicated that subjects expressed the desire for death education for educators as an aid to understanding and forming death attitudes. Subjects in the study were 160 educators--principals and assistant principals, counselors, regular teachers, and special educators--selected from 3 school systems in Louisiana.

C. For the past 4 years Ann Turnbull and colleagues at the Research and Training Center on Independent Living have been working to develop systems approach to working with families that include disabled members. The project's current focus is on developing and disseminating strategies to help families cope with the stress associated with increased independence of a disabled family member. A study was initiated to examine future planning as an effective strategy for dealing with a disabled son or daughter's transition from home to a more independent lifestyle: are families who plan in advance for transitions better able to deal with stress and, if so, what planning strategies are most successful? A second research study was initiated to develop and evaluate problem-solving strategies for families with disabled members. Researchers are working with counselors from the Topeka Resource Center for the Handicapped to develop group and individual training activities and materials. For more information about RTC/IL projects, contact: The RTC/IL, 348 Haworth, The Univ. of Kansas, Lawrence, Kansas 66045.

D. Renee Waissman (Centre National de la Recherche Scientifique, Centre D'Etudes Sociologiques, Paris, France) writes that her research during the past few years has followed a sociological approach to health and illness in an attempt to understand the processes through which social relations are established and shaped by the applications of technological innovation. These relations involve the patient both with the hospital's medical staff and with family. In this approach, illness is defined from "the social point of view," which has an impact upon medical practices, given organizational changes in the professions and in hospitals. Such changes shape these social relations into a new technical system. Study has thus been centered upon the patient, specifically children who, stricken with a terminal illness (chronic renal failure) are kept living through sophisticated techniques (namely, kidney transplants and/or various methods of dialysis). This approach has led her to analyze: 1) the way that various actors act toward illness, observable through the types of medical care; 2) illness as being socially constructed through medical practices and through the interactions of the family with the medical staff as well as with the sick child and of the family with the staff; 3) the patient as a social actor; and 4) the patient as a consumer of health care. Her interest in the chronic patient leads her to specify his/her social status in the society at large.

RECENT DISSERTATIONS

A. Elizabeth Eastwood (Service Utilization Patterns of Community-Based Mentally Retarded Persons in Massachusetts, Brandeis University, 1983) did a study of 3011 persons with mental retardation living in the community who were receiving services from the Mass. Dept. of Mental Health (DMH). The study's purpose was 1) to delineate the service utilization patterns, and 2) to test a series of hypotheses which were thought to explain both service usage and service needs. Findings indicated that medical services were most heavily used by clients, and there was a low rate of unmet need for these services. Most supportive services, such as occupational and physical therapy, home-helper and respite services,

however, had very low rates of usage. Several of these services had high rates of unmet need by clients. Using multiple regression techniques, it was found that measures of disability best explained service usage. Furthermore, being former institutional residents, who are now considered DMH priority clients, was also related to service usage. On the other hand, living with a family, independently or in special programs for persons with severe disabilities (modified group homes), was related to need for services.

B. Robert Lerner (The Handicapped Persons' Rights Movement as a Cause of the Increase in Social Security Disability Insurance Applications, University of Chicago, 1984) studied the Handicapped Persons' Rights Movement as an important social movement, responsible for enactment and enforcement of anti-discrimination legislation in recent years; as part of the "disability system in the U.S."; as well as the force responsible for the major increase in applications for Social Security Disability Insurance during the 1970s. The wider implications of his research to the study of other social movements are also discussed: 1) unlike much policy research, he was able to show that a variable of sociological interest--the intensity of the Handicapped Persons' Rights Movement--had a significant impact on a major social program and is potentially manipulable by policy makers or other interested persons; 2) the study of disability can be relevant both for social policy and for the discipline of sociology--stratification, minority group relations, etc.

C. Martin M. Sawzin (Deviance to Difference: Documenting Skills of a Child with Down's Syndrome, Boston University, 1984) analyzed a series of videotapes of a Mother and her 6 1/2 year-old daughter with Down's Syndrome who was diagnosed as moderately retarded. The case study documents over 300 interactional and communicational skills displayed and used by the child in one-9 minute period and also demonstrates the benefits of broadening the scope of interactional sequence analysis to include patterns both internal and external to situations captured on tape. Several new analytical models are developed to illustrate how communication skills draw on multiple contexts simultaneously. Also highlighted is the value of documenting human interaction patterns in contexts familiar to the subjects in question. The quantity and qualities of the findings challenge theorists, researchers, and educators of language use in 2 important ways: 1) New language and interactional stimulation techniques can be designed to develop interactional fluency and communicative skills; and 2) assessment tools are offered to document sequence participation skills that are based on pragmatic situations, and these tools are very much needed to balance the current reliance on formal rule criteria to define skillful action.

