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FUNCTIONAL ASSESSMENT IN REHABILITATION MEDICINE

Edited by

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Series Editor's Foreword

The *Rehabilitation Medicine Library* now includes a number of books that are either quite unique or the leading voice in a chorus of books. Here I recognized from its earliest moments that I was dealing with a new phenomenon: a book that can revolutionize rehabilitation medicine in a comprehensive way at the practical level. Like many aspects of health care, rehabilitation has moved very cautiously in the direction of genuine assessment of both what it does and the justification. The relationships of *process* and *outcome* are often only vaguely perceived. Useless procedures abound. Everybody believes "rehab is a good thing," but hard facts are often almost completely absent.

Politicians and administrators at all levels of hospitals and government are growing skeptical to varying degrees. As demands grow for a share of the decreasing money, decisions may be made that can harm disabled people because the medical and paramedical team cannot prove the value of some of its most cherished procedures. While *functional assessment* will not safeguard those procedures—indeed, it might lead to their early abandonment—it is a critically important feature of a new era in understanding the values of what we are doing with real people and with real expenditures of billions of dollars.

The power structure will read this book too. Fortunately, they will find here not a tale of woe but some prescriptions for sensible action; they also will learn that progress has been made already.

Drs. Granger and Gresham have been among the earliest of the physicians who recognized that we cannot just go on doing what we did because it seemed to satisfy many people—patients, families, administrators, financial people, and the health team itself. The last group often has been too busy assessing the problems of and caring for patients to do the necessary development of broader assessment tools. That simply must end!

The editors proposed and recruited a cross-section of the leading thinkers and doers in this critically important field. While much of what they write addresses the problems of disabled people in the industrially advanced western cultures, many of the models discussed surely must be a goal for eastern cultures and for southern nations where organized rehabilitation services are just beginning to emerge. Up to a billion people on the planet have significant impairments which could be addressed provided we had the

money, the workers, and—now we see—valid systems of assessment. I believe that this book will be regarded as a landmark and a "gold standard" in this vitally important aspect of medical rehabilitation. I am proud to have it in the *RML* series.

JOHN V. BASMAJIAN, M.D.

Foreword

That chronically ill and disabled persons in this country represent a growing national concern is undeniable. Approximately 35 million persons have physical or mental disabilities which limit their capacity to perform some function of daily living. Included in this number are a rapidly growing number of elderly persons who inevitably experience increasing limitations in their functioning as they advance in years. Numerous government programs have been developed over the years to assist disabled people in their struggle to live as independently as possible and to join in the social and economic mainstream of American life. Yet, the success of these programs has been varied, leaving still millions of disabled persons whose limitations consign them to isolation, lack of productivity, dependence on others, and, in far too many cases, institutionalization.

If we, as a society, are to meet the needs of disabled persons better, we need nothing less than an entirely new way of thinking about people with serious physical and mental limitations, i.e. we need to know more precisely who is "disabled" and what one's specific needs are. The current methods of defining and treating disabilities are, however, dismayingly primitive. We live in a society that has discovered the conveniences of labels which are not only insufficient, but often harmful. Disabled persons are generally categorized according to a medical diagnosis, for example, cerebral palsied, asthmatic, mentally retarded, schizophrenic, or paraplegic. These labels, however, presume that a medical diagnosis alone can yield solutions to the problems posed by disability, ignoring the equally important social, psychological, and economic factors involved in any successful habilitation or rehabilitation.

Medical labels also do a disservice to disabled persons by failing to take into account the interaction of one's strengths and weaknesses with their particular environments. As a result, doors may be closed and opportunities unexplored. For too long, we have taught blind people to fold sheets and retarded persons to put nuts and bolts into boxes, regardless of their particular characteristics and environments. These deeply rooted stereotypes are often perpetuated by our current system of special education, which is based on a categorical approach to handicapped children.

Public policies and programs whose purposes are to help chronically ill and disabled persons will not be more effective until we have more sophisticated measures of human function on which to base these programs. The

need for a new definition of disability based on functional impairment has been apparent for some time. Assessing an individual's functional performance in a specific environment would give professionals and policymakers a far better understanding of how to target services to the real needs of disabled persons. By focussing on an individual's functional performance, it also becomes possible to capitalize on his or her strengths in a positive manner, rather than simply attempt to compensate for the weaknesses. Moreover, functional assessment also directs proper attention to the possibility of modifying the environment in ways that enable functionally impaired persons to adapt to or compensate for their limitations, thus increasing their potential for living independently. That private industry has begun to realize the dramatic potential for technological applications in this area promises to increase our capacity to assist disabled persons to master their environments.

Most importantly, a functional assessment system would provide a far more accurate base on which to develop effective public policies affecting disabled persons. In the past, public policy has been hampered by the same myopic views of disability that have attenuated the effectiveness of most service programs. As public resources dwindle and dollars for human services become ever more scarce, however, the need for information which allows more accurate targeting of service needs and, thus, a more systematic approach to preventing unnecessary and costly institutionalization has become even more urgent.