FILM CLIPS by Nora Groce (Family Dev., The Children's Hospital, Boston) and Gary Kiger (Sociology, Utah State University)

A. MAY'S MIRACLE: MUSICAL GENIUS DESPITE RETARDATION color, 28 min.; produced by Canadian Broadcasting Corp.; distributed by Filmmakers Library, 133 E. 58th St., New York, NY 10022. Sale: 16mm \$450; rental: \$50; videocassette, sale only: \$400.

B. DAVID: A PORTRAIT OF A RETARDED YOUTH color, 28 min.; produced by Canadian Broadcasting Corp.; distributed by Filmmakers Library (see above). Sale: 16mm \$425; rental \$50; videocassette, sale only \$375.

These 2 films have been grouped together because they are both part of the CBC series "Man Alive" with Roy Bonisteel. Both suffer from the same flaw, although David is the far better of the two. May's Miracle

concerns Lesley, May and Joseph's 29 year-old adopted son, who is described as being blind, severely retarded, and having cerebral palsy. Despite his inability to see and extremely delayed ability to walk and talk, Lesley at the age of 16 suddenly began to play the piano, displaying what is called "a rare musical talent." We are told that the medical term for his condition is Idiot-Savant--a very imprecise term, not actually used by those who work with mentally retarded people. In fact, the viewer is left with the very definite impression that Lesley's condition deserves more accurate medical follow-up. May is sure that his music is a miracle from God, and Roy Bonisteel provides little more insight. The film begins with an interview with Lesley's parents in which May describes what a wonderful parent she has been. This follows with scenes of Lesley playing the piano while his parents and Bonisteel sit by, apparently awed by the miracle they are witnessing. It ends as Bonisteel attempts to read a dictionary definition of 'miracle,' only to be interrupted by a hymn sung by Lesley in the next room. Presumably the film's intention is to show how even those with severe mental retardation have hidden talents and surprising abilities. Depending on the viewer's orientation, the information contained in this film can only lead to the conclusion that Lesley is the result of a whim of nature or a miracle of God. Neither approach is particularly appropriate to increasing our understanding of mental retardation in the latter part of the 20th century. (Nora Groce)

David is about David McFarlane, a Toronto teenager who has Down's Syndrome. An exceptionally alert and accomplished young man, he starred in the CBC drama "One of Our Own," about a child with Down's Syndrome. David's ability to master a number of things recently thought beyond persons with Down's Syndrome can largely be attributed to his parents who treat their son's disability with intelligence, compassion, and humor. The bulk of the film is about David himself and the dynamics of his family that allow him to blossom. Because of this, David can be recommended to both lay and professional audiences--with one reservation. The reservation concerns the narrator/interviewer, Roy Bonisteel. Here, as in May's Miracle, Bonisteel's leading questions and inappropriate comments are distracting. In the opening scene of David, for example, he even refers to David as mongoloid, and perhaps because of this, views David's accomplishments as amazing. David McFarlane's story rises above such sentimentality; Lesley's does not. (Nora Groce)

C. BEST OF ALL A DANCER 1983, color, 11 min.; produced by Richard Heus; distributed by Direct Cinema, Box 69589, Los Angeles, California 90069. Sale and rental information from distributor.

Best of All a Dancer features a 32 year-old man with Down's Syndrome who incorporates his talent for drawing and painting into his dance. This film pushes us to rethink our perception of grace, imagery and style. The production, however, lacks the advocacy theme so well threaded through Richard Heus' earlier film, Feeling Good, Feeling Proud. Best of All a Dancer is a lyrical, beautiful film, but it invites us to appreciate dance passively instead of inviting us to be interested actively in developmental disabilities, all of which is not to say that it is a weak film. It is not. But, if you are seeking a powerful educational and advocacy tool, you could no worse than choosing Heus' previous work, Feeling Good, Feeling Proud (This film is reviewed in the January 1984 DCDQ). (Gary Kiger)

D. IF YOU KNEW HOW I FEEL: BRAD'S LEARNING DISABILITY 1982, color, 18 min.; written by Trudy Travis; directed by Linda Haskins; produced by Centron Films; Distributed by Coronet Films, 65 E. South Water St.,

Chicago, Illinois 60601. Sale: 16mm \$392; Video \$255; Rental: from distributor.

Brad's Learning Disability is an excellent addition to the "If You Knew How I Feel" series, and it was deservedly a top contender for the 1983 American Film Festival awards. The story line focuses on elementary-aged students and their teachers. Brad has a learning disability, has a difficult time reading, but is an ace at kickball. Kristi is rather klutzy at kickball but reads quite well. Terry is in a wheelchair, participates avidly in recreational activities and does well in school. Initially Kristi thinks Brad is lazy since he doesn't complete his assignments and is forever conning the teacher to read for him. The classroom teacher asks Kristi to help Brad by reading to him. Through their interactions, Kristi learns that Brad is, in fact, quite intelligent. She draws an analogy between her lack of talent at kickball and Brad's difficulties with reading. By the end of the film Brad is doing better with his reading skills and Kristi is picked by him for the kickball team. They give one another a chance. This film gently and clearly presents a number of complex issues: 1) to the extent that Brad's disability is "hidden," his classmates are not compassionate. When he is ridiculed by another student, Kristi jumps to his defense by pointing out that no one makes fun of their classmate who is in a wheelchair; 2) the film illustrates how self concept is dependent, in large part, upon how others respond to us. Whether the activity is kickball or reading, reactions from peers are not to be underestimated. This is a straightforward as well as sophisticated film which would serve as an excellent discussion vehicle. I suspect that students would identify easily with the characters and situations. (Gary Kiger)

BOOK ETC. NOTES

A. Teaching and Training the Handicapped through New Information Technology by Jorgen Hansen, mentioned in the 10/84 DCDQ (p. 16; L), was a study by the Commission of the European Communities, headquartered at Rue de la Loi 200, B-1049 Bruxelles, Belgium.

B. Berkovici, Sylvia M. Barriers to Normalization: The Restrictive Management of Retarded Persons. Baltimore: Univ. Park Press, 1983. Sylvia Berkovici's book is an excellent introduction to the normalization principle and its application to the lives of persons labelled mentally retarded. The normalization principle as expounded by Wolfensberger (1972) calls for the opportunity for clients to live, work, and engage in activities in as culturally normative situations as possible. The basis for the book was an 18-month ethnographic study of 40 community based residential and 3 educational sites. Several of the residential sites were described in detail and included interviews with people living in residences and caretakers. Descriptions of the interactions between residents and caretakers provided a richness of detail about these individuals' lives. Residential settings were evaluated using 2 different client-centered ratings: Wolfensberger and Glenn's (1973) Program Analysis of Service Systems (PASS) and the King et al. (1971) Revised Resident Management Practice (RRMP). Unfortunately, most community settings were evaluated as being custodial rather than being normalizing. Berkovici discusses several methods by which community settings can be facilitative of personal growth, including alternative residential models, pedagogical models, and bureaucratic and legislative mechanisms. (Reviewed by Elizabeth Eastwood, Director of Research, Belchertown State School, Belchertown, Massachusetts)

C. Buscaglia, Leo and contributors. The Disabled and Their Parents, A Counseling Challenge (revised edition). New York: Rinehart & Winston, 1983.

This book's importance can be gleaned immediately from its title; disabled persons and parents are the basic subject matter and the disabled people come first. This is not a simple "how to" manual to teach parents how to "deal with" their children, teachers how to "teach to" children, etc. Rather, Buscaglia emphasizes that living involves learning about one's own experiences, needs, and biases. Until we take responsibility for our own actions, we are never truly able to help others. Featured in the core of the book are mother-authored essays on the family as well as other material written about and by disabled people. Buscaglia maintains that family members can learn to counsel each other. Also he writes, "There will be many people throughout the lives of disabled individuals who will try to influence their behavior, even attempt to make their decisions for them, but only they will be their own best counselor" (p. 208). This revised version differs in minor ways from the 1975 edition--e.g., the literature review, list of agencies, and bibliography updates--and a revised chapter on behavioral counseling techniques. I wish that Buscaglia had made some additional changes, as the inclusion of the single parent in his address to parents. Also, while I appreciate the sentiment expressed in his quote above, I find he glosses over the communication barriers involved with severe brain damage, etc. To what extent can a child with such disabilities become his/her own "best counselor," and how can a parent help? Similarly, his discussion of "acceptance" seems simplistic. The tension between accepting a person's (or one's own) disability and yet not giving up on possibilities deserves more attention. Finally, the book includes a chapter on resources, but no discussion of the possible difficulties involved in trying to obtain help from both governmental and nonprofit agencies. (Reviewed by Lynn Schlesinger, Soc., Brandeis University)

D. Downey, John A. and Niels L. Low. The Child with Disabling Illness--Principles of Rehabilitation. New York: Raven Press. This second edition closely follows the format of the 1974 version, although there is updated material in every chapter. It is a comprehensive text on disabling conditions in childhood; it includes substantial contributions by psychiatrists, including one of its editors, and it emphasizes rehabilitation and the psychosocial aspect of being handicapped. The chapters vary--some are purely clinical in approach, while others, such as the one on cystic fibrosis, include an extensive review of the pathophysiology of the condition. Although material on rehab care is included in every chapter, separate treatises are devoted to specific problems such as the foot in cerebral palsy and meningomyelocele. This interferes somewhat with the usefulness of the book as a reference since material regarding a particular entity may appear in several sections. The chapter on spinal cord injury is not primarily centered on young children, though material on etiology, increased risk of hypercalcemia, and progressive spine deformity are included. However, this review of cord trauma can be very useful for the pediatrician who may be called upon to manage the adolescent paraplegic in a children's facility. Because many of the authors are involved with care of children in a freestanding rehab hospital, material on very early developmental assessment and intervention is not extensive. The chapter on orthotics contains many interesting and practical ideas. The book's strong points are the comprehensive discussions on asthma, juvenile arthritis, and cystic fibrosis not found in rehab texts. This was a pioneer text and continues to deserve a place in any rehab library.