Rehabilitation professionals have recognized the need for a functional assessment system for years. What is now new—and most exciting for those of us who have been touting the merits of functional assessment for some time—is the rapidly growing body of knowledge on which such a system can be built. The material in this book represents the latest state-of-the-art and technical information needed for a revolutionary shift in attitudes regarding disabled persons. As this technology becomes available in theory, policymakers will be able to be more responsive to the needs of disabled persons; as it becomes available in practice, citizens with functional limitations will be able to live more independently and with greater dignity. The information presented in this book is a first step that may begin to move us out of the dark ages toward a more enlightened view of functional limitations.

THOMAS JOE

Preface

Many convergent forces have produced the intellectual and professional climate that make this volume both relevant and timely. The process of clinical medical rehabilitation, which emerged in its current form at the close of World War II, has now matured to the point where clear documentation of outcomes is an obvious need. The application of scientific rigor to clinical as well as to laboratory observations, pioneered by Feinstein and others, has provided impetus and credibility to strivings for methodological excellence in assessing function. Common interests and overlapping goals with other disciplines have exerted a stimulating and encouraging influence. Finally, profound socioeconomic changes have shifted societal emphasis to conservation, prioritization, and cost-optimization of health and human service resources, among them medical rehabilitation.

Readers of this volume will find many answers to questions about what has so far been accomplished in the field of rehabilitation medicine related to functional assessment. In addition, the unanswered questions that must be included in research priorities of the 1980s are also clarified. Throughout, the need for a wider consensus on methodology and a more unified operational approach will be apparent. The lack of comparable data represents a major obstacle to a broadly effective approach to the challenges confronted by medical rehabilitation workers. By assembling the spectrum of contributions that follow, the editors hope to help stimulate the needed common endeavor that will begin to overcome these barriers. Meanwhile, a heightened awareness of these issues with a concomitant emphasis on outcomes, should facilitate a more rational and targeted approach to clinical program development in medical rehabilitation and enable the objective testing of the adequacy of the process.

At the national level, the need for a more unified and rigorous approach to functional assessment has been identified. The 1982 Annual Report of the National Council for the Handicapped called for a common terminology, a unifying conceptual framework, more field research, and greater communication among investigators. Internationally, similar needs and priorities are recognized. The 1983 United Nations Inquiry Regarding Assessment of Disability Legislation pinpointed a worldwide need for more research to document the nature and frequency of disability and to provide the means for documenting human needs and program effectiveness.

With publication of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) by WHO in 1980 (1), we are now ready for a vigorous new effort in functional assessment research, utilizing the conceptual and taxonomic progress that Saad Nagi, Phillip Wood, and other contributors have produced. We hope that the material assembled in this volume will be a helpful resource to those who wish to participate in this important endeavor.

The editors first developed a joint interest in functional assessment, and its importance in rehabilitation medicine, when they worked together at the Medical Rehabilitation Research and Training Center (RT-7) at the Rehabilitation Institute of the Tufts New England Medical Center, Boston, in the early 1970s. We wish to acknowledge the inspiration and early guidance provided by Alvan R. Feinstein, M.D., of the Yale University School of Medicine and author of *Clinical Judgement* (2), who showed that clinical epidemiological research could be conducted with a meticulousness and precision that had theretofore been regarded as possible only in the laboratory.

One of the editors (Carl V. Granger, M.D.) was fortunate to have been appointed to a fellowship sponsored by the World Rehabilitation Fund International Exchange of Experts in 1979. Professor Michael D. Warren of the Department of Community Health, London School of Hygiene and Tropical Medicine, and Director of the Health Services Research Unit, University of Kent, was a gracious host. The major purposes of the fellowship were to explore approaches used in Great Britain to develop terminology related to disability, to measure severity of disability, and to employ epidemiological methods for the investigation of disablement. As expected, the issues were found to be extremely complex—being interrelated and difficult to separate while being value-laden and not easily quantified. In many ways, the basic problems that impeded progress were similar in the United States and Great Britain—these being the lack of standard terminology and uniform descriptors of human functioning, little agreement on common methods for describing severity in terms of functional independence or dependence, and absence of agreed-upon methods to account for benefits, costs, and outcomes. All of these problems limit the ability to meet the needs of persons with disabilities consistently and predictably.

During this period, ideas were discussed with Phillip Wood, Elizabeth Badley, and Derek Duckworth, and they were persuaded to make important contributions to this volume. Throughout the process of assembling the contents of this volume, the editorial guidance of John V. Basmajian, M.D., has been encouraging and helpfully steadfast.

In addition, we would like to acknowledge the invaluable contributions of many colleagues who helped in developing research projects, implementing training workshops, and applying assessment technologies to clinical

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CARL V. GRANGER, M.D.
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