(reviewed by Phoebe Saturen, M.D., Dept. of Rehab Medicine, New York Medical College; original review appeared in Archives of Physical Medicine and Rehabilitation, Vol. 65, June 1984)

E. Elmer, Elizabeth. Eragile Families, Troubled Children. Pittsburgh, Pennsylvania: Univ. of Pittsburgh Press, 1977.

The purpose of this volume is to compare 17 abused children--8 years after the original incidents--with an equal number who had suffered accidents. The subjects were matched on age, sex, race and socio-economic status. There was no individualized treatment of parents or children. A second comparison was made of the first 2 groups above with a third group, a group having no reported accidents or abuse. All those groups were low in the social scale. The author reviewed three illustrative case studies in which few differences were found among the children in the various groups. She believes that there is some common factor operating, and this is identified as the families' membership in the lower social classes. Variables considered in the follow-up were health, neurological, school, language problems, nervous mannerisms, aggressive behavior, poor self concept and emotional disturbances. In other words, "the results of child abuse are less potent to the child's development than class membership." So, the current media campaign against child abuse is not what is needed--what is needed is a full-scale, coordinated attack on poverty. A selective approach via an attack on child abuse will not do justice to the problem. You cannot solve a problem by treating a symptom. The maltreatment of children is so widespread that it is a significant aspect of our society. It is more than individual pathology; it is a societal deviation and it grows and develops from the common utilization of physical punishment for children. We are pointing a finger but not extending a hand. (reviewed by Harold Silverman, College of Educ. & Human Services, Wright State Univ.)

F. Evans, Darryl Paul. The Lives of Mentally Retarded People. Boulder, Colorado: Westview Press, 1983.

This compelling, well-written book uses a unique approach as a treatise on various aspects of the lives of persons with mental retardation. The author spent 7 years in the field observing and speaking with persons with mental retardation as well as others who either worked or lived with them. The primary focus of the field study was a school for mentally retarded persons, fictitiously called the New Morning School. On the surface the book would appear to be a textbook, since the chapters cover a wide range of subjects from definition and history of mental retardation to social, educational, legal and ethical issues. Yet, in each chapter the author manages to integrate formal theoretical perspectives with field observations and sensitive discussion of issues. Throughout, he raises very provocative questions which stimulate the reader's imagination; and in the end he arrives at original conclusions regarding the subjects at hand, challenging the reader to rethink fundamental and critical assumptions. If the book has a flaw, it is that the introduction does not prepare the reader for what is to come. It focuses on the field study approach and does not justly credit the level of integration that is to follow. (reviewed by Joyce Pulcini, Florence Heller Grad. Sch. for Advanced Studies in Social Welfare, Brandeis Univ.)

G. Jacobs, Jerry. The Search for Self: A Study of the Retarded Child in the Community. Washington, D.C.: University Press of America, 1982. First published in 1969, this book was re-issued in 1982. Jacobs tape-records interviews of 14 San Francisco mothers who have a child with mental retardation enrolled in a public preschool program. Interviews

with 10 teachers of students with mental retardation and case records from a San Francisco mental health clinic serving retarded children and their families provide additional data for his study. Jacobs considers 3 major issues in his treatise. 1) The problems of diagnosis and prognosis, problematic primarily because of the lack of communication and forthrightness by the physician and the physician's expectation that parents won't "listen" anyway, is largely the cause for the "shopping around for a 'better' diagnosis" syndrome of parents. 2) The education of a person with retardation, Jacobs' parents (& teachers) tell us, is not much more promising: a lack of programs, resources, adequate teacher training and the attitude that "trainable" persons can't learn, result in teachers "playing it by ear" and "doing it because it works" when it comes to developing an appropriate curriculum; the teachers are usually quite pessimistic about the likelihood of comprehensive educational services for their students. 3) The effect of the presence of a child with retardation upon his/her siblings and parents--thoughts of infanticide, a rejection of institutional care as an option, sibling jealousy, and a "learning to live with it" is also examined. Jacobs concludes his study by asking persons and professionals alike to withhold acceptance of generally held assumptions about mental retardation until there are better grounds for accepting them. True--fear, frustration, anger and heartache are timeless; and in this sense, a re-issue of his 20 year-old study is a service. However, there have been many near revolutionary changes affecting persons with mental disability since the mid-60s that surely have effected the issues Jacob addresses. Personally, I prefer Evans' The Lives of Mentally Retarded People to Jacobs' book because Evans has maintained that sense of intimacy that Jacobs has done through the interview, while at the same time providing the reader with a thoroughly current review of the issues. (reviewed by Richard L. Meile, Soc., Univ. of Nebraska at Lincoln)

H. Pavlidis, G. and T. Miles (Eds.). Dyslexia Research and Its Application to Education. New York: John Wiley & Sons, 1981. The brain is a hardwired electronic system which processes all kinds of information and behavior. Not all of the connections are present at birth; many do not form until the second decade of life in humans. In the grand scheme of things biological, reading is a uniquely human skill and the one developed only a short time ago as our history goes. Curiosity about why some people do not learn to read is even newer, and only in the last 2 decades has progress been made in understanding the clues described by Orton 50 years ago. Despite a century of interest, this book shows that we seem no closer to an acceptable definition of dyslexia than we were in the days of "word blindness" and "strephosymbolia." We are still wondering about the meaning of those funny eye movements, and we can't agree on its cause or cure. Pavlidis and Miles have taken papers from 3 consecutive annual meetings on dyslexia held in Manchester, England, between 1978 and 1980 and chosen those that cross the boundaries between neurology, psychology and education. Ignoring the learning problems associated with brain damage, the attention deficit disorders, and the other problems of perception and conception which affect scholastic performance, they selected papers highlighting much of what is and is not known, organizing them into a cohesive work with a common style and natural development. This book, however, is particularly British and sometimes oblivious to things transatlantic. For example, in the U.S., dyslexia has been incorporated under the broader rubric of the learning disabilities, and every American school district has to provide programs for these children under the Education for All Handicapped Act of 1974, P.L.94-142 to obtain its share of Federal funds for

education. Furthermore, every college and university is bound by Section 504 of P.L. 93-112, the Rehabilitation Act of 1973, to provide similar services. The use of CT scans in research is barely commented upon. The introduction of evoked brain stem potentials into the research is unmentioned. Closer to home for the editors, the Swedish studies of brain blood flow and glucose uptake during specific tasks do not appear here. At the same time that the clinical observations of reporters such as Critchley, Rawson, Elaine Miles and Nadoo help clarify what we all see in the person with dyslexia, they say nothing about what to do or what happens when that person is diagnosed early, given adequate and appropriate help, and brought up to grade level in reading. Those of us who see these young people when they come to college have learned that dyslexia never goes away and that learning problems last a lifetime. If the treatment of this developmental disorder is effective, if the disorder subsides with age, then nothing in this book addresses older adolescents and adults who struggle with reading forever. Two months ago I received my copy of the Pediatric Clinics of North America on Learning Disabilities and now this book by Pavlidis and Miles. Neither is complete, and yet they complement one another. Alone, each has its deficiencies, but together, like cereal and milk, they can provide a satisfying view of dyslexia amid the learning disabilities today. (reviewed by Harris C. Faigel, M.D., Direc. of Univ. Health Services, Brandeis Univ. and Clin. Prof. Pediatrics, Boston Univ. School of Medicine)

I. Sourkas, Barbara M. The Deepening Shade: Psychological Aspects of Life-Threatening Illness. Pittsburgh, Pennsylvania: Univ. of Pittsburgh Press, 1982.

The Deepening Shade explores critical issues for those intimately involved with the experience of life-threatening illness. Specifically, the book is designed for mental health professionals as well as patients and families who may find affirmation among Dr. Sourkas' themes and concepts. Central to the discussion of living with a life-threatening illness is the theme of time and its altered meaning in the face of an illness such as cancer. Time, once the framework for an orientation to the past, present and future, becomes both the enemy and the savior. Dr. Sourkas examines time as it relates to the psychotherapeutic process. She analyzes diagnosis and life stages, clearly demonstrating that at each life stage there is a common anxiety among patients which is best described in her own words: "It is the fear that life will end before one has had the chance to live it as planned." Significant concepts within the book include issues of loss--loss of control, loss of identity, and loss of relationships experienced by the patient. The concept of 'neutral time' labels and provides insight into the living-dying interval when the only certainty is uncertainty. Anticipatory grief looks at the patient/families' emotional response to the inevitable pain of separation. Through the superb use of an annotated interview, Dr. Sourkas synthesizes the book's purpose as she shares and demonstrates her insight in an interview with one of her patients. One can certainly find value in each page of this brief and simple discussion. It is perhaps its simplicity that helps the reader to participate so fully and gain so much. (reviewed by Marla Kappan Chalnack, Mecklenburg Center for Human Development, Charlotte, North Carolina)

J. Weir, Robert. Selective Nontreatment of Handicapped Newborns. New York: Oxford University Press, 1984.

Robert Weir's book is essential reading for professionals and lay people seeking to understand the ethical controversy surrounding medical decision-making for severely anomalous and dying infants. In clear,

nontechnical language, the author presents the spectrum of medical, legal and ethical positions on critical care for newborns, discusses the hard choices that intensive care pediatricians face, and offers numerous case examples illustrating advantages and drawbacks of various decisions. Weir is uncommonly sophisticated about understanding the complexity of neonatal medical conditions and the array of treatment options available. Mindful of clinicians' need for concrete guidelines for decisionmaking, the ethicist/author continually emphasizes the practical applications of ethical and legal frameworks to clinical practice. He concludes by discussing the role of various decisionmakers: physicians, lawyers, parents, and hospital committees, (stressing the strengths and weaknesses of different models for involving them in making choices about whether infants should receive treatment, and if so, at what level of intervention. Weir acknowledges that many will disagree with the position he has taken. Given the wide range of opinions on treating or not treating infants (from those who would aggressively intervene with infants who will invariably die agonizing deaths, to those who would withhold treatment from Down's Syndrome infants having treatable physical anomalies). He takes a middle ground, describing conditions that should not receive treatment, but advocating treatment of the great majority of infants with severe birth conditions. He argues for medical and legal flexibility, erring toward concern for the best interests of the child. (reviewed by Dean Briggs, Dept. of Pediatrics, Univ. of Massachusetts Medical Center)

The following are first-person accounts of living with a disability.

A. Bogdan, Robert and Steven J. Taylor. Inside Out: The Social Meaning of Mental Retardation. Toronto: Univ. of Toronto Press, 1982. The implications of trying to tell it like it is as well as the methodological difficulties in trying to do so are vividly captured in Bogdan and Taylor's book. Many have argued about the importance of having first person accounts in the study of health and illness but Bogdan and Taylor should make one a believer. Over 170 of the 230 pages of this book are devoted to their edited autobiographies of 27 year-old "Ed Murphy" and 20 year-old "Pattie Burt"--2 people who have been labeled 'mentally retarded' by their families, teachers, and others in their lives. Both spent most of their early life under the guardianship of the state, either in an institution, a family-care placement, or a group home. For the past several years they are living "independently" and working on the margins of society. That they are able to do so is seen by their testimony and the judgment of their interlocutors. That they will continue or be allowed to do so will depend on the changing societal responses and responsibility to this phenomenon called mental retardation. That there are many differences between the "Eds" and the "Patties" of the world (many of which they themselves freely admit) and other people is undeniable. But what these differences are and whether they constitute some unified or even multidimensional "reality" is something that Bogdan and Taylor argue should be regarded as 'problematic.' Though they recognize that "Ed" and "Pattie" may be atypical in their articulateness, the effects of labelling as applied to them may be even more powerful, more stigmatizing and less reversible when applied to those called profoundly retarded. (reviewed by Irving Kenneth Zola)

B. Wilke, Harold H. Using Everything You've Got and Reflections on Managing Disability. Natl. Easter Seal Society, Chicago, Illinois, 1984. The Rev. Harold H. Wilke is an internationally known minister, professor, author, husband, and father of 5 young men. In 1973 he founded and

became the Director of Healing Community, a worldwide interdenominational group to help religious congregations become accessible to all persons. For 20 years he was Exec. Director of the United Church of Christ, Council for Ministry in New York; during World War II an Army Chaplain; and afterwards a Veterans Admin. Chaplain. He was born nearly 70 years ago without arms but he soon learned to replace what he did not have with his feet and his spirit. Some people called him "crippled." I call him friend. The National Easter Seal Society (2023 W. Ogden St., Chicago, Illinois 60612) has published these 2 booklets by him, capturing in print what I thought was impossible--the wisdom and even wit of this remarkable man. Using Everything is the nuts and bolts of what is too often missing in both personal and professional accounts: in vivid, concrete detail he tells how he copes with transportation, eating, household chores, child care, sports, hobbies, clothing, dressing, grooming. In Reflections he lays out the roots of his philosophy. He tells how he learned from each accomplishment as well as each rejection. Loving and resourceful parents nurtured a desire to never give up, not merely to overcome but to integrate. To paraphrase his closing words--he has stretched our horizons, reached out to the beyond, enlarged the place of our mental and spiritual habitation. (Irving Kenneth Zola)

CLASSICS REVISITED

Edgerton, Robert B. The Cloak of Competence: Stigma in the Lives of the Mentally Retarded. Berkeley: Univ. of California Press, 1967
Reviewed by Daryl Paul Evans (Soc., Univ. of Kansas)

Although this cloak is worn, it is far from threadbare. A return to Edgerton's ethnographic study of the post-institutional lives of 51 mildly mentally retarded persons, graduated from Pacific State Hospital between 1949 and 1958, was a pleasant reminder of the inspirational genesis of much subsequent work in the sociology of mental retardation. To be sure, because of the deinstitutionalization movement of the '70s, many mentally handicapped persons have not experienced the tremendous adjustment associated with moving from institutional life to "life on the outs" as described by Edgerton. But the parallel between the social experiences of Edgerton's erstwhile institutionalized respondents and those mentally handicapped persons who only have known a community-based existence are what makes Edgerton's book still relevant.

The question of how mentally handicapped people make a living; relate to their communities; establish marital, sexual, and filial bonds; spend their spare time; perceive themselves; and solve the practical problems of daily living are presented by Edgerton in a manner that remains informative to sociological researchers. This results from his focus on fundamental social issues, activities, and institutions, as well as from the richly descriptive--occasionally phenomenological--approach he takes to his respondents. In virtually all of Edgerton's case studies there are intimations of concern that have, since the publication of the book, come to be the focus of major studies in the sociology of disability. Moreover, Edgerton gave voices in print to a cohort of handicapped people who had, in all but a few research projects before his time, been the objects of study rather than the subjects.

The Cloak of Competence cannot be compared in the magnitude of its impact to a work such as Goffman's Stigma, but Edgerton's exploration of the "desperate search for self-esteem" in the lives of mentally retarded people will always have the ring of truth about it. This "cloak" is a garment worth trying on again.

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

The following edited contribution by David Pfeiffer is on a course entitled "Disability and Public Policy." His piece on "Rehabilitation" will appear in the April 1985 DCDQ.

David Pfeiffer, Professor of Public Administration at Suffolk University (Boston, Massachusetts 02108), has a background in political science, history, and theology as well as over 20 years in politics and policy formation at the local, state, and national levels. In addition, he has a disability from polio and began to use a wheelchair half-time over the last several years. He is part of a group of leaders of the disabled community in the state who have by their efforts directly changed public policy toward disabled people in Massachusetts. Building on this background, he has created 4 disability-related courses in the Master in Public Administration (MPA) at Suffolk University. All 4 courses are currently electives in the regular MPA curriculum. The average age of the students is around 28 with the average number of years of work experience (almost all in human services) being 6. Over the last 2 years the average enrollment in these courses, which meet once a week for 2 1/2 hours, has been about 21.

The first course, "Disability and Public Policy," is intended to be both the foundation course for the other 3 and the capstone course if taken as the last one. However, the courses are designed so that each can stand alone. This course examines administration and impact of public policy toward disabled persons. Much of the first four sessions is spent weaving together the themes of attitudes, socialization, and communications around the concept of stigma as put forth by Erving Goffman. The fifth session concerns developmental disabilities which are often seen as the most feared and misunderstood impairments and the individual with a developmental disability often the most stigmatized. Guest speakers during these sessions are disabled individuals--some of who work in the public sector--who bring their insight and experience into the discussion. Hence in 1983 when one of the students was the mother of a 16 year-old son with Down's Syndrome, they became the guest speakers for that session. The first part of the course is thus intended to illustrate how prejudicial attitudes toward disabled persons can produce bad policy or bad implementation of good policy.

The Disability Rights Movement and the legal framework of the policy system are covered next, since by this time students want to know what can be or has been done by and for disabled persons. The victories and defeats on the policy level are covered with these questions in mind. In addition, at this mid-point in the semester, many of the students have had their consciousness raised about the problems of disabled persons to the point that the class, in the words of one student, "makes me feel so bad." By covering the victories, without forgetting the defeats, the students seem to be better prepared to do some hard work on the major policy topics covered in the remainder of the course. One of the interesting sidelights is that at the beginning of the semester, very few class members know any people with disabilities. By the end of the semester virtually everyone mentions either a friend or family member who has a disability or admits to having a hidden one.

Finally, the topics of transportation, architectural barriers (including sensory barriers), housing, public accommodations, education, employment, and health care are examined with the last session covering independent living centers as the pattern for the future. It is in these sessions that policy makers provide invaluable input, such as the Direc-

tor of the State Office for Handicapped Affairs, the Commissioner for the Blind, the Director of the Governor's Office of Human Resources, the Chairperson of the Developmental Disabilities Council and the past chairperson of the Mass. Coalition of Citizens with Disabilities, the Director of the [Mass.] Northshore Assoc. for Retarded Citizens, the Director of the Developmental Disabilities Law Center, and a number of lawyers who litigate disability policy cases with the state. The assigned readings are varied and extensive. Students are required to write 2 papers: a study of a policy which affects disabled persons from a viewpoint worked out between instructor and class member; and one which "makes sense" of the course for the student through the use of weekly journals to help him/her reflect upon the meaning of disability in the 1980's in our society.

SPECIAL TO DODD - A REPORT FROM MANAGUA

by Mary Driscoll (Kennedy Memorial Hosp. for Children, Brighton, Mass.)

Carrying a carton of antibiotics, a used sewing machine, and therapy journals, I recently journeyed to Managua, Nicaragua on a mission. As an occupational therapist, sociologist, and political activist, I wanted to share my knowledge of my profession with Pina, the only occupational therapist in the country, and to demonstrate my solidarity with the people and their struggle. Mainly I wanted to help develop training programs, set up teacher and professional exchanges, and keep the rehab health communication lines open between the two countries.

The new Nicaraguan government is making a general commitment to improving the health of their population as well as to developing certain professions, such as occupational therapy. In part, their commitment is demonstrated by Pan American Health Organization figures which show them spending a larger proportion of its national budget on health than any other Latin American country. Secondly, there is a commitment of person power, such as in grassroots "Health Brigades," made up of women, youth, campesinos and neighborhood residents, which bring health education and preventive measures across the country.

Nicaraguan public policy recognizes that mental health is jeopardized by the constant strife in the rapidly developing country, and efforts focus on getting care to all. In 5 regions, psychiatric day hospitals are scheduled to open and walk-in psychiatric counseling centers have been set up in general hospitals. In almost every region a team of mental health workers work with grassroots groups to help patients readjust to their homes and workplaces. Occupational therapy is recognized as a major part of this process of reintegration--a process, for example, which has reduced the number of patients from 500 to 250 in Managua's psychiatric hospital. It was here I met with Pina. The O.T. Dept. is a large and attractive room which shows the creativity of a therapist with incredible material shortages. Using a team approach, she works closely with psychiatrists, psychologists, social workers, and nurses. The 5 low-level workers under her supervision must be re-trained in the psychosocial and neurodevelopmental analysis of activity and in overcoming their resistance to the professional functions of O.T. in psychiatry. The O.T. Services focus on 3 areas: 1) Improving ego strength through crafts, movement activities, and work activities; 2) Teaching occupational skills; and 3) Improving socialization by providing opportunities for development of social behaviors.

One of the biggest problems, she explained, is to shift the balance of power from the doctors to one of shared decisionmaking with the patients and health workers. It is difficult for professionals trained prior to the revolution to understand that people have a right to make

decisions about their bodies and their communities and to understand that the problem of health is more than a purely medical one.

Rehabilitation for persons with physical disabilities began in 1979. I met with Armando, a 25 year-old quadriplegic who had been at the Centro-Socio Vocational Center for nearly 2 years. There the 45 residents learn radio/TV repair, macrame, cane seating and tailoring, the choice of occupation and length of stay based on physical abilities. Since he had no need to worry about discrimination from employment (work is his guaranteed right), he viewed the problem of work as only one of material shortage. He told me that before the revolution, he was a "marginalized" person. The new government has made it possible for him to be "capacitated" and integrated into the society as a full citizen. Trained under the Ministry of Education, the health brigades for rehab are trained to educate the family and community members about how children and adults feel about their disabilities and to assist the communities to develop support systems for individuals returning to their communities.

The Nicaraguan rehab and mental health system emphasizes the non-medical system. Change in the community must augment change in the individual. As an O.T. and a sociologist, I am interested in the socialist response to those members of every society, who by reason of moderate or severe physical or mental handicaps, can participate in work only with significant social investment in their training and with ongoing support in the workplace. I found it remarkable that a developing country, with so many demands on its limited resources, should have made so significant an investment in the area of rehab and mental health. My plan is to continue to work with Pina to develop educational and training opportunities for Nicaraguan health workers in O.T.; to raise funds for purchase of therapeutic supplies and equipment; and to collect rehab journals and equipment for donation to the Boston Committee for Health Rights in Central America. Participation in these efforts is welcome.

MORE ON "DOES IT MATTER WHAT YOU CALL US?"

We have received many comments on the 7/84 FOCUS column, "Does It Matter What You Call Us?". The following is a letter we received from one of our readers, Adrienne Asch, regarding our name, DCDQ. We reprint it with her permission. What do you think?

To the Editor,

DCDQ fulfills a fine purpose and is a pleasure, but consider changing your name yet again. While I think that social scientists should not forget the distinctions among disabilities and not write of a "chronic disease" as though it posed no problem different from those of a static disability, the name is divisive politically and ignores the legally similar status of all disabilities under federal rehabilitation and civil rights laws.

Those of us working as scholars and activists on disability issues know that millions of the 36 million covered by rehabilitation and civil rights laws do not think of themselves as "disabled." Their arthritis, diabetes, heart, digestive, or respiratory conditions are private troubles; their inability to work, to get about the world easily, to live fully, they see as their personal failings and not a commentary on an obstacle-ridden society. They and the professionals who deal with them continue to think of themselves as ill and continue to eschew the word "disabled" or "handicapped," thinking it even more degrading and

stigmatizing than whatever word is used instead. Thus they rarely band together with others to voice their opposition to inaccessible environments or unlawful medical standards that bar them from employment, even though they benefit from their removal. While such people benefit from the activities of DREDF, ACCD, and other cross-disability civil rights organizations, they rarely join them or are rarely sought to do so.

Some of what prevents identification is the refusal to accept the term "disabled" or the word "disability" for these conditions, although federal and state laws cover all chronic health conditions as well as traditional disabilities. Let us continue to acknowledge differences but urge that one general term be used in the name of our newsletter and by people working with all those who are part of the population covered by the federal definition of "handicapped" under the Rehabilitation Act of 1973.

I urge that "disability" be the term used. "Disability" is short, clear, simple; it is the term espoused by leading advocacy and civil rights groups in the field. It is no shame to have a disability. Let our newsletter assist in getting that message across to scholars and practitioners alike.

Sincerely,
Adrienne Asch

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